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Benefit Finding among Caregivers of Childhood Cancer Survivors

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BENEFIT FINDING AMONG CAREGIVERS OF CHILDHOOD CANCER SURVIVORS

by

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MEDICAL/CLINICAL PSYCHOLOGY

ABSTRACT

With improved survival rates for children diagnosed with cancer brings a focus on the psychological adjustment of both children and caregivers. Benefit finding, defined as positive change in the face of adversity, has been documented among caregivers of children with cancer and other chronic illness conditions. The first manuscript is a comprehensive literature review of studies investigating benefit finding among caregivers of children with chronic illness conditions, including caregiver demographic and psychosocial, and child demographic and medical predictors, as well as outcomes of benefit finding. The second manuscript reports on predictors of benefit finding in a sample of caregivers of childhood cancer survivors, and indicated that positive spiritual coping, optimism, and illness impact uniquely predicted benefit finding. The third manuscript examined outcomes of benefit finding among caregivers, specifically as benefit finding relates to quality of life. The relationship between benefit finding and quality of life was moderated by demographic and psychosocial variables such that benefit finding was more strongly related to quality of life for caregivers with lower resources. Overall, results point to caregivers who may be at greater risk for reduced psychological health outcomes and identify points of intervention to promote positive adaptation among caregivers of childhood cancer survivors.

Keywords: benefit finding, cancer, caregiving, positive adjustment, quality of life.

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INTRODUCTION

Pediatric Cancer

Approximately 10,400 children are diagnosed with cancer every year in the United States (NCI Fact Sheet). Although cancer is the second leading cause of death in children (Jemal et al., 2009), advances in medical treatment have led to better short- and long-term prognoses for childhood cancer patients. Current cure rates for children diagnosed with cancer are approaching 85%, with 5-year survival rates near 80% (Howlader et al., 2012). Consequently, most children diagnosed with cancer survive well into adulthood. With this increase in survival rates comes a focus on long-term physical and psychological outcomes for childhood cancer survivors and their caregivers. Although a cancer diagnosis places much strain on the individual child, caregivers of these children also experience extraordinary practical and psychological difficulties both during and after treatment, which can contribute to negative psychological outcomes as well as post-traumatic growth. Thus, a focus on the psychological adjustment of caregivers from diagnosis through the survivorship period has come to the forefront of pediatric cancer research.

Caregiver Demands and Psychological Adjustment at Diagnosis and During Treatment

A family's normal way of life is drastically altered when a child is diagnosed with cancer (Long & Marsland, 2011). In particular, the diagnosis of a child places extraordinary demands on caregivers. First, as caregivers are adjusting to their child's new diagnosis, they face the difficult tasks of communicating the news to their child and providing support to the sick child and their other children. Caregivers report that providing emotional support to their ill child and his or her siblings is among the most time-consuming demands immediately following a cancer diagnosis (Svavarsdottir, 2005).

After diagnosis, children undergo testing to determine the type of cancer and the best course of treatment. A report from the Childhood Cancer Survivor Study, the largest cohort of pediatric cancer patients in the United States, indicates that over 80% of children receive chemotherapy, nearly 70% receive radiation treatment, 75% undergo surgery, and most receive a combination of these treatments (Robison et al., 2002). These treatments often result in unpleasant side effects including fatigue, hair loss, and nausea. Because cancer treatment causes white blood cell counts to drop, children are more susceptible to infection and therefore must remain out of school, sometimes for extended periods of time. Children on treatment for cancer are absent from school more often than children with other chronic illness conditions due to more frequent inpatient hospitalizations and outpatient treatment visits (Eiser & Vance, 2002). For caregivers, cancer treatment necessitates taking additional time off work and being away from their other children. Finally, the increase in home medical care for children on most treatment protocols (Anderson, 1990) creates additional demands for caregivers to learn and administer involved home-treatment procedures. These treatment protocols can last from a few months to several years depending on the child's diagnosis.

The stress of having a child with a life-threatening illness and cancer-related increase in caregiving demands can lead to psychological adjustment difficulties among caregivers. Compared to parents of healthy children, parents of children with cancer are more likely to experience distress at the time of their child's cancer diagnosis (Hoekstra-Weebers et al., 1998). Although the levels of distress may decline over time (Dahlquist, Czyzewski, & Jones, 1996), caregivers still evidence more distress than normative groups up to one year after diagnosis (Pai et al., 2007). In about 80% of families, one or more caregivers experience posttraumatic stress symptoms while their child is receiving treatment for cancer (Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005).

Several gender differences have been noted regarding parenting demands and distress. Clearly, both mothers and fathers experience caregiving demands throughout treatment, although mothers report participating in more in-home caregiving than their spouses (Svavarsdottir, 2005), likely because mothers are more likely to stay at home with their child while fathers work to maintain income and health insurance (Brody & Simmons, 2007). These differences in caregiving demands may contribute to gender differences in psychological adjustment and are consistent with epidemiological data demonstrating higher prevalence of depression among females than males (Kuehner, 2003), and research suggesting greater distress experienced by mothers compared to fathers following their child's cancer diagnosis more specifically (Pai et al., 2007). Regardless of caregiving role, however, the numerous demands placed on caregivers when their child is receiving treatment for cancer may lead to increased adjustment difficulties.

Caregiver Demands and Psychological Adjustment during Survivorship

After treatment ends, youth with cancer enter the survivorship period. Although daily caregiving demands typically lessen after treatment ends (Svavarsdottir, 2005), caregivers must remain vigilant of cancer- or treatment-related health and psychological problems that can appear as late as ten years after completion of treatment. These late effects include physical complications in various organ systems, including cardiomyopathy, lung disease, kidney damage, cirrhosis of the liver, hypothyroidism, growth delay, and obesity (Dickerman, 2007; Oeffinger et al., 2006); neurocognitive outcomes such as declines in executive functions, attention, and IQ, and academic difficulties (Butler & Mulhern, 2005); and psychological sequelae including mood disturbance and distress (Glover et al., 2003). In fact, 60% of childhood cancer survivors have at least one late effect, and 37% have two or more (Kopp, Gupta, Pelayo-Katsanis, Wittman, & Katsanis, 2012; Oeffinger et al., 2006). These concerns require continued medical follow-up and place additional stress on caregivers (Patel, Wong, Cuevas, & Van Horn, 2012).

These continued health problems create increased caregiving demands during the survivorship period. Even when children have completed treatment, they miss more days of school (11 days on average) than healthy children, perhaps due to continued follow-up of late effects from diagnosis and treatment (French et al., 2013). Parents of cancer survivors remain more involved in their child's medical follow-up appointments compared to parents of healthy children or youth with other chronic illness conditions; caregivers state that they continue to take children to their medical appointments because they need reassurance of their child's continued good health and want to provide support to their survivor. (Ressler, Cash, Mcneill, Joy, & Rosoff, 2003). Furthermore, childhood cancer survivors are more likely to live with their parents into adulthood than healthy young adults (Langeveld et al., 2003).

These continued increases in caregiving demands affect the psychological health of parents. Estimates suggest that 43% of mothers and 35% of fathers of childhood cancer survivors evidence post-traumatic stress symptoms (Kazak et al., 2004), and up to 25% of mothers still meet criteria for posttraumatic stress disorder into survivorship (Brown, Madan-Swain, & Lambert, 2003). Specifically, parents of childhood cancer survivors report more anxiety, intrusion, and avoidance symptoms than parents of healthy children (Barakat et al., 1997). Furthermore, families describe lasting emotional impact of the cancer diagnosis even after treatment ends (Norberg, Lindblad, & Boman, 2005). Caregivers report the emergence of numerous cancer-related stressors (Van Dongen-Melman et al., 1995) and cognitions, including thoughts of loss and mourning and fears of their child relapsing (Norberg & Green, 2007; Van Dongen-Melman, Van Zuuren, & Verhulst, 1998).

In sum, caregivers experience numerous demands and burden related to their child's cancer diagnosis both during treatment and after the completion of all medical therapy. These increases in demands and stressors can lead to difficulties with psychological adjustment among caregivers of childhood cancer survivors.

