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Parenting a Child with a Chronic Health Condition: Examining Caregivers' Health Outcomes

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Courtney Rae Lincoln, PhD

University of Connecticut, 2018

The prevalence of chronic health conditions (CHCs) in childhood is increasing, and more parents must learn to contend with the challenge of providing care to a child with a CHC (Cousino & Hazen, 2013; Klassen et al., 2007; Perrin et al., 2007; Pinquart, 2013; Van Cleave et al., 2010). Previous research indicates that parents of a child with a CHC experience high levels of caregiver burden and psychological distress along with high levels of perceived benefit as a result of parenting their child (Brandon, 2007; Chen & Newacheck, 2006; Guðmundsdóttir et al., 2006; Hatzmann et al., 2014; Hungerbuehler et al., 2011; Klassen et al., 2007; Nicholas & Keilty, 2007; Schneider et al., 2011). However, it is unknown how perceived benefit, caregiver burden, and psychological distress are concurrently related in parents of children with a range of ongoing health conditions. The current study used the disability-stress-coping (DSC) model (Wallander & Varni, 1998) to examine caregivers' health outcomes for parents of children with a range of CHCs. Caregivers (N = 118) of a child with a CHC completed surveys assessing each of three risk and three protective factors outlined by the DSC model as well as study outcomes: perceived benefit, caregiver burden, and psychological distress. Results indicated that caregivers' perceived stress and emotion-focused coping were most strongly associated with all three health outcomes. The DSC model functioned well when assessing caregivers' negative health outcomes, but it needs revision to effectively be used as a tool to examine caregivers' perceived benefit. Study findings help inform strength-based interventionists seeking to bolster caregivers' strength and best support burdened and distressed caregivers.

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Parenting a Child with a Chronic Health Condition: Examining Caregivers' Health Outcomes

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Chapter 1. Introduction

Parenting is a major milestone in the lives of most adults such that by the time they reach middle adulthood, most adults are not only expected to be parents, but to have adapted to this change in their lives by becoming competent, successful, and effective caregivers (Hunter, Sundel, & Sundel, 2002). However, parenting still comes with unexpected challenges, and one such challenge may arise when a child is diagnosed with a chronic health condition (CHC). A CHC is a diagnosed condition that persists for at least six months, causes some degree of functional impairment or interference with the child's daily life, and requires more than typical health services to manage (Caring and Living as Neighbors, 2012; Goodman, 2013; The Council for Youths with Chronic Conditions). Trends indicate that the prevalence of childhood CHCs in the United States is increasing (Perrin, Bloom, & Gortmaker, 2007; Van Cleave, Gortmaker, & Perrin, 2010). An estimated 15-18% of American children and adolescents have a CHC that in some way restricts their physical or cognitive functioning during daily life, and this statistic increases when considering CHCs that primarily impact the child's emotional or behavioral functioning (Perrin et al., 2007).

Children with CHCs may have a variety of physical, cognitive, emotional, and behavioral needs that exceed the needs of healthy children, and it is often parents, as primary caregivers, who are tasked with providing the bulk of this strenuous, health-related, additional care (McNeill, Nicholas, Beaton, Montgomery, MacCulloch, Gearing, & Selkirk, 2014; Perrin et al., 2007). Therefore, parents of children with a CHC (referred to simply as caregivers throughout the remainder of this dissertation) experience increased caregiving demands and increased parenting stress that parents of healthy children do not face, and the increase in physical, psychological, and social strain that results is referred to as caregiver burden (Burke, Muscara,

McCarthy, Dimovski, Hearps, Anderson, & Walser, 2014; Jubber, Olsen Roper, Yorgason, Poulsen, & Mandleco, 2013; McNeill et al., 2014; Pinquart, 2013). Nevertheless, raising a child with a CHC also allows for the potential to stimulate positive growth in caregivers due to increased adversity. Positive outcomes that follow a traumatic experience are referred to as posttraumatic growth (PTG), stress-related growth, or benefit finding (Gardner, Mrug, Schwebel, Phipps, Whelan, & Madan-Swain, 2017; Tedeschi & Calhoun, 2004). PTG may have positive impacts on caregivers' lives by inducing emotional growth, healthier lifestyles, higher functioning, improved family relationships, or changed perspectives (Colville & Cream, 2009; Gardner et al., 2017). Clearly, there is a range of positive and negative health outcomes that may result from raising a child with a CHC. Given the increased prevalence of childhood CHCs and the extensive influence a child's CHC has on caregivers' health outcomes, it is important to understand more about the unique caregiving challenge of raising a child with a CHC to support burdened caregivers and facilitate more positive, rather than negative, health outcomes.

Wallander and Varni (1992, 1995, 1998) conceptualized the disability-stress-coping (DSC) model to guide researchers in understanding how individuals and families adjust to a childhood CHC. The model defines adjustment broadly to refer to a number of patient, parent, or family health outcomes that are impacted by a child's CHC diagnosis, such as distress, psychological well-being, PTG, caregiver burden, and parental stress. The model describes three risk factors and three resistance factors (called protective factors in this study) that predict health outcomes. Wallander and Varni (1998) proposed a set of risk and protective factors to predict patient outcomes for children with a CHC and a parallel set of risk and protective factors that help to inform familial and caregiver outcomes. According to the DSC model, each family has a unique combination of risk and protective factors that are related to family members' health

outcomes. Unlike many other theoretical paradigms assessing outcomes related to chronic

illness, the DSC model is not specific to a particular childhood illness, making it an ideal model

for assessing individual differences in caregivers' health outcomes for parents of children with

various CHCs. Therefore, the DSC model was used as a guide for this research.

Theoretical Framework

The DSC model has been used as a theoretical framework to examine health outcomes in

children and families with childhood CHCs such as rheumatoid arthritis, Type I Diabetes (T1D),

sickle cell syndromes, and obesity, as well as developmental disorders and disabilities, such as

spina bifida, cerebral palsy, and other physical and cognitive delays (Brown et al., 2000; Findler,

Jacoby, & Gabis, 2016; Florian & Findler, 2001; Guðmundsdóttir, Guðmundsdóttir, & Elklit,

2006; Mullins, Molzon, Suorsa, Tackett, Pai, & Chaney, 2015; Noojin & Wallander, 1997;

Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008). With the exception of one study that

sampled parents of children with a range of chronic illnesses (Guðmundsdóttir et al., 2006), most

research using the DSC model has assessed adaptation to one CHC diagnosis at a time.

Regardless of specific diagnosis, the DSC model recognizes the disruptive nature of a CHC

(Wallander & Varni, 1998). After a child is diagnosed with a CHC, there are inevitable changes

to the child's, and likely to the whole family's, daily routine that impact the health and well-

being of each family member involved (West, Bell, Woodgate, & Moules, 2015). A

combination of empirically measured risk and protective factors (see Figure 1) helps assess

caregivers' health outcomes.

The DSC model's risk factors related to caregiver health outcomes are the child's illness

parameters, the child's functional impairment, or dependence on family members to complete

daily tasks, and the family's psychosocial stress, or major life events that may induce stress for

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the family (Wallander & Varni, 1998). In contrast, the DSC model's protective factors include an individual's stress-processing (coping) strategies, an individual's intrapersonal characteristics, or stable characteristics that describe the individual, and the family's social-ecological factors, such as family dynamics and social support resources. According to the DSC model, caregivers with fewer risk factors and more protective factors will experience more positive health outcomes and less negative health outcomes than caregivers with more risk factors and fewer protective factors. Given the scope of the DSC model, however, no single study has sought to explore each of these risk *and* protective factors together to assess health outcomes in caregivers with children who have a range of CHCs.

Although the DSC model assess a range of caregivers' health outcomes, most extant research utilizing the model has investigated negative health outcomes and conceptualizes positive health outcomes as simply the absence of negative outcomes. In accordance with this deficit-based approach, most research using the DSC model has studied caregiver health outcomes such as distress, psychopathy, guilt, anxiety, depression, and stress (Brown et al., 2000; Florian & Findler, 2001; Guðmundsdóttir et al., 2006; Mullins et al., 2015; Noojin & Wallander, 1997; Vermaes et al., 2008). Further, when researchers use the DSC model to study positive caregiver outcomes, such as well-being or family satisfaction, they tend to do so in comparison to parents of children without a CHC. Caregivers of children with a CHC tend to score worse on positive health outcomes than control parents with healthy children (Florian & Findler, 2001). Far more rare in DSC research is the type of study conducted by Findler and colleagues (2016), which examined the presence of positive health outcomes, such as happiness, from a strength-based, as opposed to a deficit-based absence of negative outcomes, perspective without the use of a "healthy" control group.

Purpose of the Study

This study explored caregivers' health in the context of providing care to a child with a CHC though the lens of the DSC model. The study examined each of the DSC model's three risk and three protective factors to assess caregiver health outcomes in a sample of caregivers with children diagnosed with a range of CHCs. Specifically, the study investigated caregivers' perceived benefit from a strength-based perspective as well as their caregiver burden and psychological distress as a result of caring for their child with a CHC. In contrast to much existing empirical research that investigates caregiving outcomes in a sample of parents whose children share the same diagnosis, this study assessed health outcomes in caregivers across multiple child diagnoses, allowing for a broader description of health outcomes regardless of the child's particular diagnosis. Importantly, the results of this study could be used to better support parents who experience the challenge of raising a child with a CHC. Learning more about what factors influence perceived benefit, caregiver burden, and psychological distress will help inform interventions that target improved health outcomes for caregivers, and improving health outcomes for caregivers would have the added benefit of improving health outcomes for their children with CHCs. The family is the most immediate context for children, and it is strained parents who provide the bulk of the care to their children with a CHC (McNeill et al, 2014; Perrin et al., 2007).

Research Objectives

This study had four specific aims. The first specific aim was to use the DSC model's risk and protective factors to investigate perceived benefit in caregivers of children with a range of CHCs. It was hypothesized that caregivers' risk factors would be negatively related to their

perceived benefit and caregivers' protective factors would be positively related to their perceived benefit.

The second specific aim of this study was to use the DSC model's risk and protective factors to investigate caregiver burden for caregivers of children with a range of CHCs. It was hypothesized that caregivers' risk factors would be positively related to their caregiver burden and caregivers' protective factors would be negatively related to their caregiver burden.

The third specific aim of the study was to use the DSC model's risk and protective factors to investigate psychological distress for caregivers of children with a range of CHCs. It was hypothesized that caregivers' risk factors would be positively related to their psychological distress and caregivers' protective factors would be negatively related to their psychological distress.

The fourth specific aim was to investigate how caregivers' health outcomes, including perceived benefit, caregiving burden, and psychological distress, coexisted in a sample of caregivers with children who have a range of CHCs. In accordance with previous research, it was hypothesized that there would be a curvilinear association between caregivers' perceived benefit and caregiver burden or psychological distress such that caregivers with moderate levels of caregiver burden or psychological distress would report the most perceived benefit. Further, it was hypothesized that there would be a positive, linear relationship between caregiver burden and psychological distress.

Chapter 2. Literature Review

Introduction

Caregivers of children with a CHC often report feeling as though their parenting experiences and dual roles as parents and caretakers are different from the experiences and roles of parents with healthy children, and they report feeling as though others perceive them to be different as well (McNeill et al., 2014; Pinquart, 2013). It is the additional strain and stress of providing extra care to children with extraordinary needs, the constant worry over the child's uncertain health, and the isolating feelings of being different from typical parents that creates physical and emotional burden and compromises psychological well-being for caregivers (Burke et al., 2014; McNeill et al., 2014; Pinquart, 2013). Parents of children with a CHC report experiencing more distress than parents of healthy children or community control group samples (Cousino & Hazen 2013; Hungerbuehler, Vollrath, & Landolt, 2011; Padden & James, 2017). In fact, many caregivers experience such distress as a result of raising a child with a CHC that they resemble traumatized populations. In one study, 13% of parents of children with a wide range of CHCs had posttraumatic stress disorder (PTSD) symptoms (Guðmundsdóttir et al., 2006; Noojin & Wallander, 1997). Similarly, Kazak and colleagues (2004) found that, of the 150 families that had experienced childhood cancer who participated in their study, 20% had at least one parent with PTSD symptoms.

Despite this distress and researchers' tendency to focus on caregivers' negative health outcomes, many caregivers report finding meaning in their caregiving role, and they experience posttraumatic growth (PTG) to a greater extent than parents of children without a CHC (Cadell et al., 2014; Colville & Cream, 2009; Hungerbuehler et al., 2011; Yonemoto, Kamibeppu, Ishii, Iwata, & Tatezaki, 2012). Caregivers are especially likely to perceive greater personal strength

and appreciation for life as a result of their caregiving role (Colville & Cream, 2009; Forinder & Norberg, 2014). When caregivers experience distress in their caregiving role, they report an inability to dwell on their negative emotions (Gannoni & Shute, 2010). Not only do they have to put their emotions aside to prioritize the needs of their child, but they also are able to find strength from the way that their child is handling his or her condition (Gannoni & Shute, 2010). Caregivers even enjoy positive feelings of empowerment and confidence when they effectively manage their child's illness and observe their child successfully managing his or her own illness as well.

Much extant literature focuses on either caregivers' positive or negative health outcomes, and less is known about how caregivers' positive and negative health outcomes may coexist. Research that does examine positive and negative outcomes in caregivers generally investigates past distress or trauma, generally at the time of diagnosis, with current PTG; therefore, little is known about how growth is related concurrently to negative outcomes, such as burden or distress. Extant literature indicates a complicated relationship between past parental distress and current PTG: Parents who experienced greater distress, more traumatic experiences, and greater posttraumatic stress (PTS) symptoms also experienced greater PTG (Colville & Cream, 2009; Forinder & Norberg, 2014; Hungerbuehler et al., 2011; Yonemoto et al., 2012). However, Colville and Cream (2009) suggest that there is likely a curvilinear relationship between past distress and PTG, such that parents who experienced extreme levels of distress, either very high or very low, experience low levels of PTG, while parents who experienced moderate levels of distress report experiencing the most growth. More research is needed to further explore the complicated association between caregivers' positive and negative health outcomes.

Few empirical studies explicitly take a theoretical approach to studying caregivers' health outcomes. The following review organizes the limited extant literature regarding caregivers' health outcomes according to the risk and protective factors proposed by the DSC model, incorporating the small number of studies that have used the DSC framework and the larger literature that has not.

DSC Model Risk Factors

The DSC model proposes three separate risk factors that are related to caregivers' health outcomes. According to the DSC model, caregivers who report more risk factors will report more negative health outcomes.

Illness parameters. The first risk factor proposed by the DSC model is the illness parameters of the child's CHC (Wallander & Varni, 1998). Such factors may include the type of CHC, the specific diagnosis and symptomology of the CHC, and the severity of the CHC. However, the child's illness parameters do not include the child's functional impairment, or degree to which the child depends on others for care, as this is captured in the DSC model's second risk factor. The child's age at diagnosis has been found to be unrelated to caregivers' health outcomes such as caregiver burden, well-being, stress, and distress (Cousino & Hazen, 2013), but there is evidence that PTG is positively related to the age of the child with a CHC (Colville & Cream, 2009). Few researchers have investigated how the child's developmental stage impacts caregivers' health, but there is some evidence that older children with a CHC tend to adhere less to their treatment protocols (Morawska, Stelzer, & Burgess, 2008), and mothers tend to exert more control over their child with a CHC as he or she ages (Im, Park, Oh, & Suk, 2014).

Empirical research has generally drawn the same conclusion regarding most illness parameters, that specific diagnosis, symptomology, and frequency of symptoms do not play a significant or differential role in caregivers' health outcomes in terms of caregiver burden, parental well-being, happiness, adjustment, or psychological distress (Brown et al., 2000; Cousino & Hazen, 2013; Findler et al., 2016; Guðmundsdóttir et al., 2006). However, most extant literature takes a diagnosis-specific approach to studying caregiver health outcomes and includes only parents of children with a particular diagnosis. Reviews and empirical studies that do investigate caregivers' health outcomes across diagnosis show mixed results, particularly regarding PTG. For example, illnesses that are more life threatening or require more traumatic treatment are related to more positive growth for parents (Colville & Cream, 2009), but illnesses requiring more diverse treatment modalities contributes to less PTG (Gardner et al., 2017). In regards to illness diagnosis, Michel and colleagues (2010) found that specific type of cancer diagnosis did not predict caregivers' PTG when all research participants were parents of children with cancer, but others have found that parents of children with cancer show more PTG than parents of children with Type I Diabetes (T1D; Colville & Cream, 2009; Hungerbuehler et al. 2011). More research is needed to learn more about how diagnosis type may impact caregivers' health outcomes.

Functional impact of the illness. The second of the DSC framework's proposed risk factors is the impact that the child's disease has on the child's and family's everyday functioning, such that children who are more dependent on others to perform daily tasks will likely have caregivers who experience more negative health outcomes. There is great consensus among both DSC research and broader research regarding this second risk factor. Research repeatedly suggests that the child's increased functional dependence on others, specifically for physical

tasks, and the complexity of the child's needs, plays an important role in increasing both mothers' and fathers' distress and depression, decreasing mothers' and fathers' quality of life and positive benefit, and decreasing family adjustment (Brehaut, Garner, Miller, Lach, Klassen, Rosenbaum, & Kohen, 2011; Cousino & Hazen, 2013; Gardner et al., 2017; Guðmundsdóttir et al., 2006; Hatzmann, Maurice-Stam, Heymans, & Grootenhuis 2009; Hatzmann, Peek, Heymans, Maurice-Stam, & Grootenhuis, 2014; Noojin & Wallander, 1997; Vermaes et al., 2008).

Psychosocial stress. Psychosocial stressors, or the events in one's life that may induce stress, are the third of the DSC model's proposed risk factors. Often times, a parent's psychosocial stressors may be unrelated to a child's CHC, such as loss or change in housing or employment or a change in family structure (divorce, birth or death of a family member). Of course, having a child with a CHC also increases the incidence of psychosocial stressors related to the child's condition. A stressful event for caregivers may be a hospital admission or medical procedure for the child, a change in the child's medication or disease maintenance schedule, or challenges at school related to the child's CHC. Only one empirical study grounded in the DSC model has assessed the impact of psychosocial stressors on caregivers' health outcomes: Brown and colleagues (2000) found that general life events and illness-related hospital visits actually did not impact caregivers' distress.