Benefit Finding

Because of the challenging nature of pediatric cancer diagnosis and treatment, most studies on psychological adjustment of caregivers focus on negative outcomes described previously, such as trauma symptoms and emotional distress (Kazak et al., 2004; Stuber, Kazak, Meeske, & Barakat, 1998). Despite these demands and stressors, caregivers may also experience positive outcomes related to their experience with cancer. These positive outcomes have been termed *benefit finding, stress-related growth,* or *posttraumatic growth* (Calhoun & Tedeschi, 2006; Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996). Although the definitions of each construct may vary slightly, researchers often use the terms interchangeably. The term “benefit finding” will be used here to represent these positive outcome constructs.

The emergence of benefit finding research occurred in the context of a positive psychology movement, which places emphasis on positive functioning and fulfilling lives (e.g., Seligman & Csikszentmihalyi, 2000). Benefit finding refers to finding benefits or positive outcomes in the face of challenges or adversity (Affleck & Tennen, 1996; Pakenham, 2010). Early research on benefit finding relied on qualitative and narrative analysis for exploration of positive outcomes after a stressful experience (e.g., Taylor, Lichtman, & Wood, 1984) and suggested that benefit finding can occur in numerous domains across diverse populations, including among individuals with illness (e.g., cancer, rheumatoid arthritis) and those experiencing a natural disaster or other traumatic event (e.g., war, plane crash) (for a review, see Helgeson, Reynolds, & Tomich, 2006). Specifically, individuals described positive changes in relationships with others, personal strength, new possibilities, spiritual growth, and appreciation of life (e.g., Calhoun & Tedeschi, 1999, 2006).

Benefit finding has been studied as both a process and an outcome. The process of benefit finding or growth is determined by multiple factors, including characteristics of the individual and of the stressor; how an individual copes with the stressor; and rumination after the stressor (Calhoun & Tedeschi, 1998, 2006; Tedeschi & Calhoun, 2004). To experience benefit finding, one must face an experience that “represents [a] significant challenge to the adaptive resources of the individual” (p. 1; Tedeschi &

Calhoun, 2004). This challenge shifts one’s worldview. Cognitive activity follows including thoughts about the event and what that means for the person and their family. These processes then lead to both positive and negative ruminative thoughts, which may lead to growth (Calhoun & Tedeschi, 1999). Similarly, benefit finding has been investigated as a coping strategy of positive reframing of the stressor (Carver, Scheier, & Weintraub, 1989).

Benefit finding has also been investigated as an outcome alongside negative psychological outcomes, such as post-traumatic stress. This work has focused primarily on predictors of benefit finding. Importantly, benefit finding does not reflect the absence of distress. Many individuals who experience growth also experience posttraumatic stress symptoms such as intrusive and avoidant thoughts (Helgeson et al., 2006). In fact, the two constructs are often found to positively correlate in people with chronic illness as well as those caring for a family member with a chronic illness (e.g., Loiselle, Devine, Reed-Knight, & Blount, 2011; Weiss, 2004). In line with Calhoun and Tedeschi’s (1998; 2006) conceptualization, these findings suggest that experiencing a stressful event is a necessary condition for benefit finding, and taking time to think about the stressor is necessary for growth to occur. Benefit finding also has been linked with numerous positive physical and psychological outcomes in both the adult and child literature, including increased well-being and quality of life, reduced pain, and reduced morbidity and mortality (e.g., Affleck, Tennen, & Croog, & Levine 1987; Bower, Kemeny, & Taylor, 1998). Research on benefit finding in adults, children, and caregivers is discussed below.

Adults with Chronic Illness

Much research on benefit finding has focused on adults with chronic illness. Adult patients with chronic illness generally report moderate levels of benefit finding (e.g., mean of 60 on a 105 point scale; Lelorain, Bonnaud-Antignac, & Florin, 2010; Stanton, Bower, & Low, 2006). Research suggests that up to 90% of patients with chronic illness perceive at least one benefit from having gone through the experience (e.g., Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2009) and perceptions of these benefits may persist for years (Tallman, Altmaier, & Garcia, 2007). Adults with chronic illness generally report higher levels of growth than comparison samples (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Areas of growth reported are consistent with those proposed by Tedeschi and Calhoun (2004) and include positive changes in relating to others, spiritual change, appreciation of life, and improved personal resources (e.g., Cordova et al., 2001; Jim & Jacobsen, 2008).

Numerous variables have been explored as predictors of benefit finding in adults, including demographic, disease, and psychosocial variables. Demographic variables show inconsistent relationships with benefit finding. For example, minority status and low socioeconomic status have predicted greater benefit finding among breast cancer survivors (Tomich & Helgeson, 2004), although greater education has also predicted greater growth (Chan, Ho, Tedeschi, & Leung 2011). In a review of benefit finding among adult cancer survivors, Stanton and colleagues (2006) found that the links between socioeconomic status, age, ethnicity, gender, and benefit finding were inconsistent.

In contrast, several disease characteristics show robust associations with benefit finding, as would be predicted by Calhoun and Tedeschi's (1998, 2006) model.

Interestingly, more stressful chronic illnesses are associated with greater benefit finding (Stanton et al., 2006), perhaps due to an increased sense of mortality and increased life disruption leading one to focus on finding meaning in one's diagnosis (Tedeschi & Calhoun, 2004). However, experiencing more late effects from the cancer treatment may be associated with less growth (Lelorain et al., 2010). Among survivors of chronic illness or those living with life-long illnesses, time since diagnosis generally shows no relationship with benefit finding (e.g., Bellizzi & Blank, 2006; Costa & Pakenham, 2012). However, among recently diagnosed individuals (e.g., within 1-2 years of diagnosis), time since diagnosis is related to greater benefit (e.g., Sears, Stanton, & Danoff-Burg, 2003); this has been hypothesized to reflect avoidance versus adaptive coping (Stanton et al., 2006).

Psychosocial variables also show strong and consistent relationships with benefit finding among adults. First, optimism has been well researched as a predictor of benefit finding. Although results are somewhat inconsistent (Bostock, Sheikh, & Barton, 2009), optimism was generally associated with greater benefit finding in cancer patients (Moore et al., 2011) and this association increased over time after completion of treatment (Antoni et al., 2001). In another study, benefit finding mediated the relationship between optimism and reduced depression in cancer patients (Tallman et al., 2007). Second, benefit finding has been related to more active and acceptance-based coping, as well as greater practicing of religion, in adult cancer survivors (Chan et al., 2011; Lelorain et al., 2010; Pakenham & Cox, 2009), but was unrelated to avoidant coping (Stanton et al., 2006). In fact, participating in a cognitive behavioral group to increase adaptive coping increased benefit finding among breast cancer survivors compared to a control group (Antoni et al., 2001).

As noted above, benefit finding is associated with numerous positive effects on physical and psychological health. Among breast cancer survivors, benefit finding was related to better quality of life up to 8 years later (Carver & Antoni, 2004). Benefit finding also has been related to positive behavior change (Costa & Pakenham, 2012), reduced distress (Katz, Flasher, Cacciapaglia, & Nelson, 2001; Tallman et al., 2007), increased happiness (Lelorain et al., 2010), and greater satisfaction with life (Mols et al., 2009) among adults with cancer who are at least one year out from completion of therapy. Furthermore, perceiving more benefits from having a chronic illness was related to less pain and increased activity (Katz et al., 2001), as well as better overall physical functioning three years after completing treatment (Tallman et al., 2007). Interestingly, there is some evidence that certain variables moderate the relationship between benefit finding and physical or psychological health outcomes. For example, Helgeson and colleagues (2006) found that benefit finding was more strongly related to well-being when a traumatic event happened more than two years prior, compared to individuals who had more recently experienced trauma. These studies suggest that finding benefits in the stressful experience of having a chronic illness may lead to better long-term psychological and physical outcomes, but this relationship may depend on other individual or disease characteristics. This question will be examined in this study.

Children with Chronic Illness

Similarly to adults, children with chronic illness experience distress after diagnosis, although to a lesser degree than adults (for a review, see Bruce, 2006).

Research is beginning to show that children with chronic illness also evidence benefit finding in similar domains as adults, including greater appreciation of and more positive view of life, improved relationships with others, and greater personal strength and self-esteem, (e.g., Barakat, Alderfer, & Kazak, 2006; Mattson, Lindgren, & Von Essen, 2008; Mattson, Ringner, Ljungman, & Von Essen, 2007). The prevalence of benefit finding among children with chronic illness parallels that of the adult literature. For example, estimates suggest that up to 84% of children and adolescents find at least one benefit in having survived cancer, and most survivors report more than one positive change (Barakat et al.). Furthermore, survivors of childhood cancer report greater benefit finding than their healthy peers experiencing less severe daily life stressors (Kamibeppu et al., 2010).

Predictors of benefit finding studied in children generally parallel those in the adult literature. First, child age has been studied. Barakat and colleagues (2006) found that children under five years of age report fewer areas of benefit than children over age five, consistent with other studies reporting greater benefit finding in older children (Currier, Hermes, & Phipps, 2009). Additionally, youth who are older at diagnosis may find greater benefit compared to children diagnosed at a younger age (e.g., < age 6) (Currier et al., 2009; Phipps, Long, & Ogden, 2007). These age differences likely reflect normative development in cognitive processes that are necessary to discern benefits. In terms of disease variables, disease status shows inconsistent relationships with benefit finding. For example, children who were survivors of leukemia or brain tumor evidenced higher levels of benefit finding than children with solid tumors (Michel et al., 2009), perhaps because of greater intensity or length of treatment protocols, although these findings did not replicate in other studies (e.g., Currier et al., 2009). Additionally, children who described their illness as life-threatening or more impactful reported greater benefit finding (Barakat et al., 2006; Michel et al., 2009).

Similar to adults, children who report greater optimism also show higher levels of benefit finding (Currier et al., 2009; Michel et al., 2009; Phipps et al., 2007). Benefit finding appears unrelated to posttraumatic stress symptoms in children but has been associated with higher self-esteem and lower anxiety (Phipps et al., 2007), although the latter finding has not replicated in other studies (Barakat et al., 2006; Currier et al, 2009). More research on predictors, correlates and outcomes of benefit finding among children and adolescents with chronic illness is needed.

Benefit Finding Among Caregivers

Because chronic illness impacts both the ill individual and his/her caregiver, caregivers may also experience positive outcomes following the experience. This literature includes caregivers of adults or youth.

Caregivers of Adults with Chronic Illness

Research investigating benefit finding among caregivers of adults with chronic illness primarily focuses on spouses of patients with a disability (Moore et al., 2011; Pakenham, 2005). Prevalence of benefit finding in this population parallels that in the adult and child literature and suggests that at least two-thirds of caregivers experience at least one benefit, and most report more than one benefit (Mock & Boerner, 2010), although patients themselves report more benefit finding than their caregivers (Pakenham, 2005). Domains of benefit finding by adults' caregivers are similar to those discussed before and include increased appreciation of life, becoming more accepting of things, increased empathy for others, increased time spent with family, a more positive view of self, and change in priorities (e.g., Kim, Schulz, & Carver, 2007; Mock & Boerner, 2010).

Predictors of benefit finding have not been as well investigated among caregivers as in adults with illness, yielding a few consistent findings. Caregivers who report greater caregiver burden or stress find more benefit in the experience (Kim, Schulz, & Carver, 2007), similar to findings in the adult literature that greater post-traumatic stress symptoms are associated with greater growth (Helgeson et al., 2006). Contrary to the adult literature, however, caregiver benefit finding appears to increase with time since diagnosis and duration of caregiving duties (Pakenham, 2005), possibly due to cumulative stress of caregiving over time. The use of religious and problem-focused coping is associated with greater perceived benefits (Kim et al., 2007), as is the perception of greater social support (McCausland & Pakenham, 2003; Weiss, 2004).

In line with the adult literature, benefit finding has been associated with positive psychological and physical health outcomes among caregivers of adults, including greater life satisfaction and better relationship satisfaction between caregiver and patient (Kim et al., 2007; Pakenham, 2005). Finding more benefits also is related to fewer depressive symptoms (McCausland & Pakenham, 2003) and better long-term psychological adjustment (Pakenham & Cox, 2008). Altogether, this limited literature shows similar patterns of benefit finding and related predictors and outcomes in caregivers of adult patients as in the patients themselves, with the exception of time since diagnosis being a stronger predictor.

Caregivers of Youth with Developmental Disabilities and Chronic Illness

Despite the substantial impact of children’s chronic health conditions on their caregivers, little research has addressed benefit finding in this population. Domains of benefit among caregivers of children also are similar to those endorsed by adults and children with chronic illness and include changed life perspective, emotional growth, family integration, and healthier lifestyle (Affleck, Allen, Tennen, McGrade, & Ratzan, 1985). Available research addresses benefit finding among caregivers of children with developmental disabilities and children with chronic illness.

Several studies have addressed benefit finding among caregivers of youth with developmental disabilities. Demographic variables associated with increased benefit finding among caregivers of children with autism spectrum disorder include younger child’s age, older caregiver age, and female gender (Pakenham, Sofronoff, & Samios, 2004). Greater caregiving demand also predicted greater benefit finding, paralleling findings with caregivers of adults (Pakenham et al., 2004). Among psychological predictors, higher levels of daily positive emotionality, wider social support networks, and active and religious coping predicted greater benefit finding in caregivers of children with autism or other developmental disabilities (Moskowitz & Epel, 2006; Pakenham et al., 2004; Samios et al., 2009). Benefit finding also was related to greater well-being among mothers of children with developmental disabilities (Foster, Kozachek, Stern, & Elsea, 2010) and higher life satisfaction among caregivers of children with autism spectrum disorders (Samios et al., 2009).

Little research has addressed benefit finding among caregivers of youth with chronic health conditions. Studies reveal a similar prevalence of finding benefit in having a child with a chronic illness as in adults and children with chronic illness. For example, 90% of mothers and 80% of fathers report finding at least one benefit in having a child diagnosed with cancer (Barakat et al., 2006). Among demographic and medical variables, higher socioeconomic status and greater disease risk have been linked with greater benefit finding among mothers of youth undergoing stem cell transplant (Rini et al., 2004), and greater illness impact predicted greater benefit finding in caregivers of childhood cancer survivors (Michel et al., 2009). Greater levels of benefit finding among mothers than fathers of children with cancer (Barakat et al., 2006) are consistent with research suggesting greater benefit finding among more active caregivers (Kim et al., 2007) and greater caregiving burden in mothers (Svavarsdottir, 2005).

There is little research on outcomes of benefit finding among caregivers of children with chronic illness, and results are generally mixed. Some studies found positive associations between benefit finding and quality of life among caregivers of children in the intensive care unit (Affleck, Tennen, & Gershman, 1985) and other populations (e.g., breast cancer survivors; Carver & Antoni, 2004), while other studies found no associations among caregivers of childhood cancer survivors (Michel et al., 2010). One possible explanation for these discrepancies is that the relationship between benefit finding and quality of life may not be the same for all caregivers, but that other factors moderate the relationship. In other worse, benefit finding may be more important for enhanced quality of life among some individuals than others, a hypothesis supported by McMillen and colleagues, who reported a stronger positive relationship between benefit finding and well-being among those who experienced more severe disasters (McMillen, Smith, & Fisher, 1997). This suggests that individuals who are more vulnerable to poor quality of life may profit more from finding benefits in challenging situations.

The Present Study

The literature reviewed above shows clearly that benefit finding is prevalent among both patients and caregivers of those with a chronic illness. The correlates of benefit finding have been most extensively studied in adults experiencing chronic illness, pointing to the importance of illness impact, optimism, and coping as predictors of benefit finding and suggesting better psychological and health outcomes among those finding more benefits in the illness experience. However, less is known about benefit finding among caregivers of children with chronic illness, and more specifically, caregivers of childhood cancer survivors. As reviewed earlier, cancer survivorship brings relief but caregivers also experience some emotional distress and continuing caregiving demands. The stressful nature of the cancer experience, combined with time to reflect on the experience (Norberg & Green, 2007), may be conducive to development of sense-making and benefit finding. Thus, the purpose of this study is to explore benefit finding in caregivers of children who have completed treatment for childhood cancer. A series of three papers will address current knowledge of benefit finding in caregivers of children with chronic health conditions, predictors of benefit finding in this population, and the role of benefit finding in caregivers' adjustment, specifically quality of life.