However, the general literature on caregiver burden suggests that changes caused by the child's illness are distressing for parents. Caregivers often report having to change their employment or work schedules to be able to provide care to their child (Chen & Newacheck, 2006; Eiser & Upton, 2007), and they are less likely to work than parents of healthy children (Hatzmann et al., 2014). Both mothers and fathers experience changes to their work schedules, but mothers are more likely to change employment, to provide more at-home care for their child,

and to perceive family income to be less adequate compared to fathers (Brandon, 2007; Chen & Newacheck, 2006; Eiser & Upton, 2007; Hatzmann et al., 2014; McNeill et al., 2014; Schneider, Steele, Cadell, & Hemsworth, 2011). Changes in parents' employment are likely to lead to changes in the family's financial status at a time when medical expenses are increasing, another important psychosocial stressor (Eiser & Upton, 2007; Gannoni & Shute, 2010). Even relatively typical stressors for parents that are unrelated to a child's illness, such as a change in family structure, can seem more overwhelming and difficult to manage in light of chronic stressors directly related to the child's CHC. Regardless of the source of the stress, research indicates that caregivers who experience greater parental stress also experience increased burden, decreased well-being, decreased PTG, and less happiness (Findler et al., 2016; Guðmundsdóttir et al., 2006; Noojin & Wallander, 1997; Schneider et al., 2011).

DSC Model Protective Factors

The DSC model also proposes three protective factors that are related to caregivers' health outcomes (Wallander & Varni, 1998). The DSC model's description of protective factors is less clear than the description of risk factors. Protective factors exist on a spectrum of adaptive or maladaptive characteristics, such that adaptive protective factors likely facilitate positive outcomes, but maladaptive protective factors actually contribute to increased negative outcomes just as much as the presence of risk factors does. Although risk factors also exist on a spectrum, rarely do risk factors become protective factors that facilitate positive health outcomes in the same way that protective factors can turn into risk factors for increased negative health outcomes.

Stress-processing. The first of the DSC model's protective factors are stress-processing strategies, which include characteristics such as cognitive processes and coping styles. Active

coping is also known as problem-focused coping, during which individuals focus on relieving distress by tackling a problem directly or addressing the situation that is causing distress and actively doing something to improve the situation (Folkman, Lazarus, Gruen, & DeLongis, 1986). In contrast, emotion-focused coping occurs when the individual's primary focus is on relieving an unpleasant emotion, rather than improving or changing the situation contributing to the emotion. Research investigating problem-focused coping and interventions that target improvements in problem-focused coping repeatedly show that it is an important protective factor that facilitates caregiver well-being and decreased perceived burden; whereas, emotion-focused coping is a significant risk factor for more negative outcomes (Brown et al., 2000; Cousino & Hazen, 2013; Fiks et al., 2015; Grey, Jaser, Whittemore, Jeon, & Lindemann, 2011; Guðmundsdóttir et al., 2006; Kazak, 2005; Klassen, Raina, Reineking, Dix, Pritchard, & O'Donnell, 2007; Noojin & Wallander, 1997; Warner, Ludwig, Sweeney, Spillane, Hogan, Ryan, & Carroll, 2011). Use of problem-focused coping is also related to experiencing positive caregiving benefits, including meaning-making and empowerment, but positive spiritual coping and emotion-focused coping also predict parents' ability to find benefit in their caregiving experience (Gannoni & Shute, 2010; Gardner et al., 2017). When parents are able to effectively manage stress and perceive less of it as a result, they feel less burdened by the stressors in their lives (Noojin & Wallander, 1997).

Intrapersonal factors. Intrapersonal characteristics, the DSC model's second protective factor, include all of the stable characteristics that may describe an individual, including temperament or disposition, personality, locus of control, self-efficacy, problem-solving ability, and related constructs. Little research grounded in the DSC model has explicitly explored the impact of intrapersonal characteristics on caregivers' health outcomes. To help fill this gap,

Vermaes and colleagues (2008) sought to investigate how intrapersonal factors were related to perceived distress in both mothers and fathers of children with spina bifida. They discovered that emotional stability was a protective factor for mothers' and fathers' distress. At the same time, mothers' extraversion and openness to experience negatively predicted their distress, and fathers' agreeableness negatively predicted their distress. Vermaes and colleagues (2008) also considered the DSC model's risk factor of functional impairment and found that severity of dysfunction was an important predictor of distress for mothers and fathers, but personality features were actually stronger predictors of distress, especially for fathers.

Caregiver burden research outside of the DSC perspective has often focused on parents' problem-solving abilities, or their confidence in problem-solving tasks, and parents' perceived control over their feelings. Caregivers who are effective problem solvers are more likely to engage in problem-focused coping (Noojin & Wallander, 1997), so it is not surprising that parents who perceive themselves to be effective problem solvers adjust and adapt better to their child's CHC than parents who do not perceive themselves to be capable problem solvers, and interventions that improve parents' problem-solving skills are efficacious in improving parental well-being (Askins et al., 2009; Law, Fisher, Fales, Noel, & Eccleston, 2014; Lindström, Åman, Anderzén-Carlsson, & Lindahl Norberg, 2015; Noojin & Wallander, 1997; Trivedi, 2013). Parents who are able to quickly and effectively solve problems are able to adequately manage their own distress as well as complete all of the daily tasks required to provide care to their child with a CHC, from monitoring a child's treatment or environmental needs to conversing with doctors and scheduling appointments (Fiks et al., 2015; Grey et al., 2011; Kazak, 2005; Warner et al., 2011).

Aside from problem-solving qualities, caregivers experience poorer psychological well-being when they have feelings of helplessness, when they lack a sense of perceived mastery, and when they lack self-efficacy related to parenting their child, but feeling as though they are in control of the events in their lives protects against increased trauma experiences (Cousino & Hazen 2013; Guðmundsdóttir et al., 2006; Klassen et al., 2007). Self-efficacy related to caregivers' ability to manage their child's CHC specifically is especially important in predicting their burden (Cousino & Hazen 2013). Mothers and fathers experience less burden when they have higher self-esteem, and mothers experience less burden when they have higher levels of optimism and spirituality (Schneider et al., 2011). Similarly, spirituality is related to finding more meaning in caregiving experiences for men and women, and self-esteem is related to finding meaning for women (Cadell et al., 2014; Schneider et al., 2011).

Social-ecological factors. The third and final protective factor proposed by the DSC model is social-ecological factors. Such factors include family structure, family dynamics, communication patterns within the family, perceptions of social support within and outside of the family, and the caregiver's and family's demographic characteristics. Caregivers are burdened by their own loneliness, feeling that their parenting experience is so unique that most other parents of healthy children cannot relate (Hughes, Johnson, Ramchandani, Quinn, D'Alesandro, Streisand, & Sullivan-Bolyai, 2015; McNeill et al., 2014); therefore, social support plays an important protective role for caregivers. Much research focuses on emotional social support, but it is clear that instrumental support and informational support are also important protective factors for caregivers (Gannoni & Shute, 2010), but many caregivers report that they need more support than they are currently receiving (Douma, Dekker, & Koot, 2006). Findler and colleagues (2016) explored social support in mothers of children with disabilities and found that

social support was a robust protective factor for parental adjustment, and higher levels of perceived social support were related to higher levels of happiness in this population. Increased social support is related to increased PTG and meaning making (Forinder & Norberg, 2014; Gardner et al., 2017).

When children are diagnosed with a CHC, the extra time that must be devoted to the child with a CHC has implications for the functioning of the family as a whole, often changing parent-child relationships, altering family communication processes, and putting a strain on marital relations (Eiser & Upton, 2007; Gannoni & Shute, 2010; West et al., 2015). Parenting couples who are enduring marital dissatisfaction, marital conflict, disparate levels of anxiety, and incongruent coping styles experience less psychological well-being and more caregiver burden than couples who are satisfied with their spousal relationship and work as a cooperative team to care for their child with a CHC (Jubber et al., 2013; Gannoni & Shute, 2010; Klassen et al., 2007; McNeill et al., 2014). Siblings of the child with a CHC may feel a sense of confusion and uncertainty as well as feeling excluded from family interactions that often revolve around their sibling's condition (Long et al., 2015). Nevertheless, siblings, particularly cooperative, responsible, and helpful older siblings can become an important source of support for caregivers, as they provide entertainment to their sibling and help care for their sibling in ways that decrease caregiver burden (Mulroy, Robertson, Aiberti, Leonard, & Bower, 2008; Platt, Roper, Mandleco, & Freeborn, 2014; Roper, Allred, Mandleco, Freeborn, & Dyches, 2014).

Childhood CHCs do not discriminate based upon demographic characteristics, as parents of all genders, races, socioeconomic statuses, family structures, and family sizes are affected by the challenge of raising a child with a CHC, and some of these parental demographic factors are related to parental distress levels. For example, mothers experience greater distress at diagnosis

of a childhood CHC and poorer psychological well-being, more depressive and PTS symptoms, and greater burden throughout the caregiving experience than do fathers (Brehaut et al., 2011; Hungerbuehler et al., 2011; Klassen et al., 2007; Schneider et al., 2011), but they also experience greater PTG and find more meaning as a result of their child's condition than do fathers (Forinder & Norberg, 2014; Hungerbuehler et al., 2011; Schneider et al., 2011). Those parents who do experience growth as a result of their caregiving experience are generally the parents that are directly involved in the everyday caregiving tasks related to their child's CHC (Cadell et al., 2014). Black parents experience poorer psychological well-being than white parents, and single parents (divorced, separated, or widowed) are more likely to experience depressive symptoms than married parents (Brehaut et al., 2011; Klassen et al., 2007). Income is negatively correlated with depressive symptoms (Brehaut et al., 2011). Neither socioeconomic status (SES) nor parents' level of education is related to PTG (Michel et al., 2010). Less is known about how family structure and family size may be related to parental distress.

Chapter 3. Present Study

This study was grounded in the DSC model and took a strength-based approach to the examination of caregivers' health outcomes. The primary outcome of interest in this study was perceived benefit, or the degree to which caregivers have experienced positive change as a result of caring for their child with a CHC. Although much existing research on positive health outcomes has examined caregivers' levels of PTG, the current study assessed caregivers' perceived benefit as opposed to PTG because study participants had children with ongoing CHCs and present trauma, burden, and distress. Given that PTG is conceptualized as growth after a traumatic event, much PTG research has focused on caregivers with children who had cancer but were in remission at the time of data collection, making the child's condition, and thus the requisite trauma, a past, rather than ongoing, event (Cadell et al., 2014), but little is known about how caregivers may perceive benefit in their current, ongoing struggle to provide care to a child with an ongoing CHC that may be life-limiting and have no cure nor potential for treatment or remission.

Perceived benefit was considered in relation to caregiver burden and psychological distress to better understand the concurrent association between levels of perceived benefit and more traditionally studied negative health outcomes. For the purpose of this study, CHC was broadly defined so caregivers whose children have a variety of CHC diagnoses and symptoms were eligible to participate. As opposed to most literature that investigates caregiver health outcomes in parents whose children have the same diagnosis, the present study assessed caregivers' health outcomes across child CHC diagnosis, rather than within the same diagnosis.

Research Questions

In the present study, the following research questions were addressed:

1. How are the DSC model's risk and protective factors associated with perceived benefit for caregivers of children with a range of CHCs?

2. How are the DSC model's risk and protective factors associated with caregiver burden for caregivers of children with a range of CHCs?

3. How are the DSC model's risk and protective factors associated with psychological distress for caregivers of children with a range of CHCs?

4. How are parents' perceived benefit, caregiver burden, and psychological distress concurrently related in a sample of caregivers whose children have a range of CHCs?

Hypotheses

In light of previous research and the tenets of the DSC model, the study hypotheses were as follows:

1. Perceived benefit

    a. Hypothesis 1a: DSC model risk factors (illness parameters, functional impairment, psychosocial stressors) will be negatively related to participants' perceived benefit.

    b. Hypothesis 1b: DSC model protective factors (stress processing, intrapersonal factors, social-ecological factors) will be positively related to participants' perceived benefit.

2. Caregiver burden

    a. Hypothesis 2a: DSC model risk factors (illness parameters, functional impairment, psychosocial stressors) will be positively related to participants' caregiver burden.

b. Hypothesis 2b: DSC model protective factors (stress processing, intrapersonal factors, social-ecological factors) will be negatively related to participants' caregiver burden.

3. Psychological distress

   a. Hypothesis 3a: DSC model risk factors (illness parameters, functional impairment, psychosocial stressors) will be positively related to participants' psychological distress.

   b. Hypothesis 3b: DSC model protective factors (stress processing, intrapersonal factors, social-ecological factors) will be negatively related to participants' psychological distress.

4. Concurrent relations

   a. Hypothesis 4a: There will be a curvilinear relationship between participants' perceived benefit and caregiver burden.

   b. Hypothesis 4b: There will be a curvilinear relationship between participants' perceived benefit and psychological distress.

   c. Hypothesis 4c: There will be a positive, linear relationship between participants' caregiver burden and psychological distress.

Chapter 4. Research Methodology

Participants

Participants consisted of caregivers who had at least one child between the ages of 2 and 18 years old with a CHC that was diagnosed more than six months ago. For the current study, a condition was considered chronic if it 1) had endured for at least six months, 2) required more than typical health services to manage, and 3) imposed limitations in the child's daily life (definition adapted from Council for Youths with Chronic Conditions).

Recruitment. Participants were recruited from three locations. The first recruitment source was a northeastern branch of a national camp that serves seriously ill children and their families. The second source was a social media website that aims to create an online community of support for all individuals facing serious health conditions. The final source was a state advocacy center in the Northeast that connects parents of children with a CHC with local resources. Recruitment took place via emails to members of recruitment sources, flyers posted to the social media accounts of recruitment sources, and pop-up advertisements on webpages associated with recruitment sources. The majority of these participants were recruited from the online support community (n = 78, 66%), followed by the state advocacy center (n = 30, 25%) and the camp (n = 10, 9%).

Eligibility. At the conclusion of recruitment, 191 parents responded to the invitation to participate in the study. However, 40 parents were not eligible to participate for the following reasons: 19 (47.5%) had a child with a CHC outside of the required age range (younger than 2 years old or older than 18 years old), 7 (17.5%) reported having a child whose CHC did not require more than typical health services, 6 (15%) did not complete all eligibility questions, 5 (12.5%) did not have a child with a diagnosed CHC, and 3 (7.5%) had a child who had been

diagnosed with a CHC within the past 6 months. Of the 151 participants who were eligible to participate, a total of N = 118 participants were included in analyses given that 33 participants did not provide enough information to be included (i.e. participants did not give a diagnosis for their child and/or did not respond to outcome measures).

Demographic characteristics. The majority of participants were female (96%), the child's biological parent (95%), married (86%), and lived full-time with their child with a CHC (96%). Most parents reported that they were one of multiple primary caregivers for their child (72%), 27% reported they were their child's only primary caregiver, and 1% reported that they were not their child's primary caregiver. Caregivers were between 28 and 68 years old (M_{age} = 43 years old). Participants reported that their child with a CHC ranged in age from 3 to 18 years old ($M_{ChildAge}$ = 11 years old), with 24% of children categorized in early childhood, 27% of children categorized in middle childhood, and nearly half (49%) in adolescence. Most participants were White (90%), with 3% being Hispanic/Latino, 3% being multiracial, 2% being Asian, 1% being Black/African American, and 1% identifying as other.

Participants reported a range of education levels from less than a high school degree to a graduate degree, with the median level of education being four years of college and the modal level of education being a graduate degree (37.5%). Participants also reported a range of estimated annual household income from less than $20,000 per year to greater than $140,000 per year, with a median income of $80,000-$99,999 per year and a modal income of more than $140,000 per year (23%). The majority of participants were employed at least part-time (62.5%), with the remaining unemployed participants being either stay-at-home parents, retired, disabled, or students. Almost all participants (95%) reported having insurance coverage. There was an average of one other adult (at least 18 years old) and one other child living in the home

with the caregiver and child with a CHC. Participants spent an average of 13 hours per day

providing care to their child during the week and an average of 17 hours per day providing care

to their child on the weekend.

Child diagnoses. Caregivers reported that their children were diagnosed with their

primary CHC at an average age of 4.64 years old, and they had been diagnosed, on average, 6.12

years ago. Children had a range of diagnoses. The most common diagnoses were Autism

Spectrum Disorder (ASD; n = 12), cerebral palsy (n = 5), asthma (n = 4) Type 1/Juvenile

Diabetes (n = 4), and Down Syndrome/Trisomy 21 (n = 4). Primary diagnoses were categorized

based on etiology, common primary symptoms, and body system that is most affected by the

condition. Diagnosis categories included: nervous system affected (n = 26, 22%), immune

system affected (n = 25, 21%), mental health diagnoses listed in the *Diagnostic and Statistical*

Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013; n = 20,

17%), genetic developmental delay (caused by a chromosomal/genetic abnormality; n = 12,

10%), circulatory system affected (n = 12, 10%), respiratory system affected (n = 8, 7%),

digestive system affected (n = 4, 3%), energy disorder, (n = 4, 3%), craniofacial disorder (n = 2,

2%), muscular system affected (n = 2, 2%), endocrine system affected (n = 1, 1%), renal system

affected (n = 1, 1%), and dwarfism (n = 1, 1%). For analysis purposes, categories that contained

less than 10% (n = 12) of the sample were grouped together into an "other" category, which

together comprised 20% of the sample (n = 23). This led to a total of 6 categories to be included

in data analyses. See Table 4 for more information on diagnosis categories and example

diagnoses in each category.

Most children (72%) had secondary diagnoses in addition to their primary diagnosis.

Children had between 0 and more than 15 secondary diagnoses, with an average of 2.57

secondary diagnoses. Secondary diagnoses were not considered when creating diagnosis types, as diagnosis types were based solely on the primary diagnosis to avoid over-complicating the categorization. Caregivers reported that their children had between 2 and 46 symptoms on a regular basis as a result of their condition, with an average of 14.79 symptoms per child. Caregivers perceived the severity of their child's CHC to be, on average, 68.69 on a 0-100 scale, with a range of 15-100. See Table 5 for descriptive statistics of the remaining variables.

Measures

Throughout the survey set, the caregiver's child with a CHC that met inclusion criteria was referred to as the "focal child." Participants completed a demographic survey created for the purpose of this study. The survey gathered information regarding the caregiver's relationship to the child with a CHC, gender, age, race, marital status, family structure (including number and ages of adults and other children in the family, inside and outside of the home), highest level of education, employment status, insurance status, and estimated annual household income. Participants also indicated if they were the primary caregiver of the child with a CHC and how often they lived with the child with a CHC as well as, on average, how many hours during a weekday and during a weekend day they provide care to their child with a CHC. Participants also completed the following surveys in accordance with constructs indicated by the DSC Model (see Table 1 and Figure 2 for information about how each construct and measure is aligned with the DSC model).

Risk factors.