First, a systematic review of existing literature was conducted to integrate the empirical research on benefit finding in caregivers of youth with chronic health conditions, formulate a theoretical framework of benefit finding in this population, and identify directions for future research. The review included studies of benefit finding or other positive adjustment outcomes among caregivers of youth with chronic health conditions up to age 18.

Second, an empirical study examined demographic, medical, and psychosocial predictors of benefit finding among caregivers of childhood cancer survivors. Consistent with research in both the adult and child literature, we hypothesized that greater benefit finding would be related to disease severity, problem-focused coping, religious coping, post-traumatic stress symptoms, optimism, perceived social support, increased caregiver demand, and greater illness impact.

Finally, an empirical study explored benefit finding as a predictor of quality of life and moderators of the relationship between these variables among caregivers of childhood cancer survivors. Predictors of quality of life among caregivers have been studied, with varied results. Specifically, absence of demographic and psychosocial resources, such as caregiver education, stress, coping strategies, social support, and optimism, may increase vulnerability to worse quality of life among caregivers. Therefore, demographic and psychosocial variables were examined as moderators of the association between benefit finding and quality of life. We hypothesized stronger positive relationships between benefit finding and quality of life for caregivers who were more vulnerable to worse quality of life.

BENEFIT FINDING AMONG CAREGIVERS OF CHILDREN WITH CHRONIC ILLNESS: A SYSTEMATIC REVIEW

by

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Abstract

Objective: To review available research on prevalence, domains, predictors, and outcomes of benefit finding in caregivers of children with chronic illness conditions.

Methods: Studies were identified through two online databases, PsycINFO and PubMed and searching reference lists of relevant articles.

Results: Twenty-one studies were identified systematically that met inclusion criteria. Few studies investigated the relationships between caregiver demographic or child demographic/medical variables and caregiver benefit finding, although available literature found that female caregivers find greater benefits as do caregivers of children with more severe illness conditions. Psychosocial variables were primarily the topic of investigation. Caregiver optimism, social support, self-efficacy, active (not passive) coping strategies, and posttraumatic stress predicted caregivers benefit finding. Few studies explored outcomes of benefit finding for caregivers.

Conclusions: Results can aid in identifying caregivers who may be at risk for worse outcomes following the diagnosis of a child with a chronic illness condition, as well as point to interventions to promote positive adaptation. A conceptual model is presented.

Introduction

Current prevalence estimates suggest that up to 18% of children and adolescents in the United States have a chronic medical condition (Van Cleae, Gortmaker, & Perrin, 2010), representing an increase in prevalence over time (Perrin, Bloom, & Gortmaker, 2007). This increase likely in part reflects improved survival rates for numerous chronic medical conditions due to better diagnosis and treatment (Halfon & Newacheck, 2010). Increasing numbers of children living with chronic medical conditions (referred to as "chronic conditions" in this review) leads to a focus on psychological outcomes for both children and their caregivers. Caring for a child with a chronic condition brings numerous practical and emotional difficulties, and a recent review suggests that caregivers of children with chronic conditions demonstrate greater parenting stress than caregivers of healthy children (Cousino & Hazen, 2013).

Despite the challenges, research suggests that caregivers of children with chronic conditions experience positive outcomes or growth as a result of this experience. Constructs of positive adjustment have been termed *benefit finding, posttraumatic growth, or stress-related growth* (Calhoun & Tedeschi, 2006; Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996). Benefit finding refers to the discovery of positive changes from living with adversity, and has typically been studied among medical populations (Affleck & Tennen, 1996). Posttraumatic growth is defined as "positive psychological change experienced as a result of the struggle with highly challenging life circumstances," which, similar to benefit finding, has been explored among medical populations and individuals who suffer other "traumatic" experiences (e.g., natural disasters, abuse) (Calhoun & Tedeschi, 1999; Tedeschi & Calhoun, 2004). Stress-related growth references growth from negative events and has included medical populations as well as community samples reporting on their “most stressful experience” (Park, Cohen, & Murch, 1996). These constructs are similar in that they all refer to changes following an adverse event, but vary in terms of the conceptualization of change as either internal growth from baseline levels of functioning (i.e., posttraumatic growth) or positive additions to one’s life in either internal or external domains (i.e., benefit finding). It is suggested that benefit finding can begin soon after facing adversity but that posttraumatic growth may take time to develop (Calhoun & Tedeschi, 1998). Although the definitions of each construct vary to some degree as described above, many researchers use these terms interchangeably. The term “benefit finding” will be used to represent these constructs in this review.

Early research on these constructs relied on qualitative and narrative analysis for exploration of positive outcomes after a stressful experience (e.g., Taylor, Lichtman, & Wood, 1984) and suggested that benefit finding can occur in numerous domains across diverse populations, including among individuals with illness (e.g., cancer, rheumatoid arthritis) and individuals experiencing a natural disaster, childhood trauma, and other major life stressors (for a review, see Helgeson, Reynolds, & Tomich, 2006). More recent quantitative studies with various populations supports these findings and point to specific areas of benefit finding, namely positive changes in relationships with others, personal strength, new possibilities, spiritual growth, and appreciation of life (e.g., Calhoun & Tedeschi, 1999; Calhoun & Tedeschi, 2006).

Several frameworks for understanding of this outcome have been recommended. First, a stress and coping framework suggests that one's appraisal of an event, coping, and the event outcome interact in complex ways to promote either positive outcomes (i.e., benefit finding) or distress (e.g., Folkman, 1997; Tennen & Affleck, 2002). Second, Tedeschi and Calhoun (2004) suggested a conceptual framework for understanding posttraumatic growth specifically, which includes individual characteristics of the person, challenges, rumination, self-disclosure, and social support. Third, resiliency frameworks suggest that coping, knowledge, perception of illness, and resources factor into general positive adaptation (e.g, McCubbin & McCubbin, 1993). Finally, the shattered assumptions construct (Janoff-Bulman, 1992) posits that traumatic events shatter one's worldview, and the rebuilding process can result in positive outcomes. None of these frameworks have been specifically investigated among caregivers of children with chronic illness.

There is a growing literature base among adults and children with chronic conditions suggesting that individuals, both adults and children, find positive outcomes despite difficult experiences. Research in the adult and child literature points to multiple psychosocial variables that are associated with greater benefit finding, including optimistic world-view (Currier, Hermes, & Phipps, 2009; Michel, Taylor, Absolom, & Eiser, 2009; Phipps, Long, & Ogden, 2007), active and acceptance coping, religiosity, (Chan, Ho, Tedeschi, & Leung, 2011; Lelorain, Bonnaud-Antignac, & Florin, 2010), and greater perceived impact of the illness (Barakat, Alderfer, & Kazak, 2006; Michel et al., 2010). Among adults with chronic conditions, benefit finding has also been associated with a number of positive health outcomes, including increased well-being and quality of life, reduced pain, and reduced morbidity and mortality (e.g., Affleck, Tennen, & Croog, & Levine 1987; Bower, Kemeny, & Taylor, 1998).

Consistent with a growing body of literature exploring benefit finding among adults with chronic conditions, researchers are also exploring the positive impact of parenting a child with a chronic condition. Due to the likely importance of benefit finding for physical and psychological health outcomes, further exploration into these constructs is warranted among caregivers. The aim of the current review is to explore benefit finding among caregivers of children with chronic conditions. To meet this aim, this review focuses on prevalence, mean levels, and domains of benefit finding experienced by caregivers, as well as variables that are associated with benefit finding, including caregiver demographic and psychosocial variables and child demographic and medical variables. Finally, outcomes of benefit finding among caregivers will be explored. This review concludes with a proposed conceptual model of benefit finding to guide future research in this area.

Method

Search Strategy

Two search strategies were used to identify relevant articles. First, PsycINFO and PubMed databases were systematically searched using combinations of the following search terms: “benefit finding,” “posttraumatic growth,” “stress-related growth,” “parent,” “caregiver,” and “chronic illness.” The search was confined to articles published in peer-reviewed journals. Second, the reference sections of articles meeting inclusion criteria were searched for additional relevant articles.

Inclusion Criteria

Studies were included in the current review if they met the following criteria: 1) sample included caregivers of children with a chronic illness condition at the time of study or caregivers of children who had survived a chronic illness; 2) study measures included either a measure of positive outcome (i.e., benefit finding, posttraumatic growth, or stress-related growth) or qualitative studies focused on these positive outcomes; and 3) child was 18 years or younger at the time of diagnosis. Studies of caregivers of children with developmental disabilities and bereaved caregivers were excluded so as to refine the scope of the review to primarily a pediatric population. These exclusion criteria were imposed as the experience of caregivers of children with a medical condition with potentially life-threatening implications may differ from caregivers of children with developmental disabilities, and to allow inclusion of medical factors as potential contributors to benefit finding. Additionally, it is likely that the experiences of bereaved caregivers differ from those of caregivers whose child survived or is currently managing a medical condition.

Results

Three other recent review articles were identified, including two examining posttraumatic growth among caregivers of childhood cancer survivors specifically (Duran, 2013; Ljungman et al., 2014), and one examining posttraumatic growth more broadly in both pediatric patients and their caregivers (Picoraro, Womar, Kazak, & Feudtner, 2014), which focused on cognitive and affective processes underlying posttraumatic growth, individual variables related to growth, and social support. The current review differs from previously published review articles both in the breadth of pediatric chronic illness conditions and its specific focus on caregivers, allowing for a more in-depth focus specifically on factors contributing to benefit finding among caregivers of children with chronic conditions.

Our primary search strategy identified 413 articles, as shown in Figure 1. An additional 50 articles were identified as potentially relevant through review of reference sections of articles meeting inclusion criteria. After removing duplicate articles, the abstracts of 280 articles were reviewed for potential inclusion in the review, resulting in the removal of an additional 204 articles. Full-text was reviewed for 76 articles. Following review of the full texts, another 55 articles being removed because they did not meet inclusion criteria. The final sample of articles included 21 articles, 18 of which were quantitative and 3 of which were qualitative. Articles included in the review are summarized in Table 1. A meta-analytic review was not feasible given the variability among articles in studied variables and outcome measures used.

Figure 1. Flowchart.

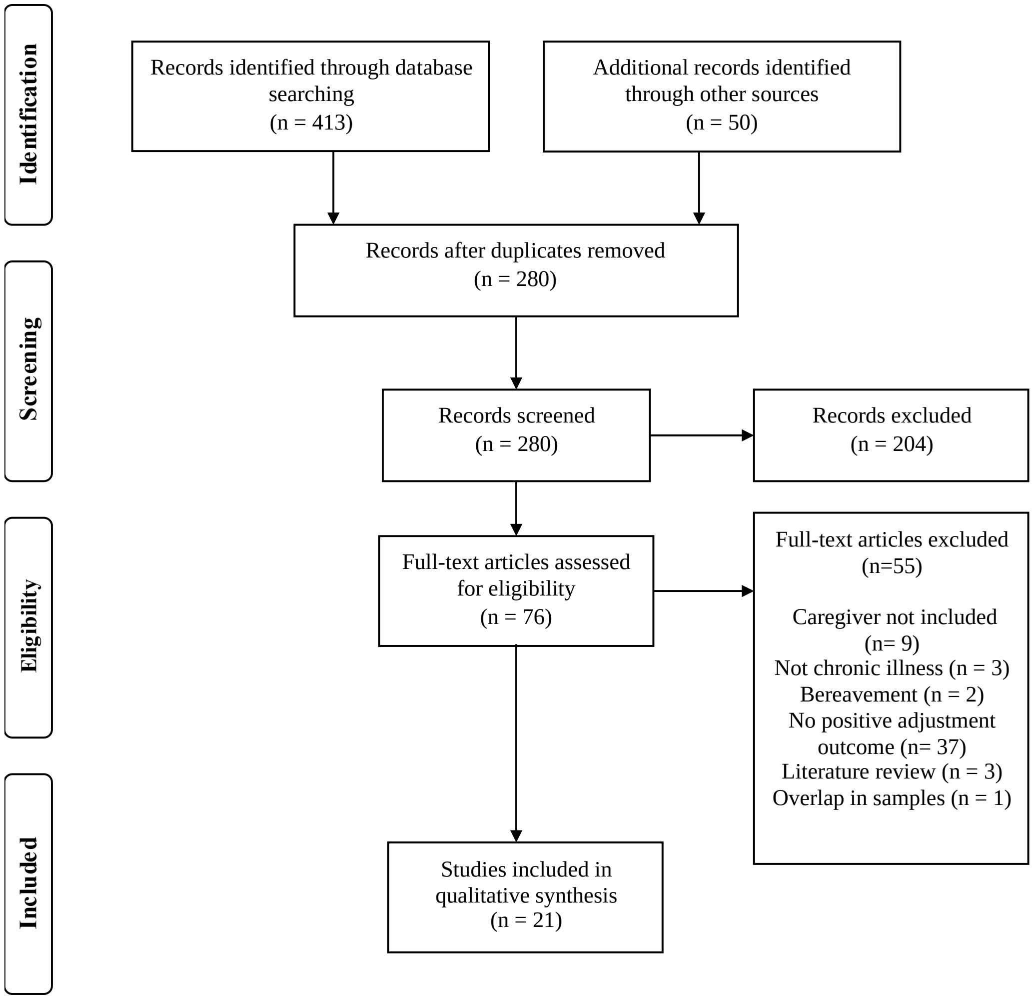


Table 1. Studies included in literature review.

Study authors/year	Sample	Chronic Illness	Outcome	Outcome Score (Sum)	Variables investigated
Baker, Owens, Stern, & Willmot, 2009	103 parents (83% female)	Craniofacial conditions	Stress-related growth (Stress-related Growth Scale)	206.4 (range 0-301)	**Type of craniofacial condition;** Child age; Child's other medical problems; Avoidant coping; **Approach coping; Social support**
Barakat, Alderfer, & Kazak, 2006	253 parents (58% female)	Cancer survivors	Posttraumatic growth (Impact of Traumatic Stressors Interview Schedule)	Not reported	Parent age; Income; Child age; Child age at diagnosis; **Time since treatment completion**[b]; Intensity of treatment; PTSS
Barr, 2011	158 parents (54% female)	Children in intensive care unit	Posttraumatic growth (PTGI)	55.0 (mothers); 47.7 (fathers)	Parent gender; **Coping strategies; Guilt**[a]; Shame; **Fear of death**[a]; **Parent stress**
Best, Streisand, Catania, & Kazak, 2001	67 families (66 mothers, 47 fathers)	Leukemia survivors	Posttraumatic growth (PTGI)	Not reported	**Anxiety/avoidance**
Cadell, Kennedy, & Hemsworth, 2012	273 caregivers (82% female)	Life-limiting illness (e.g., cancer, cystic fibrosis, cerebral palsy)	Posttraumatic growth (PTGI); qualitative interview	62.9 (range 1-126)	Time since diagnosis
Cassidy, 2013	332 female caregivers	Cancer	Benefit Finding (BFS)	3.3[c] (range 1-5)	Parent age; **Time since diagnosis**; **Self-efficacy; Resilience; Optimism; Social support; Burden; Perceived burden**
Colville & Cream, 2009	50 parents (78% female)	Children admitted to intensive care unit	Posttraumatic growth (PTGI)	49.0 (range 0-105)	Parent gender; **Child age;** Child gender; Child ethnicity; **Ventilation status;** No. of emergency admissions; **PTSS**
Forinder & Norberg,	284 parents	Stem cell transplant	Posttraumatic	Total score not	**Parent gender;** Time elapsed since