Illness parameters. To assess the DSC model's first risk factor of illness parameters, caregivers were asked to indicate their child's primary diagnosis and any secondary diagnoses, the child's age at diagnosis, child's current age (time since diagnosis was calculated by

subtracting the child's age at diagnosis from their current age), and time since the child's most recent medical crisis. Caregivers were also asked "overall, on a scale of 0 to 100, how severe would you say the focal child's condition is?". Caregivers then moved a slider that indicated a number between 0 and 100, with a higher number meaning more severe, to assess the caregiver's perception of the severity of the child's illness. Caregivers were then asked to check from a list of potential symptoms those that the focal child experienced on a regular basis as a result of their condition(s) or treatment(s). The list of symptoms was created for this study, and included a compilation of items from diagnosis-specific literature and assessments of illness factors and symptomatology. For the pilot study, the list included 42 possible symptoms. After piloting the measure, some symptoms were reworded, rearranged, clarified, and added such that the list of symptoms in the final survey set included 53 possible symptoms with an "other" option for participants to add additional symptoms their child may have experienced that were not include in the list. A sum score of all checked and other symptoms was calculated for each participant's child.

Functional impairment. The child's functional impairment as a result of his or her CHC, or the DSC model's second risk factor, was measured with the Pediatric Quality of Life Inventory (PedsQL 4.0) Generic Core Scale, a 23-item measure that assessed parents' perceptions of child's health-related quality of life on four subscales: physical functioning, emotional functioning, social functioning, and school functioning (Varni, Burwinkle, Seid, & Skarr, 2003). There are four different versions of the PedsQL 4.0 that correspond with the child's developmental stage. Caregivers were presented with the teen version (ages 13-18), child version (ages 8-12), young child version (ages 5-7) or toddler version (ages 2-4) depending on the caregiver's report of the age of the focal child. Each version of PedsQL 4.0 asked the same

questions, but included slightly different language, such as referring to the child's peers as "other teens" or "other children." The exception was the Peds QL 4.0 for toddlers, which included fewer and differently worded items for the school functioning subscale under the assumption that many children ages 2-4 do not yet attend school. Therefore, during data analysis, the two items that were missing from the Peds QL 4.0 toddler version of the school functioning subscale were also removed from the school functioning subscales of the teen, child, and young child versions.

Items were scored on a 5-point Likert scale from 0 (never) to 4 (almost always). Higher scores on the PedsQL 4.0 indicated greater functional impairment. Internal consistency of the full scale ($\alpha = .92$) and each of the subscales ($\alpha = .74-.88$) are high, and construct validity has been demonstrated (Varni et al., 2003). Test-retest reliability across an average span of 9 days ranged from $r = .75$ to $r = .90$ across the total scale and each subscale in a sample of children with traumatic brain injury (McCarthy et al., 2005). In the current study, internal consistency for the full scale was $\alpha = .91$, and internal consistency for each subscale was $\alpha = .72 - .90$.

Family stressors. The DSC model's third risk factor is psychosocial stressors. Psychosocial stress may be the result of events that are not related to having a child with a CHC, such as the loss of a job, death of a family member, or a change in residence. To quantify the occurrence of these stressful life events, participants completed an abbreviated version of the Family Inventory of Life Events and Changes (McCubbin, Patterson, & Wilson, 1983), a checklist of potential general life stressors that families may face. For this study, the abbreviated version consisted of ten potential life stressors, such as change in employment status or work hours, financial status, marital status, or amount of conflict, that are common for families with a CHC as indicated in the literature. Participants were asked to indicate if their family had

experienced each potential life stressor in the past one year. Total checked items were summed to create a family stressors (FS) total score.

CHC-related stressors. Parents of children with a CHC also experience stress from events directly related to their child's condition, such as a hospitalization or medical procedure. Such events were assessed with a measure that originally had listed 11 potential illness-related stressors that had been selected for their prevalence in the caregiver burden literature. Upon piloting the measure and assessing pilot participants' feedback and experiences, three more potential CHC-related stressors were added to the measure for a total of 14 potential CHC-related stressors. Participants were asked to rate the degree to which each event had caused participants and their family stress in the past one year. Items were rated on a five-point Likert scale derived from the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) from 0 (not at all) to 5 (extremely). In the current study, internal consistency for this newly created CHC-related stressor scale was high (α = .88).

Perceived stress. A third measure, the Perceived Stress Scale (PSS), further assessed the DSC model's third risk factor of psychosocial stress by determining the degree to which participants considered events in their life to be stressful over the past month (Cohen, Kamarck, & Mermelstein 1983). Combining multiple stress measures allowed for a more comprehensive evaluation of the DSC model's third risk factor of psychosocial stress because participants were able to indicate how often stressful family life events occurred, the degree to which objective, CHC-related events caused stress, and the degree to which participants subjectively perceived general stress. The PSS-10 includes 10 self-report items measured on a 5-point Likert scale from 0 (never) to 4 (very often) and is the recommended version of the scale as indicated by Cohen and Williamson (1988). Items were worded to be independent of context and easy to understand.

A total score was obtained by reverse scoring positively worded items and summing the scores from the ten items. Higher scores indicated greater perceived stress in the past month. As the most widely used measure of perceived stress, the PSS-10 has been found to have good internal reliability ($\alpha = .78$), with a test-retest correlation of .85 (Cohen et al., 1983; Cohen & Williamson, 1988). The PSS-10 has shown good construct and convergent validity, being correlated with various other measures of stress (Cohen et al., 1983; Cohen & Williamson, 1988). In the current study, internal consistency was $\alpha = .88$.

Protective factors.

Coping styles. To assess the DSC model's first protective factor, stress-processing characteristics, the current study used the COPE as a measure of caregivers' general coping styles during stressful situations, which may not necessarily be related to the child's CHC. The COPE is a 60-item measure that includes 15 different subscales, or coping strategies (Carver, Scheier, & Weintraub, 1989). In light of the consensus in the existing literature that problem-focused coping is a robust protective factor and emotion-focused coping places caregivers at risk for increased negative health outcomes, the present study focused on these two coping tendencies to help evaluate stress-processing factors. The COPE does not currently have a coding scheme to generate problem-focused and emotion-focused coping, but several existing subscales are related to either problem-focused coping or emotion-focused coping. In accordance with Folkman and colleagues' (1986) description of problem- and emotion-focused coping, the current study used the active coping and planning subscales of the COPE to measure a problem-focused coping style, and the focus on and venting emotions subscale of the COPE was used as an emotion-focused measure. Upon pilot testing, the religious coping subscale of the COPE was added to the survey set after many pilot participants mentioned the role that faith plays in their

life, either positively or negatively. Each of the four subscales of the COPE contains 4 items measured on a 4-point Likert scale from 1 (I usually don't do this at all) to 4 (I usually do this a lot; Carver et al., 1989). Higher scores on a subscale indicated greater use of that particular coping strategy. Internal reliability for each of the subscales has been demonstrated with Cronbach's alphas of .62, .80, .77, and .92 for the active coping, planning, focus on and venting emotions, and religious coping subscales, respectively. Test-retest reliability for the four subscales after 8 weeks were .56, .63, .69, and .86, respectively. Convergent and divergent validity of individual coping strategies have been demonstrated when compared to measures of personality (Carver et al., 1989). In the current study, internal consistencies for each subscale were high (α = .70 - .96), and the internal consistency of the problem-focused subscale that combines the active and planning coping subscales was also high (α = .87).

General self-efficacy. The second protective factor, intrapersonal characteristics, was measured in part by the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995). The GSE measured self-perceived self-efficacy that is not context-specific, or self-efficacy at a trait level. The 10-item self-report measure is scored on a 4-point Likert scale from 1 (not at all true) to 4 (exactly true). Higher scores indicated greater perceived self-efficacy. The measure is internally consistent with Cronbach's alphas between .76 and .90 (Schwarzer & Jerusalem, 1995). The GSE shows construct validity with high correlations in the expected directions to related constructs across a wide range of research and cultural contexts. No information is available regarding the measure's test-retest reliability. Internal consistency in the current study was high (α = .90)

Locus of control. Intrapersonal characteristics were further measured with the Internal Locus of Control subscale of the Levenson Multidimensional Locus of Control Scale (MLCS;

Levenson, 1974). The 8-item subscale measured the degree to which respondents believed that they have control over the things that happen in their lives. Self-report items were scored on a 6-point Likert scale from 1 (strongly disagree) to 6 (strongly agree). Higher scores indicated a greater internal locus of control, or a greater belief that one can control events in his or her life. In a sample of college students, concurrent validity was high (r = .53) with a measure of health locus of control, test-retest reliability was .60, and internal consistency was α = .68 (Moshki, Ghofranipour, Hajizadeh, & Azadfallah, 2007). Internal consistency in the current study was α = .67.

Problem-solving confidence. Previous research clearly indicates that parents' problem-solving ability is a major factor in their caregiving experiences; therefore, to further evaluate the DSC model's second protective factor of intrapersonal characteristics, participants completed the problem-solving confidence subscale of the Problem-solving Inventory (PSI; Heppner & Petersen, 1982). The problem-solving confidence subscale is an 11-item self-report subscale on a 6-point Likert scale from 1 (strongly agree) to 6 (strongly disagree) that assesses one's general confidence in his or her ability to engage in problem-solving strategies across a variety of problems. After reverse scoring negatively worded items, higher scores indicated greater problem-solving confidence. The subscale is internally consistent (α = .85) and demonstrates both construct and concurrent validity (Heppner & Petersen, 1982). Test-retest reliability is also high (r = .85) over a two-week period. In the current study, internal consistency was high (α = .92).

Family functioning. The third protective factor, social-ecological factors, was assessed in part by the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983). The FAD was created to identify problem areas in family functioning. The original measure contains 53

items on 6 subscales and a General Functioning scale; however, the current study only utilized

two subscales to assess family communication and family roles. Previous literature indicates that

marital relationships characterized by open communication, negotiation, and sharing of family

responsibilities fosters effective and satisfying childcare for couples with children with a CHC

(McNeill et al., 2014). The communication subscale of the FAD contains 6 items that assess the

degree to which information is exchanged clearly and directly between family members, while

the roles subscale contains 8 items that assess the degree to which families have established

patterns of task completion that are clear and equitable (Epstein et al., 1983). Items were

answered on a 4-point Likert scale from 1 (strongly agree) to 4 (strongly disagree). Subscale

scores age generally derived by reverse scoring negatively worded items, summing the responses

from each item, and dividing by the number of items answered. However, in the current study, a

total family functioning score was created by summing responses to items from both scales.

Items were scored such that higher scores indicated better family functioning. The FAD is valid

and reliable (α = .75 for the communication subscale and .72 for the roles subscale; Epstein et al.,

1983). Test-retest reliability only has been conducted on the General Functioning scale, and not

the subscales used in this study. In the current study, internal reliability for both subscales was

acceptable (α = .80 and .76 for the communication and roles subscales, respectively). Internal

consistency for the communication and roles subscale combined was α = .79.

Social support. Social-ecological factors were further assessed by the Multidimensional

Scale of Perceived Social Support (MSPSS), which assesses individuals' perceptions of the

social support they receive from family, friends, and significant others (Zimet, Dahlem, Zimet, &

Farley, 1988). Items assessed perceptions of emotional support and instrumental support. The

12-item self-report questionnaire used a 7-point Likert scale from 1 (very strongly disagree) to 7

(very strongly agree). The family, friends, and significant other subscales each have 4 items.

Higher total scores and subscale scores indicated greater levels of perceived social support. The

scale has good internal reliability with Cronbach's alpha of .88 for the total scale and .85, .87,

and .91 for the friends, family, and significant other subscales, respectively (Zimet et al., 1988).

The test-retest reliability over a period of 2-3 months was .85 for the total scale and .75, .85, and

.72 for the friends, family, and significant other subscales, respectively. Construct validity for

each of the subscales and the full scale have been demonstrated. Internal consistencies were high

in the current study for each subscale and for the total score (α = .89, .91, .94, and .91 for the

family, friends, significant other, and total score scales, respectively).

Outcomes.

Perceived benefit. The primary outcome of this study was caregivers' perceived benefit

as a result of providing care to their child with a CHC. The Benefit Finding Scale (BFS), a self-

report questionnaire containing 17 items, assessed participants' perceived benefit (Antoni et al.,

2001). The BFS was adapted to assess perceived benefit from the experience of having had

breast cancer, but the measure was originally created to assess perceived benefit in caregivers

whose children had special needs. For the purpose of this study, participants were asked how

much they agreed with a list of potential benefits that may arise as a result of having a child with

a chronic health condition on a 5-point Likert scale from 0 (not at all) to 4 (extremely). As tested

in a population of breast cancer patients, the BFS has shown excellent internal consistency (α =

.95), good discriminant validity with measures of optimism and distress, and good test-retest

reliability (r = .91) at 3 months, though no psychometric information is available in a sample of

parents with children with a CHC (Antoni et al., 2001). Piloting the measure with a group of

parents of children with a range of CHCs indicated that revised instructions were clear and

applicable to the population. However, some items were reworded after pilot feedback indicated

that some items were phrased too deterministically. For example, one items asked if "having a

child with a chronic condition has taught me that everyone has a purpose in life." This item was

reworded to ask if "having a child with a chronic condition has *helped* teach me that everyone

has a purpose in life." The reworded BFS had high internal consistency (α = .93).

    Caregiver burden. Caregiver burden was measured with the Caregiver Burden Inventory

(CBI; Novak & Guest, 1989). The CBI has a total of 24 items and assesses burden in five

categories including time dependence burden, developmental burden, psychological burden,

social burden, and emotional burden. Items were assessed on a 5-point scale from 0 (never) to 4

(almost always) with higher scores indicating greater perceived caregiver burden. Each of the

five subscales, which contain 4-5 items each, have high internal consistency ranging from

Cronbach's alpha of .73 to .86. Construct and content validity have been demonstrated given

that the items were derived from previously validated measures of caregiver burden. In a sample

of parents of children with Rett Syndrome, the CBI showed high internal consistency (α = .91)

and construct and face validity were demonstrated with measures of general health (Lane et al.,

2017). No test-retest reliability information exists for the CBI.

    Upon pilot feedback, one item was added to the measure that indicates "my caregiving

efforts aren't understood by others in my family." This item mirrors the item that indicates "my

caregiving efforts aren't appreciated by others in my family," which pilot participants described

as different from, but just as important as, the degree to which caregiving efforts are understood.

The internal consistency of each of the five subscales ranged from (α = .83 - α = .91). The

additional item was added to the social burden subscale, and doing so increased the internal

consistency of the subscale from α = .80 to α = .83. The total scale had high internal consistency

(α = .94), which remained the same when including the additional item.

Psychological distress. Caregivers' multidimensional distress was assessed using the

Brief Symptom Inventory-18 (BSI-18), an abbreviated version of the Brief Symptom Inventory,

which was itself derived from the Symptom Checklist (Derogatis & Melisaratos, 1983). The

BSI-18 is a self-report measure of psychological well-being on the one end, and psychological

distress on the other end, as indicated by three subscales: somatization, depression, and anxiety

(Meijer, de Vries, & van Bruggen, 2011). The measure asks individuals to self-assess the extent

to which they have been bothered in the past week by psychological symptoms such as nausea or

upset stomach (somatization), feeling blue (depression), or feeling tense or keyed up (anxiety).

Items were rated on a 5-point Likert scale from 0 (not at all) to 4 (extremely) and subscales or

total scores are derived from the sum of individual items. Higher scores indicated decreased

psychological well-being, or greater psychological distress. The internal consistency of the four

subscales as well as the total score range from Cronbach's alpha .71-.89, while the test-retest

reliability of the subscales and total scale range from .68-.82 across 15 days (Andjreu, Galdón,

Dura, Ferrando, Murgui, García, & Ibáñez, 2008). Convergent validity is strong, showing high

correlations with similar constructs, such as anxiety and depression. Internal consistency in the

current study was high for the somatization, depression, and anxiety subscales (α = .90, .89, .95,

respectively) and for the total scale (α = .89).

Procedures

First, a pilot study assessed the feasibility and appropriateness of the measures created for

the study and those measures that were selected for the study but had not been validated in a

sample of caregivers of children with a CHC. Pilot participants were a convenience sample (N =

10) of caregivers with at least one child with at least one diagnosed CHC recruited from the local community, local parent advocacy center, and word of mouth. Pilot participants met in a one-on-one or focus group format, were sent an email with a link to the full survey set on Qualtrics, read the information sheet, and completed the survey. Participants were timed to gather information about how long the survey would take to complete and were asked to assess the measures selected for the study. Pilot questions asked participants to reflect on the wording used in the survey (if questions were confusing, offensive, inapplicable, or inappropriate); if questions should be changed, altered, or reworded; if anything was missing from the survey; and if there was any other feedback or suggestions participants may have had for the survey. Pilot participants received a $10 gift card in thanks for their participation. As noted above, upon completion of the pilot study, some survey items were added, rearranged, and reworded, and some survey instructions were clarified based on feedback from pilot participants.

For the main study, participants clicked a Qualtrics survey link posted on social media flyers or recruitment emails. They first completed eligibility questions and were thanked for their interest if they were not eligible for the study. Participants who were eligible were given further instructions and asked to complete the survey. Upon completion, participants were thanked for their participation, but not individually compensated. However, recruitment sources were given $5 for every participant who completed the study via links used on recruitment material used at their site. Recruitment sources could choose to accept compensation as a donation to their organization or use the money to make a donation to another organization on behalf of their organization. All study procedures were approved by the University of Connecticut Institutional Review Board.

Analytic Plan

First, sum scores were created for all measures. Surveys that were left more than 50% blank by participants were excluded from data analysis, and sum scores for surveys that were at least 50% complete were calculated by imputing mean scores for individual items missing at random. A categorical variable for diagnosis type was created from the list of primary diagnoses reported by caregivers. Demographic variables that lacked variability, such as parents' marital status or employment status were dichotomized (into married or not married, employed or not employed, for example) to include in analyses.

Descriptive statistics and bivariate correlations were run to assess relations among study variables. Then, to answer each of the first three research questions, which asked how the DSC model's risk and protective factors were associated with caregivers' perceived benefit, caregiver burden, and psychological distress, respectively, a series of multiple linear regressions that included the DSC models' risk and protective factors as independent variables were conducted. Specific independent variables that measured the first risk factor of illness parameters included categorical diagnosis type, the child's age at diagnosis, years since diagnosis, time since last medical crisis, illness severity, and number of symptoms. Number of secondary diagnoses was not included in analyses due to its high correlation with number of symptoms, causing multicollinearity concerns. Number of secondary diagnoses was not as normally distributed as number of symptoms, likely because of the unreliability of data pertaining to the number of secondary diagnoses. Some parents did not indicate all of their child's secondary diagnoses (for example, one parent wrote "all relate" and another listed some secondary diagnoses and finished with "etc."), and some parents may have considered other symptoms or conditions to be secondary diagnoses, when they may not have been diagnosed as such. Instead of being

included in data analyses, secondary diagnoses were used to understand the nuance and complexity of the CHCs that characterized the sample. The second risk factor of child's functional impairment was specifically measured with the Peds QL total score variable and average hours of care that parents provided to children. Due to multicollinearity concerns, average hours of care provided during a weekday and during a weekend were averaged to create an "average hours of care" variable to be used in analyses. Specific independent variables related to the third risk factor of psychosocial stress included total family stressors, CHC-related stressors, and perceived stress.