2013	(56% female)		growth (PTGI)	reported	transplant; **Trauma appraisal; Social Support; PTSS**[a]
Helgeson, Becker, Escobar, & Siminerio, 2012	132 caregivers (92% female)	Diabetes	Benefit finding (Positive Contributions Scale)	Not reported	Depressive symptoms
Hensler, Katz, Wiener, Berkow, & Madan-Swain, 2013	25 fathers	Cancer survivors	Benefit finding (BFS); qualitative interview	4.10[c] (1-5 scale)	n/a
Hungerbuehler, Vollrath, & Landolt, 2011	126 parents (53% female)	Cancer or Type I diabetes	Posttraumatic growth (PTGI)	2.19[c] (range 0-4)	**Parent gender; Child diagnosis; Initial length of hospital admission; Distress; Quality of family relationships**
Konrad, 2006	11 mothers	Acquired disabilities (e.g., paraplegia)	Qualitative interview	n/a	n/a
Li, Cao, Cao, Wang, & Cui, 2012	208 parents (82% female)	Congenital disease (e.g., congenital heart disease, Hirschsprung disease)	Posttraumatic growth (PTGI)	52.44 (range 1-95)	**Parental age; Education;** Income; No. of children in household; **Emotional intelligence; PTSS; Resilience; Self-efficacy;** Perceived social support
Lindwall, Russell, Huang, Zhang, Vannatta, Barrera, et al., 2014	171 parents (82% female)	Stem cell transplant	Benefit finding (BFS)	Mean 65.0 (baseline); 68.9 (follow-up)	n/a (intervention study)
McDowell, Titman, & Davidson, 2010	4 parent dyads	Stem cell transplant	Qualitative interview	n/a	n/a
Michel, Taylor, Absolom, & Eiser, 2009	45 parents (89% female)	Cancer survivors	Posttraumatic growth (PTGI)	2.7[c] (range 0-5)	Parent socioeconomic status; Education; Child diagnosis; PTSS; **Illness perception**
Moskowitz & Epel, 2006	71 mothers	Chronic illness (e.g., neurological disorders, GI illnesses)	Posttraumatic growth (PTGI)	60.04 (range 6-126)	**Daily positive emotion;** Daily negative emotion; Cortisol

O’Hanlon, Camic, & Shearer, 2012	54 parents (70% female)	Craniofacial conditions	Posttraumatic growth (PTGI)	36.74 (range 0-95)	Parent also affected with condition
Rini, Manne, DuHamel, Austin, Ostroff, Boulad, et al., 2004	144 mothers	Stem cell transplant	Benefit finding (2 items)*:	n/a	**Parent education; No. of children in home; Medical risk; Optimism**
Schneider, Steele, Cadell, & Hemsworth, 2011; Cadell, Hemsworth, Smit Quosai, Steele, & Davies, 2014	273 caregivers (82% female)	Life-limiting illness	Posttraumatic growth (PTGI)	62.9 (range 6-126)	**Parent gender; Meaning in caregiving; Self-esteem**[a]; Optimism; **Spirituality;** Depression, Burden
Yonemoto, Kamibeppu, Ishii, Iwata, & Tatezaki, 2012	58 parents (48% female)	Survivors of high-grade osteosarcoma	Posttraumatic growth (PTGI)	44.9 (range 1-126)	Parent age; Parent gender; Child age at diagnosis; Child gender; State of affected limb; Time since end of treatment; **PTSS**

Note. BFS = Benefit Finding Inventory (Antoni et al., 2001); PTGI = Posttraumtic Growth Inventory (Tedeschi & Calhoun, 1996); PTSS=posttraumatic stress symptoms; bold represents significant findings; [a] = Mothers only. [b] = Fathers only. [c] = Mean. *=“When I think of my child’s illness”… 1. “…I have been looking for positive things that have come out of it for my family” 2. “…I have been able to find positive things that have come out of it for my family.”

Prevalence and Mean Levels of Benefit Finding

Of the studies included in this literature review, 17 (94% of the quantitative articles) included mean or sum scores of caregiver benefit finding. Due to the use of varied scales to measure benefit finding, scores are somewhat difficult to compare but most research suggests caregivers of children with chronic conditions experience at least small to moderate amounts of benefit finding. Specifically, among studies utilizing the Posttraumatic Growth Inventory (PTGI), caregivers of children with chronic conditions experienced mean levels of benefit finding ranging from 2.10 to 3.02 (on a scale of 0 to 5; sums range 44-63, out of a total 126), representing changes from “a small degree” to “a moderate degree” (e.g., Cadell, Kennedy, & Hemsworth, 2012; Yonemoto, Kamibeppu, Ishii, Iwata, & Tatezaki, 2012). On the Benefit Finding Inventory, which was developed more recently and has been used relatively less frequently, caregivers’ mean levels of benefit finding ranged from 2.7 to 3.3 on a 1-5 scale, corresponding to finding benefits from “a little” to “quite a bit” (Cassidy, 2013; Michel et al., 2009). Standard deviations on the PTGI as reported in ten studies ranged from .15 to 1.23, representing much variability among studies, while standard deviations on the Benefit Finding Inventory in three studies ranged from .69 to .70.

Another way to characterize levels of benefit finding among caregivers is to examine proportions of caregivers studied who found benefits. Studies that report on percentages of caregivers experiencing benefit finding suggest that most to all caregivers experience benefits to some degree. For example, Hungerbuehler, Vollrath, and Landolt (2011) found that nearly two-thirds of caregivers of children with either cancer or Type I diabetes experienced a moderate amount of benefit finding. Hensler and colleagues

(2013), in a study of fathers of childhood cancer survivors, found that all fathers reported at least one positive change, nearly half indicated positive change in two domains, and 16% reported positive change in three domains. Similarly, in a study of parents of childhood cancer survivors, Barakat and colleagues (2006) found that 90% of mothers and 80% of fathers endorsed at least one positive change from caring for a child with cancer, and nearly half of all parents experienced four or more positive changes. Among caregivers of children with congenital diseases, over half of caregivers experienced benefit finding (Li, Cao, Cao, Wang, & Cui, 2012). Taken together, most or all parents in the included studies experienced at least some degree of benefit finding.

The difference in benefit finding experiences among male and female caregivers has been minimally investigated, and is difficult to determine given the preponderance of female caregivers in pediatric research. However, studies that include adequate sample sizes of male caregivers generally show that female caregivers have greater levels of benefit finding than do male caregivers, both for total score and specific domains. For example, in two studies of caregivers of children with a wide variety of severe chronic illnesses and life-limiting conditions, mothers experienced greater benefit finding than fathers (Hungerbuehler et al., 2011; Schneider, Steele, Cadell, & Hemsworth, 2011). However, another study found no differences in benefit finding scores among male and female caregivers of children in neonatal intensive care units (Barr, 2011).

Although there are few longitudinal studies assessing benefit finding, there is some evidence suggesting that benefit finding may not be a stable construct across the illness trajectory. Specifically, in a cross-sectional study of caregivers, Cassidy (2013) found that among parents of children with cancer, mean levels of benefit finding were stable in the first 6 months after diagnosis and then increased up to 24 months post-diagnosis. After 25 months, benefit finding scores stabilized. Similarly, Rini and colleagues (2004) found that among caregivers of children undergoing stem cell transplantation, benefit finding levels were similar immediately prior to their child's transplant and 6 months later. In another longitudinal study of caregivers of children undergoing stem cell transplantation, benefit finding levels were higher 24 weeks post-transplant than immediately prior to transplant (Lindwall et al., 2014). Taken together, of the few cross-sectional and longitudinal studies investigating changes in benefit finding experiences among caregivers of children with chronic conditions, results suggest that this construct may be stable for a period of time after diagnosis or a major medical event, increase for months to a year, and then stabilize.