Specific independent variables related to the first protective factor of stress-processing factors were problem-focused coping, emotion-focused coping, and religious coping. Independent variables associated with the second protective factor of intrapersonal characteristics included self-efficacy, internal locus of control, and problem solving confidence. Finally, specific independent variables that measured the third risk factor of social-ecological factors were family functioning total score and perceived social support. The DSC model indicates that demographic characteristics should be included as social-ecological protective factors. Demographic factors included in regression analyses were caregivers' age, highest level of education, estimated annual household income, number of other adults in the home, number of siblings in the home, dichotomized marital status, dichotomized employment status, and dichotomized number of primary caregivers (one or multiple). In general, total scores of all measures were used in regression analyses when possible instead of individual subscale scores to reduce the number of independent variables entered into regression equations.

To assess hypotheses 1a, 2a, and 3a, that parents' risk factors would be negatively related to their perceived benefit and positively related to their caregiver burden and psychological

distress, respectively, all of the DSC model's risk factors (categorical diagnosis type, the child's age at diagnosis, years since diagnosis, time since last medical crisis, illness severity, number of symptoms, functional dependence, average hours of care, family stressors, CHC-related stressors, and perceived stress) were included as independent variables in linear regression models, and perceived benefit, caregiver burden, and psychological distress were entered as the dependent variables, respectively. Then, to assess hypotheses 1b, 2b, and 3b, that parents' protective factors would be positively related to their perceived benefit and negatively related to their caregiver burden and psychological distress, respectively, all of the DSC model's protective factors (problem-focused coping, emotion-focused coping, religious coping, self-efficacy, internal locus of control, problem solving confidence, family functioning total score, perceived social support, and demographic characteristics - caregivers' age, highest level of education, estimated annual household income, number of other adults in the home, number of siblings in the home, dichotomized marital status, dichotomized employment status, and dichotomized number of primary caregivers) were entered into linear regression models as independent variables with perceived benefit, caregiver burden, and psychological distress as the dependent variables, respectively. When analyzing protective factors, the DSC model's stress-processing, intrapersonal, and social-ecological protective factors excluding demographic characteristics were entered into the second step of the regression equation (after covariates were entered into the first step), and demographic characteristics were entered into the next step of the regression equation. Analyzing demographic characteristics in a separate step of the regression model allowed for an exploration of which demographic characteristics should be considered protective factors or how such characteristics may influence parents' outcomes, questions that are not clearly addressed in the current conceptualization of the DSC model. There is evidence that the

child's developmental age impacts parenting behaviors and parents have different needs depending on their child's developmental stage (Colville & Cream, 2009; Im et al., 2014; Mednick, Cogen, Henderson, Rohrbeck, Kitessa, & Streisand, 2007; Morawska et al., 2008; Svavarsdottir, Tryggvadottir, & Sigurdardottir, 2012), indicating that regression analyses should control for the child's developmental stage. However, given the large number of independent variables included in regression analyses, a single variable for child's chronological age was included as a covariate in the first step of all regression analyses as opposed to using multiple categorical variables that dummy coded for developmental stage (early childhood, middle childhood, and adolescence).

Finally, a separate pattern of analyses was used to address the fourth research question regarding concurrent levels of caregiver health outcomes. To address hypotheses 4a and 4b, which propose a quadratic association between perceived benefit and caregiver burden and psychological distress, respectively, two curvilinear regressions were conducted. In both regression analyses, perceived benefit was the dependent variable. Quadratic variables were created by squaring both the caregiver burden total score and the psychological distress total score variables. To reduce multicollinearity in curvilinear analyses, the raw, unsquared caregiver burden and psychological distress variables were first mean centered, and then the variables were squared to create quadratic terms. In the first regression, the mean centered caregiver burden variable was entered in the second step of a hierarchical regression (after chronological age was entered as a covariate in the first step). In the third step, the quadratic term, mean centered caregiver burden squared, was entered into the equation. A significant change in r^2 is indicative of a curvilinear association. Similarly, in the second curvilinear regression analysis, mean centered psychological distress and mean centered psychological distress squared were entered

as independent variables in step two and step three of a hierarchical regression, respectively. To assess the last hypothesis, 4c, a simple correlation revealed the linear association between caregiver burden and psychological distress. As with previous linear regressions, all analyses related to the fourth research question included the child's chronological age as a covariate and chronological age was entered as the first step in all regression analyses. Continuous variables were assessed for normality with skewness and kurtosis statistics, multicollinearity was assessed with the variance inflation factor (VIF), and Cook's Distance assessed whether or not any single case had too great an impact on a single regression equation.

Power analysis. Few of the currently existing empirical studies that evaluate caregiver health outcomes calculate effect sizes unless they are calculated to compare outcomes of parents with chronically ill children to those without. In a systematic review conducted by Cousino and Hazen (2013), the average effect size for comparing outcomes in parents of children with a CHC and healthy controls was found to be .40. The primary outcome of interest in this study was the association between protective factors and perceived benefit. According to the previous description of this regression analysis, a total of 8 primary protective factors were measured. Additional analyses also included 8 demographic characteristics that were assessed as social-ecological protective factors. The 8 primary protective factors included as independent variables and the covariate of child's age were used to conduct a power analysis using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) based upon a recent study investigating perceived benefit. Gardner and colleagues (2017) found an effect size of .3 in their study of perceived benefit. Assuming the same effect size and 95% power, N = 85 participants were needed to provide adequate power to assess the primary association of interest. With a sample size of n = 82

(accounting for missing data) in this regression analysis, the regression model of interest was

slightly under powered.

Chapter 5. Results

Descriptive Statistics and Bivariate Relations

There was not enough variability in many demographic characteristics to analyze differences in outcomes based on caregivers' gender, relationship to the child, race, and insurance status. Caregivers' dichotomized marital status was not significantly related to their perceived benefit, caregiver burden, or psychological distress. However, parents who were their child's only primary caregiver experienced significantly more caregiver burden than parents who were one of multiple caregivers ($t_{(101)} = 2.20$, $p < .05$), and parents who were unemployed reported significantly more psychological distress than parents who were employed ($t_{(101)} = 3.12$, $p < .01$). An analysis of variance (ANOVA) revealed that there were no differences in caregivers' perceived benefit, caregiver burden, or psychological distress based on their source of recruitment; therefore, recruitment source was not included as a covariate in subsequent regression analyses.

An ANOVA revealed that there were significant differences in participants' caregiver burden based on diagnosis type ($F = 2.40$, $p < .05$). Tukey's post-hoc analysis indicated that caregivers of children with an immune system disorder reported significantly less caregiver burden than parents of children with a nervous system disorder ($p < .05$). An ANOVA also revealed that caregivers' psychological distress differed based on diagnosis type ($F = 3.05$, $p < .05$), with Tukey's post-hoc analysis indicating that caregivers of children with an immune system disorder reported significantly less psychological distress than caregivers of children with a mental health condition ($p < .05$). Caregivers' perceived benefit did not significantly differ based on child's diagnosis type, but caregivers of children with genetic developmental delays scored higher on perceived benefit than caregivers of children with any other type of diagnosis.

Given that the only significant difference between diagnosis types and outcome variables were related to immune system disorders, immune system disorders were used as the reference group when diagnosis types were included in subsequent regression analyses.

Pearson's correlations indicated that caregivers' perceived benefit was negatively related to the child's chronological age ($r = -.22$, $p < .05$) and positively related to some of the DSC model's risk factors, including average hours of care provided to the child ($r = .29$, $p < .01$) and CHC-related stress ($r = .23$, $p < .05$). Caregiver burden and psychological distress were both positively correlated with a number of risk factors as well, including child's number of symptoms ($r = .49$, $p < .001$; $r = .34$, $p < .001$, respectively), child's functional impairment ($r = .51$, $p < .001$; $r = .33$, $p < .001$, respectively), family stressors ($r = .28$, $p < .01$; $r = .30$, $p < .01$, respectively), CHC-related stressors ($r = .68$, $p < .001$; $r = .38$, $p < .001$, respectively), and caregivers' perceived stress ($r = .54$, $p < .001$; $r = .54$, $p < .001$, respectively). Caregiver burden was also positively related to child's illness severity ($r = .29$, $p < .01$) and number of secondary diagnoses ($r = .21$, $p < .05$).

Pearson's correlations also revealed caregivers' health outcomes were related to the DSC model's protective and demographic factors. Perceived benefit was positively correlated with caregivers' self-efficacy ($r = .22$, $p < .05$) and negatively related to caregivers' age ($r = -.24$, $p < .05$) and number of other adults in the home ($r = -.28$, $p < .01$). Both caregiver burden and psychological distress were positively related to emotion-focused coping ($r = .39$, $p < .001$; $r = .37$, $p < .001$, respectively). However, caregiver burden and psychological distress were negatively related to caregivers' internal locus of control ($r = -30$, $p < .01$; $r = -30$, $p < .01$, respectively), perceived social support ($r = -31$, $p < .01$; $r = -.36$, $p < .001$, respectively), income ($r = -30$, $p < .01$; $r = -.23$, $p < .05$, respectively), and number of other adults in the home ($r = -$

.30, $p < .01$; $r = -.22$, $p < .05$, respectively). Caregivers' psychological distress also was

negatively correlated with self-efficacy ($r = -.35$, $p < .001$), problem-solving confidence ($r = -.47$, $p < .001$), and family functioning ($r = -.23$, $p < .05$). Whereas perceived benefit was not

correlated with either caregiver burden or psychological distress, caregiver burden and

psychological distress were positively correlated with each other ($r = .46$, $p < .001$). See Tables

6-9 for more information regarding correlations between study variables.

Regression Analyses

Tests of regression assumptions were performed prior to conducting regression analyses.

The only continuous variable that was not normally distributed was number of other adults in the

home, which was positively skewed with the majority of participants having 0, 1, or 2 other

adults in the home. Therefore, number of other adults in the home was log transformed for all

analyses. No other variable was significantly skewed (>2.0) or kurtotic (>10.0), so no other

variables were transformed. The regression analyses including all DSC risk factors as described

previously would not run when both the child's age at diagnosis and years since diagnosis were

entered in the same model because of a violation of multicollinearity. Therefore, two separate

regression analyses assessing risk factors were run for each research question: the first regression

included the child's age at diagnosis and the second regression included the years since the

child's diagnosis. Results did not differ when one variable was used over the other. Reported

results are those including years since diagnosis. No other indicators included in any regression

model had a VIF greater than 5.0, and there were no Cook's Distances that exceeded 1.0, so no

additional changes were needed to the regression analyses previously described.

In sum, regression analyses that assessed DSC risk factors included categorical diagnosis

type, years since diagnosis, time since last medical crisis, illness severity, number of symptoms,

functional dependence, average hours of care, family stressors, CHC-related stressors, and perceived stress as independent variables and health outcomes (perceived benefit for research question 1, caregiver burden for research question 2, and psychological distress for research question 3) as dependent variables. The child's chronological age was included as a covariate in all regression analyses. Regression analyses that assessed DSC protective factors included problem-focused coping, emotion-focused coping, religious coping, self-efficacy, internal locus of control, problem solving confidence, family functioning total score, and perceived social support as independent variables in the second step of the regression analysis. Demographic factors, including caregivers' age, highest level of education, estimated annual household income, number of other adults in the home, number of siblings in the home, dichotomized marital status, dichotomized employment status, and dichotomized number of primary caregivers, were added to the model in the next step of the regression analysis. Health outcomes (perceived benefit for research question 1, caregiver burden for research question 2, and psychological distress for research question 3) were the dependent variables. The child's chronological age was included as a covariate in the first step of all regression analyses.

Research question 1: Perceived benefit. The first research question aimed to investigate the association between perceived benefit and the DSC model's risk and protective factors, with the first hypothesis proposing that participants' risk factors would be negatively related to their perceived benefit. This hypothesis was not supported, as the DSC model's risk factors as a whole were not significantly related to caregivers' perceived benefit ($F_{(15, 73)} = 1.77$, $p > .05$) in the first regression analysis (see Table 10). However, individual risk factors were significantly related to perceived benefit. Specifically, average hours of care provided to the child was positively related to perceived benefit ($\beta = .32$, $p < .05$) and perceived stress was the

only risk factor that was significantly negatively related to perceived benefit in the model (β = -.27, $p < .05$). Further, time since the child's last medical crisis approached significance (β = -.20, $p < .10$).

The next regression analysis assessed hypothesis 1b (see Table 11), that caregivers' protective factors would be positively related to their perceived benefit. The DSC model's protective factors excluding demographic characteristics were significantly related to caregivers' perceived benefit ($F_{(9, 73)}$ = 2.09, $p < .05$), and accounted for 10.7% of the variance in perceived benefit. However, protective factors were not significantly related to perceived benefit over and above the variance in perceived benefit attributed to the child's age (ΔR^2 = .16, $p > .05$). Emotion-focused coping was the only independent variable significantly related to perceived benefit (β = .32, $p < .01$).

When demographic characteristics were added to the model, all protective factors and demographic factors as a whole continued to be significantly related to perceived benefit ($F_{(17, 65)}$ = 2.06, $p < .05$), explaining 18.0% of the variance in perceived benefit. Demographic factors were not significantly related to perceived benefit over and above the variance attributed to the DSC model's other protective factors (ΔR^2 = .15, $p > .05$). Caregivers' emotion-focused coping remained significantly related to perceived benefit (β = .34, $p < .01$), as was caregivers' age (β = -.33, $p < .05$). Number of other adults in the home (β = -.23, $p < .10$) approached significance. It was hypothesized that protective factors would be positively related to perceived benefit, but caregivers' age was negatively associated with perceived benefit, and only emotion-focused coping served as a protective factor related to perceived benefit.

Research question 2: Caregiver burden. The second research question aimed to investigate the association between caregiver burden and the DSC model's risk and protective

factors. Hypothesis 2a predicted that participants' risk factors would be positively related to caregiver burden. Collectively, the DSC model's risk factors were significantly related to caregiver burden ($F_{(15, 73)} = 7.27$, $p < .001$) and accounted for 51.7% of the variance in caregiver burden (see Table 12). Risk factors were significantly related to caregiver burden beyond the impact of the child's chronological age ($\Delta R^2 = .60$, $p < .001$). Specifically, caregivers of children with a mental health condition were more likely than caregivers of children with an immune system disorder to report increased caregiver burden ($\beta = .19$, $p < .05$). CHC-related stress ($\beta = .32$, $p < .01$) and caregivers' perceived stress ($\beta = .27$, $p < .01$) were both positively related to caregiver burden. Time since the child's last medical crisis approached significance ($\beta = .16$, $p < .10$). The significant regression and positive associations between individual risk factors and caregiver burden supported hypothesis 2a.

Hypothesis 2b predicted that caregivers' protective factors would be negatively related to caregiver burden. The DSC model's protective factors excluding demographic factors were significantly related to caregiver burden ($F_{(9, 73)} = 3.06$, $p < .01$) above and beyond the variance in caregiver burden attributed to the child's chronological age ($\Delta R^2 = .27$, $p < .01$; see Table 13). Protective factors collectively accounted for 18.4% of the variance in caregiver burden. Emotion-focused coping was positively related to caregiver burden ($\beta = .25$, $p < .05$), and caregivers' perceived social support was negatively related to caregiver burden ($\beta = -.39$, $p < .01$). The significant regression model indicates that protective factors were related to caregiver burden, but only caregivers' perceived social support was related to their burden in the hypothesized, negative direction.

When demographic factors were added to the regression model, protective factors and demographic factors combined were not significantly related to caregiver burden ($F_{(17, 65)} = 1.70$,

$p > .05$). However, caregivers' perceived social support remained significantly related to caregiver burden ($\beta = -.36$, $p < .01$), and emotion-focused coping only approached significance ($\beta = .23$, $p < .10$). No demographic characteristics were significantly related to caregiver burden. These results indicated that only caregivers' perceived social support served as a protective factor against increased caregiver burden.

Research question 3: Psychological distress. The third research question aimed to investigate the association between psychological distress and the DSC model's risk and protective factors. Hypothesis 3a proposed that participants' risk factors would be positively related to psychological distress. Collectively, the DSC model's risk factors were related to parents' psychological distress ($F_{(15, 73)} = 7.44$, $p < .001$) after controlling for the child's chronological age ($\Delta R^2 = .60$, $p < .001$) and accounted for 52.3% of the variance in psychological distress (see Table 14). Specifically, average hours spent providing care to the child ($\beta = .20$, $p < .05$) and caregiver' perceived stress ($\beta = .74$, $p < .001$) both were related positively to caregivers' psychological distress. Caregivers of a child with a mental health condition were almost significantly more likely to report increased psychological distress compared to caregivers of children with an immune system disorder ($\beta = .17$, $p < .10$). The positive association between risk factors and psychological distress supported hypothesis 3a.

Hypothesis 3b predicted that caregivers' protective factors would be negatively related to psychological distress. The DSC model's protective factors were significantly related to psychological distress ($F_{(9, 73)} = 6.54$, $p < .001$) after controlling for the child's chronological age ($\Delta R^2 = .45$, $p < .001$) and accounted for 37.8% of the variance in psychological distress (see Table 15). Emotion-focused coping was positively related to caregiver burden ($\beta = .40$, $p < .001$); whereas, caregivers' problem-solving confidence ($\beta = -.35$, $p < .05$) and perceived social

support ($\beta = -.25$, $p < .05$) were negatively related to psychological distress, partially supporting hypothesis 3a.

When demographic characteristics were added to the model, the DSC model's protective factors and demographic factors together were significantly related to psychological distress ($F_{(17, 65)} = 4.17$, $p < .001$), but demographic characteristics did not contribute to psychological distress more than protective factors alone ($\Delta R^2 = .08$, $p > .05$). Emotion-focused coping remained positively related to psychological distress ($\beta = .34$, $p < .001$) and parents' perceived social support remained negatively related to psychological distress ($\beta = -.26$, $p < .05$). With the addition of demographic characteristics, problem-solving confidence only approached significance ($\beta = -.26$, $p < .10$) and being employed was almost significantly negatively related to psychological distress ($\beta = -.20$, $p < .10$). No other demographic characteristics were significantly related to psychological distress. The continued positive association between emotion-focused coping and psychological distress indicated that emotion-focused coping may not serve as a protective factor against psychological distress.