Domains of Benefit Finding

As discussed previously, benefit finding has been conceptualized as a multifaceted construct spanning several domains. Specifically, Calhoun and Tedeschi (1999; 2006) suggest five aspects: Relating to Others, New Possibilities, Personal Strength, Appreciation of Life, and Spiritual Change. Accordingly, several studies do not report on overall levels of benefit finding due to the variability in scores among the domains, and some researchers suggest utilizing only domain subscales due to this variability. Of the studies included in this review, 12 (57%) reported broadly on areas of benefit finding: 8 studies measured the five areas just described and 4 studies reported on domains of benefit finding more broadly through item-level analyses or percentages of parents reporting benefit finding in particular domains. Of the studies that explored the five specific domains, Personal Strength uniformly was noted as one of the areas of greatest benefits, and Appreciation of Life was also noted to be one of the greatest benefits (e.g., Cadell et al., 2012; O’Hanlon, Camic, & Shearer). The domain of New Possibilities showed variable results, with some studies finding it to be among the higher domains of benefits and some studies finding it to be among the lowest areas (Schneider, Steele, Cadell, & Hemsworth, 2011; Moskowitz & Epel, 2006). Although it is difficult to determine if this discrepancy is a function of illness group as the varied illnesses were not specifically reported in each study, this finding could represent more changes in this domain among caregivers of children with life-limiting illness (Schneider et al., 2011) compared to other types of chronic conditions (Moskowitz & Epel, 2006). Spiritual change was almost uniformly noted to be one of the areas of least benefit (e.g., Cadell et al., 2012; Forinder & Norberg, 2013). Even studies utilizing different measures of benefit finding (e.g., stress-related growth inventory; Baker, Owens, Stern, & Willmot, 2009) showed that personal strength and the treatment of others were among the greatest areas of benefit and religiosity was the lowest.

Similarly, among studies which utilized item-level analyses or percentages of parents endorsing areas of benefit finding, more caregivers noted that they experienced an increase in Personal Strength and Appreciation of life than Spiritual Change or New Opportunities, consistent with the difference in mean levels of these constructs among caregivers (Forinder & Norberg, 2013). This study also found that a greater proportion of mothers than fathers experienced changes in all of the domains of benefit finding, also consistent with research documenting greater benefits among female caregivers than males in general. A qualitative study of fathers of childhood cancer survivors reported that 56% found benefits in their relationships with others, 48% experienced spiritual change, and 40% of endorsed increased ability to manage life's challenges (Hensler et al., 2013). Another study of caregivers of childhood cancer survivors (Barakat et al., 2006) reported that 86% of mothers and 62% of fathers noted a positive impact in how they think about life, similar to Calhoun and Tedeschi's (1999, 2006) Appreciation of Life construct. This study also found that 58% of mothers and 48% of fathers treated others more positively. These figures are consistent with results on mean levels of benefit finding.

Predictors of Benefit Finding

Caregiver demographic variables. Of the studies included in this review, 12 (57%) assessed relations between benefit finding and caregiver demographic variables. The most frequently studied variables included caregiver gender, age, and indicators of socioeconomic status, such as education and income. For gender, as discussed previously, results generally agree that female caregivers have higher levels of benefit finding than male caregivers. This pattern was supported among caregivers of children who underwent stem cell transplant (Forinder & Norberg, 2013), parents of children with cancer and Type I diabetes (Hungerbuehler, 2011) and caregivers of children with life-limiting illnesses (Schneider et al., 2011). However, not all studies found this relationship. Specifically, studies of caregivers of osteosarcoma survivors or children in intensive care units did not find associations between benefit finding and caregiver gender, perhaps due to small samples sizes (Barr, 2011; Colville & Cream, 2009; Yonemoto et al., 2012).

Caregiver age shows inconsistent relationship with benefit finding. Cassidy (2013) found that among caregivers of children with cancer, older caregivers found greater benefits than younger caregivers, although age was not a unique predictor of benefit finding after accounting for psychosocial variables. In contrast, among parents of children with congenital diseases, older caregivers found fewer benefits than younger caregivers (Li et al., 2012). Further, there was no association between parental age and benefit finding in a study of caregivers of osteosarcoma survivors (Yonemoto et al., 2012). These discrepancies could be related to varied age ranges studied. Indeed, the studies showing positive or no relationship between age and benefit finding used generally older caregiver samples (age range 19-74 and 41-79) whereas the study finding a negative relationship utilized a younger caregiver sample (age range 20-50).

Studies exploring caregiver education, income, or other indicators of socioeconomic status yielded mixed results. Among caregivers of children with congenital disease, parents with moderate levels of education (high school diploma) experienced greater benefits than caregivers with either lower (less than a high school degree) or higher education (some college) (Li et al., 2012). Another study exploring education found that among mothers of children who underwent stem cell transplant, those with higher education experienced greater benefit finding 6 months after the transplant, although not prior to the transplant (Rini et al., 2004). Another study of caregivers of childhood cancer survivors found no association between benefit finding and education level of parents (Michel et al., 2009), which could potentially have been limited by studying a linear relationship between education and benefit finding, as other studies suggested a curvilinear relationship. Socioeconomic status (measured as either income or postal code from which income was estimated) was not associated with benefit finding among parents of children with congenital disease nor childhood cancer survivors in multiple studies (Barakat et al., 2006; Li et al., 2012; Michel et al., 2009).

Other demographic variables have been minimally investigated in relation to caregivers’ benefit finding. For instance, the number of other children in the household was not associated with benefit finding among mothers of children who underwent stem cell transplant (Rini et al., 2004). O’Hanlon and colleagues (2012) revealed that benefit finding did not differ among caregivers who also had their child’s condition (craniofacial conditions) compared to those who did not.

Child variables. Of the articles included in this review, 10 (48%) assessed relations between child demographic or medical variables and caregiver benefit finding. Child demographic variables generally show inconsistent or negligible relationships with benefit finding. Specifically, child gender or ethnicity was not related to benefit finding among parents of children admitted to an intensive care unit (Colville & Cream, 2009), and child gender was unrelated to benefit finding among parents of childhood cancer survivors (Yonemoto et al., 2012). However, in one study of children in an intensive care unit, caregivers of older children showed greater benefit finding (Colville & Cream, 2009). By contrast, Barakat and colleagues (2006) found no association of patient current age or patient age at diagnosis (cancer survivors) with caregiver benefit finding. Similarly, there was no association of patient age and caregiver positive adjustment in a study of caregivers of children with craniofacial conditions (Baker et al., 2009).

Medical variables investigated included time since diagnosis of the child’s medical condition and time since treatment completion for the disease. In a cross-sectional study of caregivers of children with a variety of chronic conditions, Cassidy (2013) found that caregivers of children who had been diagnosed for less than 6 months and more than 25 months had lower levels of benefit finding than caregivers of children who were diagnosed for 7-24 months, suggesting that benefit finding may take some time to develop but then stabilize over time. This trend was similar for all domains of benefit finding with the exception of the family domain, which showed generally consistent levels of benefit finding regardless of time since diagnosis.

Regarding time since treatment completion, Barakat and colleagues (2006) found that longer time since treatment completion predicted lower benefit finding among fathers (but not mothers) of childhood cancer survivors. In contrast, Yonemoto and colleagues (2012) found no association with benefit finding for caregivers of osteosarcoma patients, and Cadell and colleagues (2012) found a similar lack of relationship among caregivers of children with a variety of life-limiting illness conditions. Relatedly, Forinder and Norberg (2013) found no relationship between caregivers' benefit finding and length of time since child's stem cell transplant.

Other medical variables have been explored to a lesser degree. For example, caregivers of osteosarcoma survivors' benefit finding did not differ based on the outcome of their child's affected limb (e.g., amputation) (Yonemoto et al., 2012). Caregivers of children who were ventilated in an intensive care unit (compared to children not ventilated) showed greater benefit finding, perhaps suggesting an effect of medical severity (Colville & Cream, 2009). Similarly, among caregivers of children undergoing stem cell transplantation, medical risk (defined as higher toxicity due to the treatment and higher potential for mortality) was positively related to mothers' experience of benefit finding both prior to and 6-months after their child's stem cell transplant (Rini et al., 2004). Longer initial hospital admission after diagnosis predicted greater benefit finding in a study of caregivers of children with either cancer or Type I diabetes (Hungerbuehler et al., 2011) which lends support to a positive association between medical severity/risk and caregivers' benefit finding. In contrast, Barakat and colleagues (2006) did not find an association between treatment intensity in childhood cancer survivors and caregivers' benefit finding. Michel and colleagues (2009) also did not find an association with type of cancer diagnosis and caregivers' benefit finding.