Research question 4: Concurrent relations. The fourth research question aimed to examine the concurrent associations between perceived benefit, caregiver burden, and psychological distress. Curvilinear regression analysis assessed hypothesis 4a, that caregivers' perceived benefit and caregiver burden would have a curvilinear association (see Table 16). Analyses revealed that caregiver burden was related to perceived benefit in a quadratic pattern, such that caregivers perceived more benefit at moderate levels of burden ($F_{(3, 104)} = 5.03$, $p < .01$; $\beta = -.29$, $p < .01$). This association was significant beyond the variance in perceived benefit attributed to the child's chronological age and a linear association with caregiver burden ($\Delta R^2 = .07$, $p < .01$) and accounted for 10.2% of the variance in perceived benefit. This finding

supported hypothesis 4a. Hypothesis 4b, that there would be a curvilinear association between perceived benefit and psychological distress, was not supported (see Table 17). Regression analyses revealed that there was neither a linear nor a curvilinear association between perceived benefit and psychological distress above the variance in perceived benefit attributed to the child's chronological age.

Hypothesis 4c predicted a positive, linear association between caregiver burden and psychological distress. There was a positive association between caregiver burden and psychological distress as indicated by the significant, positive correlation between the two variables ($r = .46, p < .001$). Further regression analyses indicated that caregiver burden was significantly related to psychological distress ($F_{(2, 100)} = 51.57, p < .001; \beta = .46, p < .001$) above and beyond the variance attributed by the child's chronological age ($\Delta R^2 = .21, p < .001$), and psychological distress was significantly related to caregiver burden ($F_{(2, 100)} = 13.96, p < .001; \beta = .47, p < .001$) above and beyond the variance attributed by the child's chronological age ($\Delta R^2 = .22, p < .001$). These results supported hypothesis 4c.

Chapter 6. Discussion

The DSC model previously has been used most frequently to investigate negative health outcomes for parents of children with a CHC, with only one study having used the DSC model to examine positive health outcomes in parents of children with developmental disabilities (Findler et al., 2016). The primary objective of the current study was to use the DSC model to take a strength-based perspective in the investigation of caregivers' positive health outcomes, namely perceived benefit, in relation to parenting a child with a CHC. The study also investigated how the DSC model's risk and protective factors were associated with more traditional negative health outcomes, such as caregiver burden and psychological distress. In accordance with the tenets of the DSC model, it was hypothesized that risk factors would be related to less positive and more negative health outcomes and protective factors would be related to more positive and less negative health outcomes.

Research Question 1: Perceived Benefit

The first research question asked how parents' perceived benefit was related to the DSC model's risk and protective factors, with hypotheses 1a and 1b predicting that parents' risk factors would be negatively related to perceived benefit and parents' protective factors would be positively related to perceived benefit, respectively. As a whole, the DSC model's risk factors were not significantly related to parents' perceived benefit, which did not support hypothesis 1a. Current findings revealed no association between most of the child's illness parameters and parents' perceived benefit, results that are in line with previous research indicating that illness parameters do not play a large role in caregivers' health (Brown et al., 2000; Cousino & Hazen, 2013; Findler et al., 2016; Guðmundsdóttir et al., 2006). However, trending toward significance was the negative association between time since the child's last medical crisis and caregivers'

perceived benefit, indicating the importance of acute medical events in the context of ongoing health struggles when assessing caregivers' perceived benefit. The DSC model's second risk factor, the child's functional dependence on others to perform daily tasks, has been found to be important in predicting caregivers' positive health outcomes in past research (Gardner et al., 2017). However, in the current study, the child's functional impairment was not related to caregivers' perceived benefit. Surprisingly, average hours of care caregivers provided to children was significantly associated with caregivers' perceived benefit, but in an unexpected direction. In accordance with the DSC model, average hours of care provided to children was conceptualized as a risk factor for decreased perceived benefit, but current results showed that average hours of care provided to children was actually positively related to caregivers' perceived benefit, indicating that it was not a risk factor for decreased benefit in caregivers of children with a range of CHCs. This finding supports research suggesting that parents who gain the most benefit from their difficult caregiving experiences are those who are directly involved in providing care to their child on an everyday basis (Cadell et al., 2014).

The only risk factor significantly associated with decreased perceived benefit in the current study was caregivers' perceived stress. Neither CHC-related stress nor general family stressors were related to perceived benefit. Although existing literature has investigated a link between stress and negative health outcomes, less research has investigated the link between stress and positive health outcomes. When investigating positive health outcomes in the current study, it seems that the degree to which caregivers perceived events to be taxing, distressing, and beyond their ability to manage was more important than the objective occurrence of a stressful life event, whether it was related to the child's condition or not.

Collectively, the DSC model's protective factors were related to parents' perceived benefit. Individually, the only stress-processing factor that was related to perceived benefit was emotion-focused coping, which was positively associated with perceived benefit. There is evidence outside of the caregiver literature that emotion-focused coping (rather than problem-focused coping) is more often used and especially adaptive when faced with a stressor that is perceived as uncontrollable (such as the diagnosis of an illness or the death of a family member; Carver et al., 1989; Folkman, 1984; Folkman & Lazarus, 1980; Haines et al., 2016; Kendall & Terry, 2008; Roussi, 2002). When children have a CHC, caregivers may be able to help children manage the condition, but the child's CHC may be perceived as uncontrollable in that it is not likely to disappear or be cured, helping to explain why emotion-focused coping was related to a positive outcome in the current study.

None of the DSC model's second protective factors of intrapersonal characteristics that were analyzed in this study, including problem solving confidence, self-efficacy, and internal locus of control, were significantly related to perceived benefit; however, social ecological factors, especially demographic factors, were related to perceived benefit. For example, caregivers' age was related to perceived benefit, but the negative association indicated that age might not be a protective factor, as the DSC model would suggest, when investigating caregivers' perceived benefit. Researchers have seldom investigated the link between caregivers' age and perceived benefit from caring for a child with a CHC, and those that have did not find a significant relation (Gardner et al., 2017). However, one study of parents of children with intellectual disabilities in Japan revealed a negative association between parents' age and their distress (Kono & Mearns, 2013), and there is evidence in the general parenting literature that parents' age is positively related to health outcomes such as happiness and well-being and

negatively related to health outcomes such as stress and depressive symptoms (Nelson, Kushlev, & Lyubomirsky, 2014). Nelson and colleagues (2014) explain that it is not necessarily parents' age that impacts their well-being, but rather parents' material and emotional resources, which generally increase with age. However, in the current study, when other demographic factors that provide more information about caregivers' resources, such as education or income, were included in regression analyses, only caregivers' age was significantly related to perceived benefit. In the current sample of caregivers providing specialized, health-related, often strenuous and taxing care to their child with a CHC, it may be that older caregivers are more weary and suffer more from the physical and emotional consequences of providing this extra care to their child with a CHC than their younger counterparts, which in turn may lead older caregivers to perceive less benefit from their caregiving experiences.

Another finding that did not support study hypotheses was the negative association between the number of other adults in the home and perceived benefit, which was trending toward significance, implying that caregivers who lived with more other adults perceived less benefit from caregiving. Simply asking how many other adults live in the home provided no information about who those other adults were, the relationship dynamics between them, their level of involvement in child care, or the amount of social support they provided; therefore, it is unclear from the current results why having more adults in the home was related to decreased perceived benefit. Nevertheless, results indicated that social support and general family functioning were not significantly related to caregivers' perceived benefit, so there may be explanations outside of feelings of support and family dynamics that were driving the negative association between number of adults in the home and caregivers' perceived benefit. For example, if there are two adults in a home that both provide care to the child and these two adults

disagree on key parenting values or the way that they manage their child's illness, having

multiple adults in the home would likely provide more stress, as opposed to more benefit.

Research Question 2: Caregiver Burden

In addition to investigating caregivers' positive health outcomes, the current study also

examined more traditional negative health outcomes, including caregiver burden and

psychological distress. The second research question examined how the DSC model's risk and

protective factors were associated with parents' caregiver burden, with hypotheses 2a and 2b

predicting that caregivers' risk factors would be positively related to caregiver burden and

caregivers' protective factors would be negatively related to caregiver burden, respectively.

Most illness parameters, the DSC model's first risk factor, were not significantly related to

caregiver burden, with the exception of diagnosis type. This finding supports previous research

that indicates illness parameters are generally not related to negative health outcomes (Brehaut et

al., 2011; Cousino & Hazen, 2013; Guðmundsdóttir et al., 2006; Hatzmann et al., 2009;

Hatzmann et al., 2014). Much research investigates parents' negative health outcomes in relation

to parenting a child with a specific CHC diagnosis, but the current study including caregivers of

children with a range of diagnoses revealed that caregivers of children with a mental health

diagnosis had greater caregiver burden than caregivers of children with an immune system

diagnosis. This supports previous research findings that parents of children with CHCs that are

characterized by emotional distress or emotional difficulties, such as anxiety or depression, tend

to have parents who experience decreased well-being (Cousino & Hazen, 2007; Klassen et al.,

2007). One other illness parameter was trending toward significance in that the time since the

child's last medical crisis was significantly positively related to caregivers' burden at the $p < .10$

level. Again, this result indicates the potential importance of the time since the child's last acute

medical event when considering both caregivers' positive and negative health outcomes in the context of parenting a child with a chronic, ongoing condition.

The DSC model's second risk factor, the child's functional impairment, was not significantly related to caregiver burden in the current sample, despite repeated evidence in extant literature that functional impairment is one of the most robust predictors of parents' negative health outcomes (Brehaut et al., 2011; Cousino & Hazen, 2013; Guðmundsdóttir et al., 2006; Hatzmann et al., 2009; Hatzmann et al., 2014; Vermaes et al., 2008). However, the DSC model's third risk factor, stress-processing, was strongly related to caregiver burden. Both CHC-related stressors and perceived stress were positively related to caregiver burden. Previous research has found that experiencing a greater number of stressors is associated with increased burden (Schneider et al., 2011). Most existing research has explored the impact of general life stressors or parenting stress, but few studies have explicitly explored the impact of direct CHC-related stressors. Those that do either study CHC-related stress in a qualitative way or study specific CHC-related stressors, such as complex treatments or trouble in school, individually. The current study explored the impact of a composition of CHC-related stressors, and found that CHC-related stress does play an important role in increasing caregivers' experiences of burden. Similarly, the degree to which caregivers perceived events in their lives to be stressful and beyond their ability to manage contributed to their experiences of felt burden.

Results suggest that the DSC model's protective factors were related to decreased caregiver burden, but one protective factor was actually related to increased burden. Specifically, caregivers' emotion-focused coping was positively related to caregiver burden. This finding is in line with extant research that indicates problem-focused coping is a protective factor against increased negative outcomes, but emotion-focused coping is actually a risk factor

for increased negative health outcomes (Brown et al., 2000; Cousino & Hazen, 2013; Fiks et al., 2015; Grey et al., 2011; Guðmundsdóttir et al., 2006; Kazak, 2005; Klassen et al., 2007; Noojin & Wallander, 1997; Warner et al., 2011). However, the finding that emotion-focused coping and caregiver burden are positively related is noteworthy in light of general coping literature that suggests that emotion-focused coping is an adaptive way to manage uncontrollable stressors, including health-related stressors (Carver et al., 1989; Folkman, 1984; Folkman & Lazarus, 1980; Kendall & Terry, 2008; Roussi, 2002). Though caregivers cannot change their child's diagnosis and therefore having a child with a CHC can be considered a stressor that cannot be controlled, caregivers can exert control over the way they experience burden or provide care to their child with a CHC, which could explain the positive association between emotion-focused coping and caregiver burden.

None of the DSC model's intrapersonal protective factors included in the current study were significantly related to caregiver burden. Further, no demographic factors were related to caregiver burden. However, caregivers' perceived social support was negatively associated with their burden. Caregivers often report being burdened by feelings of loneliness and feelings of being different from other parents, but satisfactory levels of emotional and instrumental social support help mitigate experiences of burden (Gannoni & Shute, 2010; Hughes et al., 2015; McNeill et al., 2014).

Research Question 3: Psychological Distress

The third research question examined how the DSC model's risk and protective factors were associated with parents' psychological burden, with hypotheses 3a and 3b predicting that caregivers' risk factors would be positively related to psychological distress and caregivers' protective factors would be negatively related to psychological distress, respectively. Current

results support previous research that indicates illness parameters are not strongly related to caregivers' negative health outcomes (Brehaut et al., 2011; Cousino & Hazen, 2013; Guðmundsdóttir et al., 2006; Hatzmann et al., 2009; Hatzmann et al., 2014). Similar to the association with caregiver burden, caregivers of children with a mental health diagnosis reported more psychological distress than caregivers of children with an immune system disorder at the $p < .10$ level. Again, having a child with a mental health diagnosis seems to be a risk factor for increased negative health outcomes for caregivers, at least when compared to parents of children with an immune system disorder.

Although the child's level of functional impairment did not impact the psychological distress of caregivers in the current sample, the more time caregivers in this sample engaged in providing care to their child with a CHC, the more psychological distress they reported. In terms of psychological distress for the current sample, how functionally limited the child was because of his or her CHC was not as important as how these functional limitations led to increased hours of care for caregivers. The final risk factor that was positively associated with psychological distress was perceived stress levels. Caregivers' general family stressors and CHC-specific stress were not related to their psychological distress. Again, it seems in the current sample that the presence of objective stressors were not as meaningful for caregivers' psychological distress as the way that caregivers perceive events as stressful and beyond their capacity to manage.

The DSC model suggests that effective stress-processing, or coping, strategies would decrease caregivers' negative health outcomes, but in the current sample, caregivers' emotion-focused coping was positively related to psychological distress. Similar to the association with caregiver burden, it seems that emotion-focused coping was a risk factor, rather than a protective factor, for caregivers' psychological distress. Although caregivers' problem-focused coping was

not related to their psychological distress, caregivers' confidence in their problem solving ability was negatively related to their psychological distress when demographic characteristics were not included in the regression model. Caregivers' problem solving confidence was only trending toward significance when demographic characteristics were added to the model, indicating that caregivers' problem solving confidence was less important to their psychological distress when variance due to demographic factors, or markers of their resources, was taken into consideration.

Caregivers' perceived social support was the only social-ecological factor that was related to parents' psychological distress. Again, the presence of social support has been found in past research to be a strong protective factor against caregivers' negative health outcomes (Gannoni & Shute, 2010; Hughes et al., 2015; McNeill et al., 2014), and the current results support the protective ability of perceived social support.

Research Question 4: Concurrent Relations

The final research question sought to examine the concurrent associations between all caregiver health outcomes, hypothesizing a curvilinear association between perceived benefit and caregiver burden (hypothesis 4a), a curvilinear association between perceived benefit and psychological distress (hypothesis 4b), and a positive, linear association between caregiver burden and psychological distress (hypothesis 4c). Results supported hypothesis 4a in that moderate levels of caregiver burden were related to the highest levels of perceived benefit, whereas high and low levels of caregiver burden were related to lower levels of perceived benefit. This finding is in line with findings from Colville and Cream (2009), who concluded that caregivers who experience extreme levels of distress, whether high or low, experience low levels of PTG. Caregivers who were not very burdened by their caregiving experience seem to find low levels of perceived benefit, as their caregiving may not be an undue or unusual

experience. Caregivers on the other end of the spectrum who were highly burdened by their experience may have been so overwhelmed by their caregiving tasks that they were unable to see beyond their strain to get to a point where they saw benefit in their situation. Rather, highly burdened caregivers may have been so consumed with managing their child's condition and their energy may have been so focused on their own burden that they did not have resources remaining to perceive a positive benefit from their caregiving role. Colville and Cream (2009) also suggest that there may be a ceiling effect in finding benefit in a stressful situation such that parents who are extremely burdened do not find any more benefit than parents who are moderately burdened.

A similar association was hypothesized to exist between perceived benefit and psychological distress (hypothesis 4b). However, results revealed no significant relationship between perceived benefit and psychological distress. Perceived benefit and psychological distress were not significantly correlated, nor were they linearly or curvilinearly related in regression analyses. In the current sample of caregivers, it seems that their levels of burden were important in their ability to find meaning in caregiving, but their degree of psychological distress was not. The measure of psychological distress used in this study was a general measure of distress, with subscales including somatization, depression, and anxiety. No questions in this measure assessed distress in direct relation to caregiving, but instead measured general distress in parents' everyday lives during the past week. By contrast, the measure of caregiver burden asked questions directly related to the care provided to children as a result of their CHC, which could explain why caregiver burden was related to perceived benefit but caregivers' general distress was not.

Finally, caregiver burden and psychological distress were positively and linearly related as hypothesized (hypothesis 4c). It is not surprising that caregivers who were more burdened by their caregiving experience reported more somatization, depression, and anxiety symptoms. Caregiver burden has been found in previous research to be negatively related to caregivers' mental health (Chaney et al., 2016; Chang, Chiou, & Chen, 2010). It is widely found that having a child with a CHC is related to decreases in parents' physical and mental health (Brehaut et al., 2011; Chang et al., 2010; Miodrag, Burke, Tanner-Smith, & Hodapp, 2015; McNeill et al., 2014; Nicholas & Keilty, 2007), and parents who are suffering from depression have more difficulty managing their child's illness (Morawska et al., 2008).

DSC Risk Factors and Parents' Health Outcomes

The current study uniquely investigated the utility of the DSC model in examining both caregivers' positive and negative health outcomes. Results align well with findings from previous research, but are not always in line with tenets of the DSC model. Research indicates that many illness parameters, including the child's symptomatology, age at diagnosis, and time since diagnosis, are not related to caregivers' health outcomes (Brehaut et al., 2011; Cousino & Hazen, 2013; Findler et al., 2016; Guðmundsdóttir et al., 2006; Hatzmann et al., 2009; Hatzmann et al., 2014). Results of this study support past research findings in that each of these illness parameters were not related to caregivers' health outcomes in the current sample as well. One exception is that the time since the child's last medical crisis was trending toward significance in its relation to both perceived benefit and caregiver burden. Time since the child's last medical crisis has not been examined as a factor related to caregivers' health, with researchers instead choosing to study age at diagnosis or time since diagnosis. However, with the ongoing, chronic nature of CHCs included in this study, it may be that the occurrence of acute medical events may

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trigger changes in the consistency or routine of illness management and play an important role in caregivers' health. Indeed, during interviews conducted as part of the pilot study for this research, many participants spontaneously discussed their child's last medical crisis, emphasized the importance of changes that occurred as a result of the child's last medical crisis, and/or explained that their current health was a result of the time it had been since the child's last acute medical event.

The only other illness parameter that was related to caregivers' health outcomes was having a child with a mental health condition. Previous research has indicated that caregivers of children with emotional or behavioral symptoms experience the greatest distress and suffer from decreased well-being (Cousino & Hazen, 2007; Klassen et al., 2007). It may be that there is something qualitatively different about a mental health diagnosis affecting emotional and behavioral functioning that induces more negative health outcomes for caregivers when compared to a condition that primarily impacts the child's physical health. For example, mental health diagnoses are often more stigmatized than physical health diagnoses, and parents may know less about how to help their child manage mental health symptoms while at the same time potentially receiving less support from family and friends who do not understand or pass judgment about the child's mental health condition. There is also evidence of a genetic component to some mental health conditions, indicating that children with mental health diagnoses may also have parents with mental health diagnoses, which may lead to increased parental psychological distress (Franić, Middeldorp, Dolan, Ligthart & Boomsma, 2010; Rice, Harold, & Thapar, 2002). Further, extant research has found that parents with increased psychological distress before their child's CHC diagnosis are more likely to experience persistence in their psychological distress (Carpentier, Mullins, Wolfe-Christensen, & Chaney,

2008; Cousino & Hazen, 2013) and are likely to have difficulty managing, or helping their child

to manage, the CHC (Morawska et al., 2008). Future research should gather more information

about parents' mental health, perhaps asking research participants about their own mental health

diagnoses, to further investigate how parenting a child with a mental health condition may differ

from parenting a child with a different type of CHC diagnosis.

Contrary to most extant literature that indicates that the child's degree of functional

impairment is one of the most significant factors associated with caregivers' health outcomes

(Brehaut et al., 2011; Cousino & Hazen, 2013; Gardner et al., 2017; Guðmundsdóttir et al., 2006;

Hatzmann et al., 2009; Hatzmann et al., 2014; Vermaes et al., 2008), the child's functional

impairment in the current study was not related to any health outcomes in regression analyses

despite the positive correlation between functional impairment and caregivers' health outcomes,

including both caregiver burden and psychological distress. It appears that when all other risk

factors are included in regression analyses, functional impairment no longer carries as much

weight in its association with perceived benefit or negative health outcomes. However,

caregivers' average hours of care provided to children was significantly related to perceived

benefit and psychological distress. Perhaps it is not necessarily the child's functional impairment

that impacts caregivers' health, but rather the subsequent level of care that must be provided to

children as a result of their functional limitations. Contrary to what may have been expected

based on its categorization as a risk factor, caregivers' average hours of care for children was

positively related to their perceived benefit, but this finding is in line with previous research that

indicates that caregivers who gain the most benefit from their difficult caregiving experiences are

those that are directly involved in providing care to their child on an everyday basis (Cadell et

al., 2014).

The final risk factor that was consistently related to both parents' positive and negative health outcomes was caregivers' perceived stress. Perceived stress was negatively related to caregivers' perceived benefit and positively related to their burden and psychological distress. Although CHC-related stress also was positively associated with caregiver burden, an association that supports previous research (Schneider et al., 2011), general family stressors were not significantly related to any caregiver health outcomes in this study (Brown et al., 2000). Existing research indicates that caregivers who experience more stress, regardless of the source of the stress, experience more negative and less positive health outcomes (Findler et al., 2016; Guðmundsdóttir et al., 2006; Noojin & Wallander, 1997; Schneider et al., 2011). Some life events (change in marital status, change in employment status, change in residence) or CHC-related events (change in treatment, hospital stay, trouble at school due to the child's condition) are widely acknowledged stressful events with which many caregivers must contend. However, previous research and the current finding that perceived stress was related to caregivers' health outcomes indicates that it is not necessarily whether or not a stressful event has occurred that is related to caregivers' health outcomes, but rather the way that the event is cognitively appraised and the degree to which caregivers feel they have the resources to manage the situation (Chaney et al., 2016; Cousino & Hazen, 2013; Folkman, 1984; Folkman & Lazarus, 1980; Folkman et al., 1986; Gamwell, Mullins, Tackett, Suorsa, Mullins, & Chaney, 2016; Ryan, Mullins, Ramsey, Bonner, Jarvis, Gillaspy, & Chaney, 2013). The Perceived Stress Scale (Cohen et al., 1983) used in this study to measure perceived stress is not context-dependent, but rather asked participants to rate the degree to which they experienced general stress over the past month as measured by feelings of upset and powerlessness without connecting these feelings to a specific event or stressor in particular. It appears, then, that caregivers who are overwhelmed, unable to cope,

lack confidence in their ability to manage problems, and feel upset, angry, or nervous about events in their life, regardless of what these events are or what their relationship to the child's CHC is, suffer negative health consequences.

DSC Protective Factors and Parents' Health Outcomes

The DSC model indicates that stress-processing factors, or coping styles, are important to protect against caregivers' negative health outcomes. Previous research has indicated that problem-focused coping is inversely related to negative health outcomes (Brown et al., 2000; Cousino & Hazen, 2013; Fiks et al., 2015; Grey et al., 2011; Guðmundsdóttir et al., 2006; Kazak, 2005; Klassen et al., 2007; Noojin & Wallander, 1997; Warner et al., 2011). Results of the current study revealed no significant associations between problem-focused coping and perceived benefit, caregiver burden, or psychological distress. Similarly, previous research and the current qualitative pilot study indicated that religious or spiritual coping influence patients' and caregivers' adjustment and health outcomes (Carney & Park, 2018; Gannoni & Shute, 2010; Garner et al., 2017; Park et al., 2017), but no such association was discovered in the current sample. Instead, emotion-focused coping was found to be significantly, positively associated with all study outcomes, including perceived benefit, caregiver burden, and psychological distress. Despite its classification as a protective factor in the DSC model, emotion-focused coping has been associated with increased negative health outcomes (Brown et al., 2000; Cousino & Hazen, 2013; Fiks et al., 2015; Grey et al., 2011; Guðmundsdóttir et al., 2006; Kazak, 2005; Klassen et al., 2007; Noojin & Wallander, 1997; Warner et al., 2011), and the same association was found in the current study. However, extant literature has found that emotion-focused coping also plays a role in improving positive outcomes, namely parent's ability to find meaning in their caregiving experience (Gannoni & Shute, 2010; Garner et al., 2017).

It seems that the DSC model should be revised to clarify the role that parents' particular coping strategies may play in impacting parents' positive and negative health outcomes. That emotion-focused coping was positively related to both positive and negative health outcomes implies that this coping strategy can act as both a protective factor and a risk factor when assessing parents' health outcomes. There is evidence that indicates that individuals employ a range of different coping strategies depending on the event or stressor, and coping is context-dependent, such that a coping style that may be adaptive in one situation may be maladaptive in another situation (Driscoll et al., 2016; Folkman, 1984; Haines et al., 2016; Rubio, Dumitrache, Cordon-Pozo, & Rubio-Herrera, 2016). Therefore, it would be wise of researchers interested in caregivers' health outcomes to investigate parents' coping strategies in reference to a particular situation, specifically in regards to managing their child's CHC or the stress created by their child's CHC. It may be that managing some uncontrollable CHC-related stressors, such as the unpredictable nature of many CHCs, may be effectively done in an emotion-focused way, while some other more controllable CHC-related stressors, such as calling doctor's offices or insurance companies, may best be tackled with a problem-focused strategy (Haines et al., 2016). Future research should investigate which stressors are best managed in an emotion- or problem-focused way. There is further evidence that, when faced with a particularly taxing and overwhelming stressor, such as a CHC, individuals employ a variety of coping strategies, including problem- and emotion-focused coping, simultaneously, and being in control of one's emotions is the first step in managing any situation (Folkman, 1984). Therefore, the repeated positive associations between emotion-focused coping and caregivers' health outcomes may simply point to the frequency with which parents use emotion-focused coping and may not be indicative of any predictive relation between emotion-focused coping and health outcomes at all.

The second protective factor proposed by the DSC model, caregivers' intrapersonal characteristics, was not associated with caregivers' positive or negative health outcomes. Many existing interventions that target a decrease in caregivers' negative health outcomes aim to increase their problem solving capacity and/or problem solving confidence (Askins et al., 2009; Law et al., 2014; Lindström et al., 2015; Noojin & Wallander, 1997; Trivedi, 2013). However, in the current study, caregivers' problem solving confidence was only related to their psychological distress when demographic factors were not taken into consideration, and it was unrelated to perceived benefit or caregiver burden. Further, caregivers' general self-efficacy and internal locus of control were not significantly related to their health outcomes. Previous research indicates that caregivers who lack self-efficacy in their ability to effectively manage their child's illness suffer increased trauma and that a perceived mastery of caregiving tasks is protective for caregivers (Cousino & Hazen, 2013; Guðmundsdóttir et al., 2006; Klassen et al., 2007). It could be that intrapersonal factors were generally unrelated to caregivers' health outcomes in this study because study measures assessed caregivers' problem solving confidence, self-efficacy, and locus of control in a general sense, not specific to managing their child's CHC.

The DSC model's final protective factor involves the family's social-ecological context. One weakness of the DSC model is that it fails to meaningfully include demographic characteristics into the conceptualization of social-ecological factors, aside from briefly acknowledging that demographic characteristics exist (Wallander & Varni, 1998). Therefore, the current study included an investigation of the ways that demographic characteristics are related to caregivers' health outcomes. Previous research indicates that parents with more resources (i.e. higher education, higher income) and parents with the support of a spouse are less likely to experience negative health outcomes, but that these factors are not influential in parents' positive

outcomes, specifically PTG (Brehaut et al., 2011; Klassen et al., 2011; Michel et al., 2010). Two demographic factors (caregivers' age and number of other adults in the home) were negatively related to caregivers' perceived benefit in the current study, indicating that these demographic factors may be risk, rather than protective, factors. As mentioned previously, the physical demands of caring for a child with a CHC could be more taxing for older parents, thus decreasing their perceived benefit, and more information regarding the relationship and task division between multiple caregivers in a home would be needed to draw conclusions about the association between number of adults in the home and caregivers' perceived benefit. No demographic factors were significantly related to caregivers' negative health outcomes.

Instead of focusing on demographic characteristics, social-ecological factors as described by the DSC model primarily refer to caregivers' perceived social support and family functioning. The current results supported past research that indicates that social support does act as a protective factor against caregivers' negative health outcomes (Brown et al., 2000; Findler et al., 2016; Hazmann et al., 2009; Klassen et al., 2007; Nicholas & Keilty, 2007). However, family dynamics, including family communication and division of roles, were found to be unrelated to caregivers' health outcomes in the current study. Qualitative research often finds that family dynamics, especially clear patterns of communication, division of caregiving tasks, and a sense of teamwork and togetherness, are crucial to effectively manage the child's CHC (McNeill et al., 2014), but it does not appear that family dynamics that facilitate effective family management of the child's condition also impact individual parents' health outcomes.

Study Implications

Research implications. The current research is the first known study to simultaneously assess all three of the DSC model's risk and protective factors in relation to caregivers' positive

and negative health outcomes in a sample of caregivers of children with a range of CHCs. As such, four conclusions can be made about the utility of the DSC model from the current results. First, in the current sample of well-resourced caregivers, the DSC model should be restructured when used to assess caregivers' positive health outcomes, such as perceived benefit. In its current form, the DSC model seems to be a relatively useful tool to understand *what* factors may impact caregivers' perceived benefit, but based on results of the current study, it may not accurately describe *how* these factors impact caregivers' perceived benefit. For example, increased hours of care provided to the child was related to increased perceived benefit in this study despite being conceptualized by the DSC model as a risk factor. Further, the DSC model generally considers demographic characteristics to be protective factors for caregivers, but the model does not adequately explain how or why demographic factors may be protective. In fact, current results indicate that some demographic factors, such as caregivers' age and number of other adults in the home, may actually act as risk factors for caregivers' perceived benefit, despite being unrelated to more negative health outcomes, such as caregiver burden and psychological distress. Further research is needed to understand how risk and protective factors, including demographic characteristics, are related to caregivers' positive health outcomes, in particular, and exactly how the DSC model should be re-conceptualized to examine caregivers' positive health outcomes.

Second, current results indicate that two factors make especially important contributions to parents' health outcomes in the current sample: caregivers' perceived stress and emotion-focused coping. As such, future investigations of caregivers' health outcomes should include an assessment of each of these factors, and any variation of the DSC model should include both perceived stress and emotion-focused coping as important constructs. However, as mentioned

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previously, more information regarding if and when emotion-focused coping acts as a protective versus a risk factor is needed.

Third, although illness parameters are not generally related to caregivers' health outcomes, one illness parameter in particular requires further investigation. Specifically, the time since the child's last medical crisis should be added to the DSC's conceptualization of illness parameters. Time since the child's last medical crisis is not often included in research regarding parents' health outcomes, but both qualitative and quantitative findings from the current study and its pilot effort indicate this is an important construct related to caregivers' current health that warrants more research.

Fourth, results of the current study combined with findings from previous research suggest that caregivers' intrapersonal characteristics are not related to their health outcomes in a general sense, but it is more likely that their intrapersonal characteristics related directly to providing care and managing their child's CHC impact caregivers' health outcomes. For example, the current study measured caregivers' general problem-solving confidence and general self-efficacy, and results indicated that neither was related to caregivers' health outcomes. However, previous research indicates that caregivers who have confidence in their ability to solve problems directly related to their child's CHC and who have a high degree of efficacy when it comes to managing their child's CHC have better health outcomes (Askins et al., 2009; Cousino & Hazen, 2013; Guðmundsdóttir et al., 2006; Klassen et al., 2007; Law et al., 2014; Lindström et al., 2015; Noojin & Wallander, 1997; Trivedi, 2013). An amendment to the DSC model's protective factors could be made to indicate that intrapersonal factors offer protection for positive health outcomes and against negative health outcomes only when considered in relation to the child's CHC.

Practice implications. The results of this study help researchers and clinicians gain a better understanding of caregivers' health outcomes for a homogenous group of well-resourced parents when they are faced with the challenge of parenting a child with a CHC. It is widely acknowledged that parents of children with a CHC experience poorer health outcomes than parents of healthy children (Burke et al., 2014; Cousino & Hazen 2013; Hungerbuehler et al., 2011; Jubber et al., 2013; McNeill et al., 2014; Pinquart, 2013), and to optimally support parents who may be experiencing burden or psychological distress, clinicians must first understand what factors are related to these negative health outcomes. Findings suggest that interventions should seek to decrease parents' felt stress and increase parents' perceived social support, as both are related to parents' caregiver burden and psychological distress.

Generally, the most effective way to reduce felt stress is to improve one's coping processes; however, results of the current study indicate that problem-focused coping and religious coping are unrelated to caregivers' health, and results are mixed in terms of the effectiveness of emotion-focused coping to positively impact caregivers' health. Whereas emotion-focused coping may be useful to increase perceived benefit, it is also related to increased caregiver burden and psychological distress and would likely not be a good target for interventionists. Results are clearer in terms of the usefulness of perceived social support. Although perceived support was unrelated to perceived benefit, it was negatively related to caregiver burden and psychological distress, making it an ideal target for interventionists. Interventions that aim to increase perceived social support will decrease parents' sense of isolation, loneliness, and feelings of being different from other parents of healthy children, factors that have been found to be related to increased burden (Brandon, 2007; Hughes et al., 2015; McNeill et al., 2014; Pinquart, 2013). Indeed, many existing interventions specifically

seek to improve parents' perceived support through support groups or the use of peer mentors who also have a child with a CHC (Hughes et al., 2015; Mackey, Herbert, Monaghan, Cogen, Wang, & Streisand, 2016; Nicholas & Keilty, 2007; Sullivan-Bolyai, Bova, Leung, Trudeau, Lee, & Gruppuso, 2010). An evaluation of one social support intervention for parents of children with Autism Spectrum Disorder (ASD) found that participants reported fewer mental health symptoms and used more adaptive coping as a result of participating in the intervention (Clifford & Minnes, 2013). It seems, then, that focusing on improving social support for parents of children with a CHC would not only decrease parents' negative health outcomes, but also decrease felt stress through the use of adaptive coping strategies.

One strength of this study is that it considers factors related to caregivers' health outcomes for parents of children with a range of CHCs. Most existing research focuses on the experiences of caregivers whose children share a diagnosis. However, the current results indicate that the type of condition that a child has is generally unrelated to their caregivers' health outcomes in this sample of well-supported participants, except in the case of mental health diagnoses. Many support groups and interventions that aim to support caregivers are diagnosis-specific, but the current results suggest that interventions could include caregivers of children with a range of diagnoses, including immune system disorders, nervous system disorders, circulatory system disorders, and genetic developmental delays. This may be especially important for parents of children with genetic developmental delays, many of which are caused by rare genetic or chromosomal abnormalities. For caregivers of children with these types of rare condition, it would be very difficult to create a support group of parents whose children share a specific diagnosis, but if social support interventions were open to parents with a range of

diagnoses, these parents of children with rare conditions would still be able to receive the support they need to improve their health.

Further, although many caregivers report benefitting from participating in support groups, some parents report dissatisfaction with support that comes from other parents with whom they are not compatible, even if both parents have children with the same diagnosis (Nicholas & Keilty, 2007). Creating support groups or interventions that target a larger and more varied group of caregivers may help parents participating in such programs to feel as though they have a whole community of people who support them and share in their experience and a range of caregivers from whom they can receive support and guidance, which would likely increase their well-being and decrease their feelings of isolation that heighten their felt burden. Study results indicate that the exception may be caregivers of children with mental health conditions, who seem to experience burden and distress differently from caregivers of children with other conditions. Given the lack of significant differences in caregivers' risk and protective factors and the lack of difference in caregivers' health outcomes as a function of diagnosis and other illness parameters, future research should consider if there are other details about a child's condition, such as the child's life expectancy, the prevalence of the child's condition, or the perceived stigma of the child's condition, that may impact caregivers' health outcomes.

Another strength of this study is its strength-based perspective in understanding caregivers' positive health outcomes and the protective factors that may help increase caregivers' perceived benefit and decrease their perceived burden and psychological distress. Most studies that examine caregivers' health outcomes do so with a deficit-based approach, focusing on the factors that put parents most at risk for experiencing high levels of burden and distress. Interventionists who assume that their participants are by definition lacking or deficient in some

quality will structure their intervention and interact with their participants in a way that may perpetuate negative outcomes or alienate participants who recognize the strengths they already have (Rogoff, Coppens, Alcalá, Aceves-Azuara, Ruvalcaba, López, & Dayton, 2017). For caregivers, a more successful approach would likely be to administer strength-based interventions that recognize the potential growth and benefit in their participants' caregiving context and work to improve these perceptions of benefit. Participants in strength-based interventions, which seek to empower participants by building on personal assets, are better able to partner with interventionists to problem solve and achieve behavioral goals (Rapp, Goscha, & Fukui, 2015; Sams, Garrison, & Bartlett, 2016). Strength-based interventions have been successful when used with participants with mental health concerns in a healthcare setting (Rapp et al., 2015; Sams et al., 2016; Tse et al., 2016) and would likely be effective for caregivers of children with a CHC as well. This study helps remind researchers, interventionists, and caregivers that parents of children with a CHC are strong and they can remain positive even in their difficult parenting journey.

Finally, it is important to remember that improving parents' well-being likely will improve parents' caregiving ability as well. For example, research suggests that caregivers who experience greater burden are less likely to understand and effectively utilize health care services and their children experience increased unmet healthcare needs as a result (McManus, Carle, Acevedo-Garcia, Ganz, Hauser-Cram, & McCormick, 2011). Further, parental well-being plays an important role in shaping parent-child relationship and their child's well-being. The family context is the most immediate context for children; therefore, supporting parents has the dual benefit of supporting children as well. Research is clear that parents struggling with their own mental health have worse parent-child relationships and strained parents have less supportive,

affectionate, and responsive relationships with healthy and ill children (Im et al., 2014; Newland, 2015; Pinquart, 2013). There is further evidence in the caregiving literature that burdened informal caregivers engage in less positive and supportive caregiving behaviors (Smith et al., 2011). Improving the mental, emotional, and physical health of informal parent caregivers will have meaningful implications on their children's well-being by improving the quality of their relationships and the quality of the care they provide to their child with a CHC.

Study Limitations

The implications of the current study must be considered in light of study limitations. One limitation of the current research is the cross-sectional nature of the study design. Given that data were only collected at a single time point and no longitudinal data were gathered, the results yield no information regarding causality. Even the regression analyses conducted as part of this study must be interpreted in light of the cross-sectional design and the predictive direction cannot be confirmed with the data gathered from this study. Future researchers would be wise to study caregivers' health outcomes longitudinally to examine how outcomes change over time and to confirm the direction of the predictive relationships between the variables. Further, as mentioned, due to the number of independent variables used in linear regression analyses and the amount of missing data, linear regression analyses assessing the association between risk and protective factors and study outcomes were slightly underpowered. Therefore, caution must be taken when interpreting the results of statistical analyses and drawing conclusions about how the DSC model's risk and protective factors were related to caregivers' perceived benefit, caregiver burden, and psychological distress.

The study was also limited by its reliance on self-report measures to assess each of the variables. With no objective measure of caregivers' own mental health or well-being and no

objective or medically verified information regarding their child's CHC, the data collected may have been biased by the participant reporting the information. For example, it is possible that caregivers who were experiencing a large degree of burden or distress may have perceived their child's condition to be worse than it actually was or otherwise inaccurately reported information regarding their child's condition. Including medical information about the child's CHC in future research could help alleviate this bias. However, due to HIPAA constraints and the online, anonymous nature of participant recruitment, objective or other-report information was not possible in the current study.

There were further limitations as a result of participant recruitment for this study. The third protective factor proposed by the DSC model is social-ecological factors, which includes perceptions of social support. Each of the recruitment sources for this study explicitly focuses on providing informational, instrumental, and social support and resources to parents of children with a range of CHCs, support and resources that many caregivers often lack (Douma et al., 2006; Gannoni & Shute, 2008; Nicholas & Keilty, 2007). In this way, the current sample is not a representative sample of caregivers of children with a CHC. Therefore, it is likely that the participants in this study tended to report increased social support, or increased social-ecological protective factors, compared to the larger population of caregivers with a child with a CHC, and they may have reported more benefit, less burden, and less psychological distress because they receive more support than an average group of caregivers of children with a CHC. In the future, it would be important to seek research participants who experience a range of support levels. Not only would caregivers experiencing the lowest levels of support represent increased need as caregivers who may likely reap the most benefit from the study results and subsequent

interventions, but it is also important to recruit participants who would yield a wide range of outcomes and data points for the proposed study variables.

Similarly, the current data were derived from a sample that was very homogenous in terms of demographic variability, and study results cannot be generalized to caregivers with different demographic characteristics. The vast majority of participants were white, married, relatively wealthy, and well educated. Each of these demographic characteristics indicates a level of support, advantage, cumulative privilege, and greater access to resources and healthcare that would not be experienced by non-White, not married, and/or poorly educated caregivers with less income, who likely perceive less benefit, more burden, and more distress in caring for their child with a CHC. Therefore, it is important to note that the findings and implications of the current study are limited in their generalizability and should not be applied to caregivers outside of this study's sampling frame. Further, the current study offers no information regarding fathers' health outcomes when they have a child with a CHC, as the majority of the sample were biological mothers of children with a CHC. It is important to consider how fathers' experiences may differ from mothers', particularly at a time when stay at home fathers are becoming more common and more fathers are engaged in daily care for their children. Examining how best to support burdened or distressed fathers while increasing their perceived benefit is crucial to fathers', families', and children's health and well-being.

Conclusion

Results of the current study advance the caregiving literature by examining, from a strength-based perspective, what factors best support well-resourced mothers of children with a range of CHCs. Regression analyses revealed that caregivers' perceived stress and emotion-focused coping played crucial roles in caregivers' health outcomes, and specific child diagnoses

and illnesses parameters, with the exception of time since the child's last medical crisis, were generally unrelated to caregivers' health. Although the DSC model seemed to function well in relation to caregivers' negative health outcomes, revisions are needed in the way that researchers and clinicians may use the DSC model to understand parents' perceived benefit from their caregiving situation. Findings from this research suggest that interventions should seek to improve caregivers' perceived social support and decreased their perceived stress. One way to do this is to open support interventions to a range of caregivers whose children have different diagnoses but who are similarly burdened or distressed by their caregiving experience. It is also important to note that parents may perceive benefit from their experience of caring for a child with a CHC and that there is more to their role as a caregiver than burden and distress. Helping caregivers to remember the benefit they may experience and helping them to decrease their felt burden or distress would ultimately lead to improved health and well-being for children and whole families, not to mention the individual parent. Regardless of the study findings, it is important for future research to investigate how a more diverse, representative sample of mothers and fathers of all races, ethnicities, marital statuses, and education and income levels are impacted by their caregiving experiences.

Table 1

Study measures

DSC Type	Construct	Measure	Items	α	Citation
Risk factor: illness factors	Features of the child's illness	Questions regarding the child's diagnosis, age at diagnosis, and symptoms. Items are a compilation of items from diagnosis-specific assessments of illness factors and symptomology.			
Risk factor: functional impairment	Functional impairment	Pediatric Quality of Life (PedsQL 4.0)	23 items on 4 subscales; 5-pt Likert scale	.74-.92	Varni et al. (2003)
Risk factor: psychosocial stress	General life stressors	Abbreviation of Family Inventory of Life Events and Changes	10 items; yes/no response	N/A	(McCubbin et al., 1982)
	Illness-related stressors	List of potential CHC-related stressors compiled from previous literature on a 5-point Likert scale			
	Perceived stress	Perceived Stress Scale (PSS)	10-items; 5-pt Likert scale	.78	Cohen et al. (1983)
Protective factor: stress-processing factors	Problem- & emotion-focused, & religious coping	4 subscales of the COPE	4 items per subscale; 4-pt Likert scale	.62-.92	Carver et al. (1989)
Protective factor: intrapersonal factors	Self-efficacy	Generalized Self-Efficacy Scale (GSE)	10 items; 4-pt Likert scale	.76-.90	Schwarzer & Jerusalem, (1995)
	Locus of Control	Internal Locus of Control subscale of the Levenson Multidimensional Locus of Control Scale	8 item subscale; 6-pt Likert scale	.68	Levenson (1974)
	Problem solving	Problem Solving Confidence subscale of the Problem Solving Inventory (PSI)	11 items 6-pt Likert scale	.85	Heppner & Petersen, (1982)
Protective factor: social-ecological factors	Family functioning	Communication and Roles subscales of the Family Assessment Device (FAD)	6 and 8 items respectively; 4-pt Likert scale	.72-.75	Epstein et al. (1983)
	Perceived Social Support	Multidimensional Scale of Perceived Social Support (MSPSS)	12 items on 3 subscales; 7-pt Likert scale	.85-.91	Zimet et al. (1988)
Outcome	Perceived benefit	The Benefit Finding Scale (BFS)	17 items on 5-pt Likert scale	.95	Antoni et al. (2001)
Outcome	Caregiver burden	Caregiver Burden Inventory (CBI)	24 items on 5 subscales; 5-pt Likert scale	.73-.86	Novak & Guest, (1989)
Outcome	Well-being	Brief Symptom Inventory-18 (BSI-18)	18 items on 3 subscales; 5-pt	.71-.89	Derogatis & Melisaratos,

		Likert scale	(1983)

Table 2

Caregiver demographic information (N=118)

Variable	M (Range)	SD	N	%
Age	42.89 (28-68)	7.67		
Other adults in the home	1.09 (0-5)	0.73		
Other siblings in the home	0.88 (0-3)	0.89		
Gender				
Male			4	4.0
Female			108	96.0
Relationship to child				
Biological parent			106	94.5
Adoptive parent			5	4.5
Grandparent			1	1
Race				
White			101	90.0
Black/African American			1	1.0
Hispanic/Latino			3	3.0
Asian			2	2.0
Multiracial			3	3.0
Other			2	2.0
Marital Status				
Married			96	86.0
Not married			16	14.0
Highest level of education				
High school or Less			6	5.0
Some college			16	14.0
2 year college			12	11.0
4 year college			31	28.0
Some graduate school			5	4.5
Graduate degree			42	37.5
Employment Status				
Not employed			42	37.5
Employed			70	62.5
Estimated annual household income				
< $20k			6	6.0
$20k-$39,999			11	11.0
$40k-$59,999			14	13.5

$60k-$79,999	14	13.5
$80k-$99,999	12	11.5
$100k-119,999	13	12.5
$120k-$139,999	9	9.0
> $140k	24	23.0
Primary caregiver*		
Only primary caregiver	28	27.0
One of multiple caregivers	76	72.0
Not the primary caregiver	1	1.0
Live with the child		
All of the time	101	96.0
Most of the time	3	3.0
Some of the time	1	1.0
Insurance status		
Has insurance	99	95.0
Does not have insurance	5	5.0

Table 3

Child characteristics

Variable	Mean (Range)	SD	N	%
Age at diagnosis (Yrs)	4.64 (0-17)	6.64		
Current age (Yrs)	10.8 (3-18)	4.74		
Time since diagnosis (Yrs)	6.12 (0-18)	4.27		
Severity	68.69 (15-100)	19.93		
Number of symptoms	14.79 (2-46)	7.57		
Number of secondary diagnoses	2.57 (0-15)	2.75		
Average hours of care/day	14.67 (0-24)	6.65		
Time since last medical crisis				
< 30 days ago			43	37.0
1-3 months ago			19	16.0
3-6 months ago			15	13.0
6-12 months ago			11	9.5
1-3 years ago			18	15.5
3-5 years ago			7	6.0
> 5 years ago			4	3.0

Table 4

Child CHC diagnosis types

Type	n	%	Description	Examples
Genetic Developmental Delay	12	10	Genetic condition that causes pervasive developmental delay, often including intellectual disability (separate from diagnosed developmental delay or intellectual disability defined in the DSM-5 by virtue of the genetic/chromosomal etiology)	Down Syndrome/Trisomy 21, Fragile X Syndrome, Rett Syndrome, 22Q
Mental Health	20	17	Mental health diagnosis included and described in the DSM-5	Autism (Spectrum Disorder), Generalized Anxiety Syndrome, Anorexia Nervosa, Borderline Personality Disorder
Immune System	25	21	Disorder characterized by a heightened, weakened, or otherwise abnormal immune response	Anaphylactic Food Allergies, Diabetes Type 1, Immune Deficiency, Eosinophilic Esophagitis (EOE)
Nervous System	26	22	Condition that causes symptoms primarily related to the brain, neural connections, or nervous system, including pain disorders	Cerebral Palsy, Microcephaly, Epilepsy/Lennox-Gestaut Syndrome, Chronic Regional Pain Syndrome
Circulatory System	12	10	Condition that causes symptoms primarily related to the heart, blood, and circulatory system	Sickle Cell Disease, Heart Transplant, Hemophila A, Postural Orthostatic Tachycardia Syndrome (POTS)
Other	23	20	Any condition, including respiratory or digestive conditions, that do not fit into any other category but are not common enough in the current sample to have a separate category	Asthma, Short Bowel Syndrome, Mitochondrial Disease, Duchenne Muscular Dystrophy

Table 5

Descriptive statistics of main study variables (N=118)

Construct	n	Mean	SD	Range	Possible Range	Reliability
Child's Functional Impairment	110	44.35	16.59	3.15-80	0-84	0.91
General Life Stressors	118	2.27	2.07	0-9	0-10	NA
CHC-Related Stressors	112	27.75	11.59	0-52	0-52	0.88
Perceived Stress	93	21.83	6.88	4-39	0-40	0.88
Problem-Focused Coping	93	25.40	4.56	15-32	8-32	0.87
Emotion-focused Coping	94	10.30	3.06	4-16	4-16	0.80
Religious Coping	94	9.10	4.55	6-16	4-16	0.96
Self-Efficacy	93	30.62	4.95	18-40	10-40	0.90
Internal Locus of Control	97	30.50	6.03	16-43	8-48	0.67
Problem-Solving Confidence	96	50.15	9.76	24-66	11-66	0.92
Family Functioning	96	35.13	5.78	18-47	14-56	0.79
Perceived Social Support	98	59.12	13.28	13-84	12-84	0.91
Perceived Benefit	110	44.11	14.31	4-68	0-68	0.93
Caregiver Burden	115	44.57	18.66	0-85	0-100	0.94
Psychological Distress	103	19.45	15.53	0-70	0-72	0.89

Table 6

Correlation matrix with illness parameters and outcomes

Variable	1	2	3	4	5	6	7	8	9	10	11
1 Child's Age	-	-	-	-	-	-	-	-	-	-	-
2 Child's Age at Diagnosis	.59***	-	-	-	-	-	-	-	-	-	-
3 Years since Diagnosis	.47***	-.44***	-	-	-	-	-	-	-	-	-
4 Time since Last Medical Crisis	.02	-.06	.08	-	-	-	-	-	-	-	-
5 Average Hours of Care	-.36***	-.12	-.27**	-.10	-	-	-	-	-	-	-
6 Severity	-.01	.05	-.07	-.21*	.39***	-	-	-	-	-	-
7 Number of Secondary Diagnoses	-.03	-.06	.04	-.11	.09	-.03	-	-	-	-	-
8 Number of Symptoms	.09	.17	-.80	-.22*	.09	.22*	.48***	-	-	-	-
9 Perceived Benefit	-.22*	-.14	-.10	-.17	.29**	.17	.09	.12	-	-	-
10 Caregiver Burden	-.11	.03	-.15	.01	.17	.29**	.21*	.49***	.12	-	-
11 Psychological Distress	.03	.11	-.09	-.12	.07	.10	.15	.34***	-.02	.46***	-

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

Table 7

Correlation matrix with risk factors (excluding illness parameters) and outcomes

Variable	1	2	3	4	5	6	7
1 Child's Functional Impairment	-	-	-	-	-	-	-
2 Family Stressors	.26**	-	-	-	-	-	-
3 CHC-Related Stress	.56***	.35***	-	-	-	-	-
4 Perceived Stress Scale	.42***	.44***	.44***	-	-	-	-
5 Perceived Benefit	.06	.01	.23*	-.11	-	-	-
6 Caregiver Burden	.51***	.28**	.68***	.54***	.12	-	-
7 Psychological Distress	.33***	.30**	.38***	.72***	-.02	.46***	-

Note: * *p* < .05; ** *p* < .01; *** *p* < .001

Table 8

Correlation matrix with protective factors (excluding demographic characteristics) and outcomes

Variable	1	2	3	4	5	6	7	8	9	10	11
1 Problem-Focused Coping	-	-	-	-	-	-	-	-	-	-	-
2 Emotion-Focused Coping	-.08	-	-	-	-	-	-	-	-	-	-
3 Religious Coping	.07	.07	-	-	-	-	-	-	-	-	-
4 Self-Efficacy	.59***	-.25*	.11	-	-	-	-	-	-	-	-
5 Internal Locus of Control	.30**	-.22*	.05	.42***	-	-	-	-	-	-	-
6 Problem Solving Confidence	.53***	-.24*	.07	.74***	.48***	-	-	-	-	-	-
7 Family Functioning	.07	-.06	-.09	.19	.23*	.24*	-	-	-	-	-
8 Social Support	.17	.04	-.07	.19	.25*	.22*	-.39***	-	-	-	-
9 Perceived Benefit	.16	.20	.16	.22*	.09	.18	.18	.17	-	-	-
10 Caregiver Burden	.01	.39***	.07	-.15	-.30**	-.20	-.11	-.31**	.12	-	-
11 Psychological Distress	-.20	.37***	.16	-.35***	-.30**	-.47***	-.23*	-.36***	-.02	.46***	-

Note: * *p* < .05; ** *p* < .01; *** *p* < .001

Table 9

Correlation matrix with demographic characteristics and outcomes

Variable	1	2	3	4	5	6	7	8
1 Parent's Age	-	-	-	-	-	-	-	-
2 Parent's Education	-.08	-	-	-	-	-	-	-
3 Income	.18	.19	-	-	-	-	-	-
4 Other Adults in Home (Lg1)	.05	-.10	.31**	-	-	-	-	-
5 Siblings	-.01	.13	.26**	.34***	-	-	-	-
6 Perceived Benefit	-.24*	-.00	-.12	-.28**	-.15	-	-	-
7 Caregiver Burden	-.03	.05	-.20*	-.30**	-.18	.12	-	-
8 Psychological Distress	-.04	.18	-.23*	-.22*	.08	-.02	.46***	-

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

Table 10

Multiple linear regression model with DSC risk factors as independent variables and perceived benefit as the dependent variable (n=88)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					1.96	0.01	
Constant	48.85	3.39		0.00			
Child's age	-0.42	0.30	-0.15	0.16			
Model 2					1.78	0.12	0.25
Constant	48.64	8.91		0.00			
Child's age	0.05	0.41	0.02	0.91			
Developmental diagnosis	0.60	5.90	0.01	0.92			
Mental health diagnosis	-5.25	4.87	-0.14	0.28			
Nervous system diagnosis	2.26	4.16	0.07	0.59			
Circulatory system diagnosis	-3.50	5.32	-0.08	0.51			
Other diagnoses	1.86	4.60	0.06	0.69			
Time since diagnosis	0.18	0.40	0.06	0.66			
Most recent medical crisis	-1.48	0.83	-0.20	0.08			
Average hours of care	0.65	0.26	0.32	0.01			
Severity	-0.03	0.08	-0.04	0.71			
Number of symptoms	-0.14	0.29	-0.08	0.63			
Functional impairment	-0.07	0.14	-0.09	0.62			
Family stressors	0.90	0.80	0.14	0.26			
CHC-related stressors	0.22	0.17	0.19	0.19			
Perceived Stress	-0.55	0.26	-0.27	0.04			

Table 11

Multiple linear regression model with DSC protective factors as independent variables and perceived benefit as the dependent variable (n=82)

Variable	B	SE B	β	p	F	R²	ΔR²
Model 1					3.44	0.03	
Constant	49.61	3.43		0.00			
Child's age	-0.57	0.31	-0.20	0.07			
Model 2					2.09	0.11	0.16
Constant	-0.02	16.41		1.00			
Child's age	-0.31	0.33	-0.11	0.35			
Problem-focused coping	0.27	0.39	0.09	0.48			
Emotion-focused coping	1.41	0.51	0.32	0.01			
Religious coping	0.02	0.33	0.01	0.96			
General self-efficacy	0.22	0.47	0.08	0.65			
Internal locus of control	-0.04	0.28	-0.02	0.89			
Problem solving confidence	0.29	0.23	0.21	0.21			
Family Functioning	-0.05	0.31	-0.02	0.87			
Perceived social support	0.11	0.13	0.11	0.37			
Model 3					2.06	0.18	0.15
Constant	30.86	20.42		0.14			
Child's age	0.40	0.40	0.14	0.32			
Problem-focused coping	0.43	0.39	0.15	0.26			
Emotion-focused coping	1.54	0.51	0.34	0.00			
Religious coping	-0.09	0.33	-0.03	0.79			
General self-efficacy	0.55	0.47	0.20	0.25			
Internal locus of control	-0.03	0.29	-0.01	0.92			
Problem solving confidence	0.14	0.23	0.10	0.56			
Family Functioning	-0.24	0.31	-0.10	0.45			
Perceived social support	0.16	0.13	0.16	0.23			
Parent age	-0.58	0.26	-0.33	0.03			
Highest level of education	-1.12	0.98	-0.13	0.26			
Family's estimated income	-0.01	0.74	0.00	0.99			
Number of adults in the home	-26.23	15.50	-0.23	0.10			
Number of siblings in the home	-1.21	1.76	-0.08	0.49			
Married	-6.07	5.28	-0.15	0.25			
Employed	2.34	3.54	0.08	0.51			
Multiple caregivers	2.23	3.63	0.07	0.54			

Table 12

Multiple linear regression model with DSC risk factors as independent variables and caregiver burden as the dependent variable (n=88)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					0.09	-0.10	
Constant	48.08	4.52		0.00			
Child's age	-0.12	0.40	-0.03	0.77			
Model 2					7.27	0.52	0.60
Constant	-10.73	8.69		0.22			
Child's age	-0.32	0.40	-0.09	0.42			
Developmental diagnosis	4.25	5.76	0.07	0.46			
Mental health diagnosis	9.69	4.75	0.19	0.05			
Nervous system diagnosis	4.08	4.06	0.10	0.32			
Circulatory system diagnosis	3.50	5.19	0.06	0.50			
Other diagnoses	-1.35	4.49	-0.03	0.77			
Time since diagnosis	0.14	0.39	0.03	0.73			
Most recent medical crisis	1.55	0.81	0.16	0.06			
Average hours of care	0.42	0.25	0.16	0.10			
Severity	0.03	0.08	0.03	0.73			
Number of symptoms	0.37	0.28	0.15	0.20			
Functional impairment	0.20	0.14	0.18	0.15			
Family stressors	0.07	0.78	0.01	0.93			
CHC-related stressors	0.50	0.16	0.32	0.00			
Perceived Stress	0.73	0.25	0.27	0.00			

Table 13

Multiple linear regression model with DSC protective factors as independent variables and caregiver burden as the dependent variable (n=82)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					0.26	-0.01	
Constant	49.09	4.58		0.00			
Child's age	-0.21	0.41	-0.06	0.61			
Model 2					3.06	0.18	0.27
Constant	68.90	20.51		0.00			
Child's age	-0.57	0.41	-0.15	0.17			
Problem-focused coping	0.70	0.48	0.18	0.15			
Emotion-focused coping	1.44	0.64	0.25	0.03			
Religious coping	0.21	0.41	0.05	0.61			
General self-efficacy	-0.37	0.59	-0.10	0.53			
Internal locus of control	-0.46	0.35	-0.15	0.20			
Problem solving confidence	-0.07	0.28	-0.04	0.81			
Family Functioning	0.22	0.38	0.07	0.57			
Perceived social support	-0.51	0.16	-0.38	0.00			
Model 3					1.70	0.13	0.04
Constant	75.82	27.54		0.01			
Child's age	-0.19	0.54	-0.05	0.72			
Problem-focused coping	0.86	0.52	0.22	0.10			
Emotion-focused coping	1.35	0.69	0.23	0.05			
Religious coping	0.09	0.45	0.02	0.84			
General self-efficacy	-0.30	0.63	-0.08	0.63			
Internal locus of control	-0.25	0.40	-0.08	0.53			
Problem solving confidence	-0.14	0.31	-0.08	0.66			
Family Functioning	0.19	0.42	0.06	0.65			
Perceived social support	-0.51	0.18	-0.38	0.01			
Parent age	-0.26	0.34	-0.11	0.45			
Highest level of education	0.36	1.33	0.03	0.79			
Family's estimated income	-0.35	0.99	-0.05	0.73			
Number of adults in the home	-16.66	20.91	-0.11	0.43			
Number of siblings in the home	-1.85	2.37	-0.09	0.44			
Married	3.91	7.12	0.08	0.58			
Employed	-1.55	4.77	-0.04	0.75			
Multiple caregivers	-2.78	4.90	-0.07	0.57			

Table 14

Multiple linear regression model with DSC risk factors as independent variables and psychological distress as the dependent variable (n=88)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					0.33	-0.01	
Constant	18.29	3.97		0.00			
Child's age	0.20	0.35	0.06	0.57			
Model 2					7.44	0.52	0.60
Constant	-26.94	7.60		0.00			
Child's age	0.11	0.35	0.03	0.75			
Developmental diagnosis	-5.34	5.04	-0.10	0.29			
Mental health diagnosis	7.65	4.16	0.17	0.07			
Nervous system diagnosis	1.11	3.55	0.03	0.76			
Circulatory system diagnosis	5.44	4.54	0.11	0.23			
Other diagnoses	2.83	3.93	0.07	0.47			
Time since diagnosis	0.07	0.34	0.02	0.83			
Most recent medical crisis	-0.04	0.71	-0.01	0.95			
Average hours of care	0.47	0.22	0.20	0.04			
Severity	-0.04	0.07	-0.05	0.55			
Number of symptoms	0.29	0.25	0.14	0.24			
Functional impairment	-0.07	0.12	-0.08	0.55			
Family stressors	-1.04	0.68	-0.14	0.13			
CHC-related stressors	0.10	0.14	0.08	0.47			
Perceived Stress	1.74	0.22	0.73	0.00			

Table 15

Multiple linear regression model with DSC protective factors as independent variables and psychological distress as the dependent variable (n=82)

Variable	B	SE B	β	p	F	R²	ΔR²
Model 1					0.02	-0.01	
Constant	18.79	3.82		0.00			
Child's age	0.05	0.34	0.02	0.89			
Model 2					6.54	0.38	0.45
Constant	40.48	14.92		0.01			
Child's age	-0.21	0.30	-0.07	0.48			
Problem-focused coping	0.31	0.35	0.10	0.38			
Emotion-focused coping	1.94	0.47	0.40	0.00			
Religious coping	0.14	0.30	0.04	0.63			
General self-efficacy	-0.02	0.43	-0.01	0.95			
Internal locus of control	0.03	0.26	0.01	0.91			
Problem solving confidence	-0.51	0.21	-0.35	0.02			
Family Functioning	-0.20	0.28	-0.08	0.47			
Perceived social support	-0.27	0.11	-0.25	0.02			
Model 3					4.17	0.40	0.08
Constant	38.77	19.09		0.05			
Child's age	-0.16	0.38	-0.05	0.68			
Problem-focused coping	0.31	0.36	0.10	0.39			
Emotion-focused coping	1.63	0.48	0.33	0.00			
Religious coping	-0.02	0.31	-0.01	0.94			
General self-efficacy	-0.19	0.44	-0.06	0.67			
Internal locus of control	0.23	0.27	0.09	0.41			
Problem solving confidence	-0.38	0.22	-0.26	0.08			
Family Functioning	-0.28	0.29	-0.11	0.33			
Perceived social support	-0.28	0.12	-0.26	0.03			
Parent age	0.00	0.24	0.00	0.99			
Highest level of education	1.03	0.92	0.11	0.26			
Family's estimated income	-0.83	0.69	-0.13	0.23			
Number of adults in the home	-9.78	14.49	-0.08	0.50			
Number of siblings in the home	2.17	1.64	0.13	0.19			
Married	6.14	4.93	0.14	0.22			
Employed	-6.35	3.31	-0.20	0.06			
Multiple caregivers	0.35	3.39	0.01	0.92			

Table 16

Multiple curvilinear regression model with caregiver burden as the independent variable and perceived benefit as the dependent variable (n=107)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					5.41	0.04	
Constant	51.02	3.34		0.00			
Child's age	-0.67	0.29	-0.22	0.02			
Model 2					3.16	0.04	0.01
Constant	50.59	3.37		0.00			
Child's age	-0.63	0.29	-0.21	0.03			
Caregiver burden	0.07	0.07	0.09	0.34			
Model 3					5.03	0.10	0.07
Constant	51.40	3.27		0.00			
Child's age	-0.40	0.29	-0.13	0.17			
Caregiver burden	0.01	0.07	0.02	0.85			
Caregiver burden squared	-0.01	0.00	-0.29	0.00			

Table 17

Multiple curvilinear regression model with psychological distress as the independent variable and perceived benefit as the dependent variable (n=102)

Variable	B	SE B	β	p	F	R^2	ΔR^2
Model 1					5.34	0.04	
Constant	50.97	3.48		0.00			
Child's age	-0.69	0.30	-0.22	0.02			
Model 2					2.65	0.03	0.00
Constant	50.96	3.49		0.00			
Child's age	-0.69	0.30	-0.22	0.02			
Psychological distress	-0.01	0.09	-0.01	0.90			
Model 3					1.77	0.02	0.00
Constant	50.81	3.57		0.00			
Child's age	-0.70	0.31	-0.23	0.02			
Caregiver burden	-0.03	0.12	-0.03	0.81			
Psychological distress squared	0.00	0.00	0.03	0.82			

Figure 1

Risk and protective factors associated with caregivers' health outcomes using the disability-stress-coping model
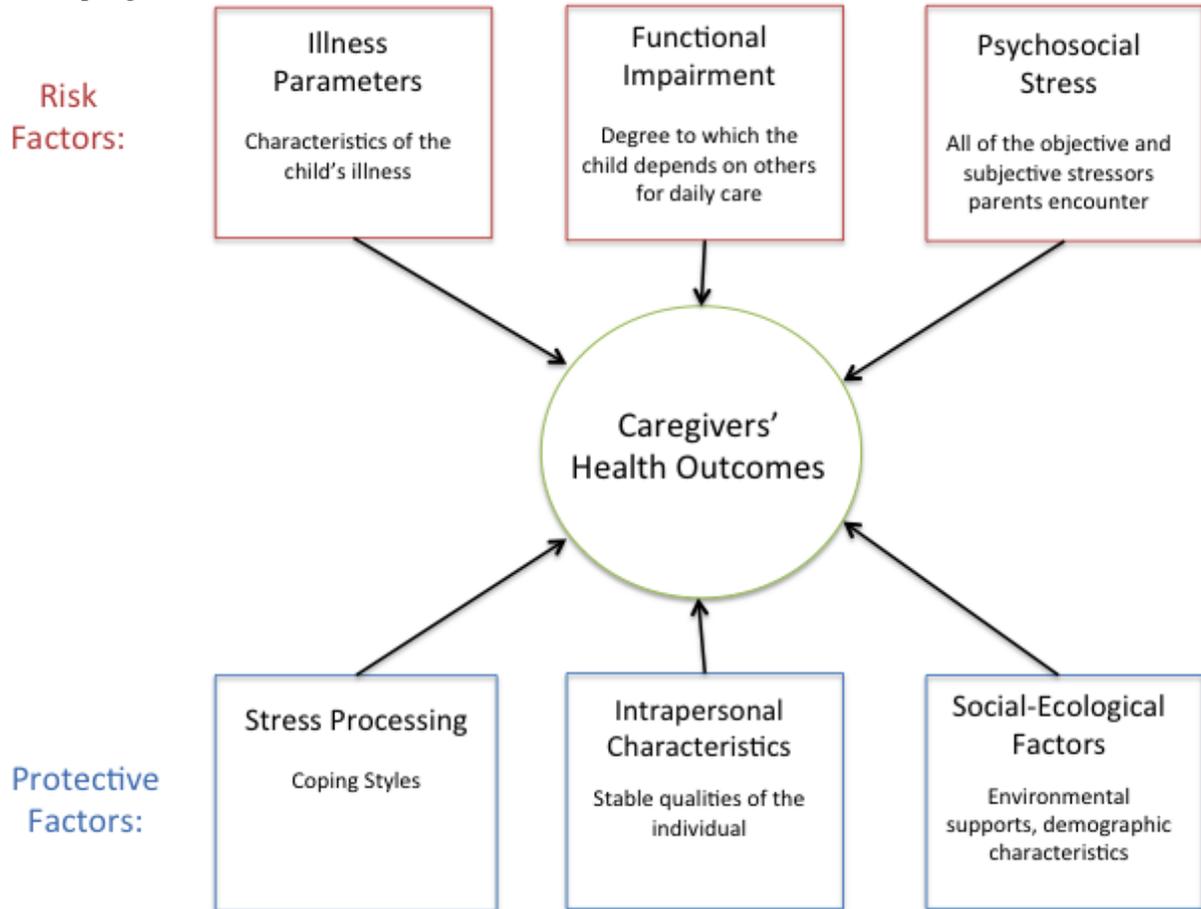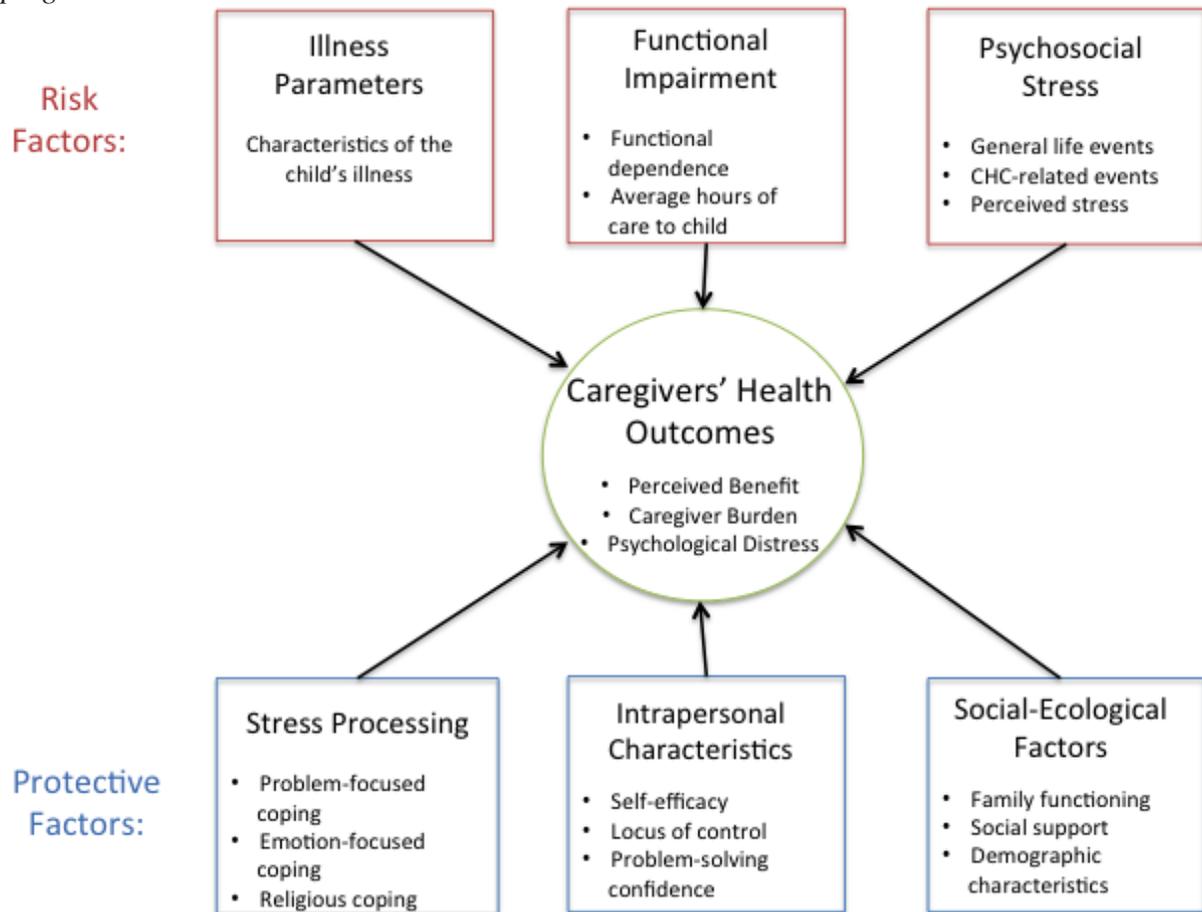
Figure 2

Study constructs related to caregivers' health outcomes as inspired by the disability-stress-coping model

Risk Factors:

Illness Parameters

Characteristics of the child's illness

Functional Impairment

- Functional dependence
- Average hours of care to child

Psychosocial Stress

- General life events
- CHC-related events
- Perceived stress

Caregivers' Health Outcomes

- Perceived Benefit
- Caregiver Burden
- Psychological Distress

Protective Factors:

Stress Processing

- Problem-focused coping
- Emotion-focused coping
- Religious coping

Intrapersonal Characteristics

- Self-efficacy
- Locus of control
- Problem-solving confidence

Social-Ecological Factors

- Family functioning
- Social support
- Demographic characteristics

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