Caregiver psychosocial variables. Of studies in this review, 16 (76%) included analyses of associations between one or more caregiver psychosocial variables and benefit finding. The most commonly investigated psychosocial variable was posttraumatic stress symptoms. The literature generally suggests that greater posttraumatic stress symptoms are associated with greater benefit finding, as shown among caregivers of children with congenital diseases, childhood cancer survivors, children in the intensive care unit, and fathers (but not mothers) of children who underwent stem cell transplant (Colville & Cream, 2009; Forinder & Norberg, 2013; Li et al., 2012; Yonemoto et al., 2012). However, two other studies found no significant correlations between posttraumatic stress and benefit finding among caregivers of childhood cancer survivors (Barakat et al., 2006; Michel et al., 2009).

Social support and optimism were the second most frequently investigated psychosocial variables. Social support was positively related to benefit finding among caregivers of childhood cancer survivors and parents of children with craniofacial conditions (Baker et al., 2009; Cassidy, 2013). A third study found that social support was only related to two domains of benefit finding: Relating to Others and Personal Strength (Li et al., 2012). It seems likely that increased social support could lead to appreciation of the help given by others at a difficult time, and it could be that support from others takes the form of reassurance of one’s strength. Interestingly, in a study of caregivers of children who underwent stem cell transplant, social support was positively related to the Relating to Others domain of benefit finding for mothers, but was negatively related to the New Opportunities domain of benefit finding for fathers (Forinder & Norberg, 2013). The authors suggest that it could be that certain types of social support are more important for benefit finding, whereas other types of social support may increase rumination which may lead to decreased experience of benefit finding.

Optimism was positively related to benefit finding in caregivers of childhood cancer survivors and those who underwent stem cell transplant (Cassidy, 2013; Rini et al., 2004). In fact, among caregivers of stem cell transplant survivors, optimism predicted benefit finding both prior to transplant and 6-months post-transplant, suggesting the stable importance of optimistic world-view throughout their child’s illness experience. Optimism was unrelated to benefit finding in a study of caregivers of children with life-limiting illness conditions, such as cancer and neurodegenerative disorders (Schneider et al., 2011).

Self-esteem and self-efficacy were also studied in relation to benefit finding, and were unequivocally positively related to benefit finding in three separate studies of caregivers of childhood cancer survivors, congenital disease, or life-limiting diseases (Cassidy, 2013; Li et al., 2012; Schneider et al., 2011). These findings suggest a positive contribution of generally feeling capable of managing and overcoming adversity. Similarly, resilience, as assessed by quantitative measures of the ability to cope with and recover from stress, was shown to have a positive effect on benefit finding among caregivers of children with cancer or congenital diseases (Cassidy, 2013; Li et al., 2012). Additionally, the ability to find meaning in the caregiving experience was positively related to benefit finding in caregivers of children with life-limiting illness conditions (Schneider et al., 2011).

Only two studies investigated the relationship between the use of varied coping strategies and benefit finding. Among caregivers of children with craniofacial conditions (Baker et al., 2009), approach coping was associated with greater benefit finding whereas avoidant coping was not related to finding benefits. In another study of caregivers of infants in an intensive care unit (Barr, 2011), confrontive coping, self-controlling coping, and positive reappraisal coping were positively related to benefit finding for both fathers and mothers. The coping strategies of seeking social support, accepting responsibility, escape-avoidance, and planful problem-solving were all related to benefit finding only for mothers. Distancing was unrelated to benefit finding for caregivers of either gender. These findings suggest that some coping strategies may be particularly important for benefit finding, and that some strategies may only be important for one type of caregiver.

Parent mental health symptoms were explored in two studies (10%). Depressive symptoms and diagnosis of depression were unrelated to benefit finding in both studies of caregivers of children with life-limiting illness or children with diabetes (Helgeson et al., 2012; Schneider et al., 2011).

Caregiving burden was examined in two studies (10%). One study found that greater caregiving burden predicted lower benefit finding among caregivers of children with cancer (Cassidy, 2013), but another study found no relationship between caregiver burden and benefit finding in caregivers of children with severe illnesses (Schneider et al., 2011). A variety of additional psychosocial variables were investigated in only one study and therefore understanding their relationships with benefit finding without replication is difficult and currently not warranted. These variables include spirituality, meaning in the caregiving role, guilt, shame, fear of death, quality of family relationships, illness perception, emotional intelligence, anxiety/avoidance, and trauma appraisal.

Outcomes of Benefit Finding

Although exploration of the link between benefit finding and other outcomes (e.g., health, quality of life) among adults with chronic conditions is common, only three studies (14%) in this review investigated outcomes of benefit finding among caregivers of children with chronic conditions. Among caregivers of children who underwent stem cell transplantation (Rini et al., 2004), benefit finding prior to the transplant did not predict overall psychosocial adaptation 6 months later after accounting for baseline levels of adaptation. Another study of caregivers of childhood cancer survivors found that caregiver benefit finding was unrelated to child benefit finding, but was marginally associated with caregiver quality of life (Michel et al., 2009). The third study found that benefit finding uniquely predicted life satisfaction for caregivers of children with type I diabetes (Helgeson et al., 2012). Taken together, results are mixed regarding the effect of benefit finding on more general psychosocial adaptation, but lend preliminary support that benefit finding may help foster other positive psychological outcomes. Given the link among adults suggesting that benefit finding predicts both psychosocial and health outcomes, this association warrants future research with caregivers.

Discussion

The current review sought to synthesize the literature on predictors and outcomes of benefit finding among caregivers of children with chronic medical conditions. Results indicated that benefit finding occurs to a moderate degree among caregivers in both intra- and interpersonal domains. Female caregivers generally showed greater levels of benefit finding than male caregivers, but the results for the role of other caregiver demographic variables in benefit finding were inconsistent. Among child medical variables, caregiver benefit finding has a generally positive association with the severity of the child's medical condition, but inconsistent links with other child medical variables. Among caregiver psychosocial variables, benefit finding is consistently related to various active (but not passive) coping strategies, and optimism, social support, self-efficacy, and posttraumatic stress. Few studies investigated outcomes of benefit finding, such as physical or psychological health outcomes, but benefit finding was related to increased quality of life among caregivers.

Although the rationale for gender differences in caregiver benefit finding is not entirely clear, it could be that female caregivers take on more of a caregiving role, which fosters greater benefit finding compared to fathers, although this explanation has not been tested empirically. In general, caregiver demographic variables were not the focus of any study of benefit finding and over half of the studies included in this review did not report any results for demographic variables' relations with benefit finding, making these associations even more difficult to parse out. Similarly, child medical variables were not the main focus in most studies reviewed, and although child medical severity generally showed a positive relationship with caregiver benefit finding, the measurement of severity varied widely across studies. More studies employing better measures of treatment severity and/or medical risk would help further elucidate these findings.

Finally, psychosocial variables showed the most consistent relationships with benefit finding, although most studies included in this review investigated only one or a few variables at a time, which makes understanding the unique contributions to benefit finding difficult to determine. However, taken together, evidence suggests that optimism, social support, self-efficacy, posttraumatic stress, and various active (but not passive) coping strategies in particular are related to benefit finding, which is important given the malleability of these factors. Interestingly, only two studies investigated coping strategies in relation with benefit finding. Given the importance of coping following the diagnosis of a child with cancer, future studies should further explore the relationship of various ways of coping with benefit finding. Results also indicate that caregiver mental health symptoms (e.g., emotional distress, depression) may not inhibit caregivers from finding benefits in their experience, and in fact experiencing greater posttraumatic stress may promote greater benefit finding.

Although the reasons for inconsistent relationships between predictor variables and benefit finding across studies are not entirely clear, there are several factors that may explain these differences. First, the outcome measure varied among studies and included the PTGI, Benefit Finding Inventory (BFI), stress-related growth inventories, or yes/no questions about the perception of benefits. These measurement differences may account for some of the variability in findings. For example, optimism was positively related to benefit finding in several studies of caregivers using the BFI or similar questions about benefit finding, but was unrelated to posttraumatic growth measured by the PTGI.

Although many items are quite similar between the BFI and PTGI, the PTGI includes several items about self-discovery and internal cognitive restructuring that may take place as a result of a traumatic event. The BFI items represent both external and internal positive changes that have occurred as a result of a situation, and potentially may be affected by one's ability to think positively about life events. Therefore, optimism may represent a more similar construct to benefit finding than to posttraumatic growth, which could explain the discrepant findings when utilizing different measures.

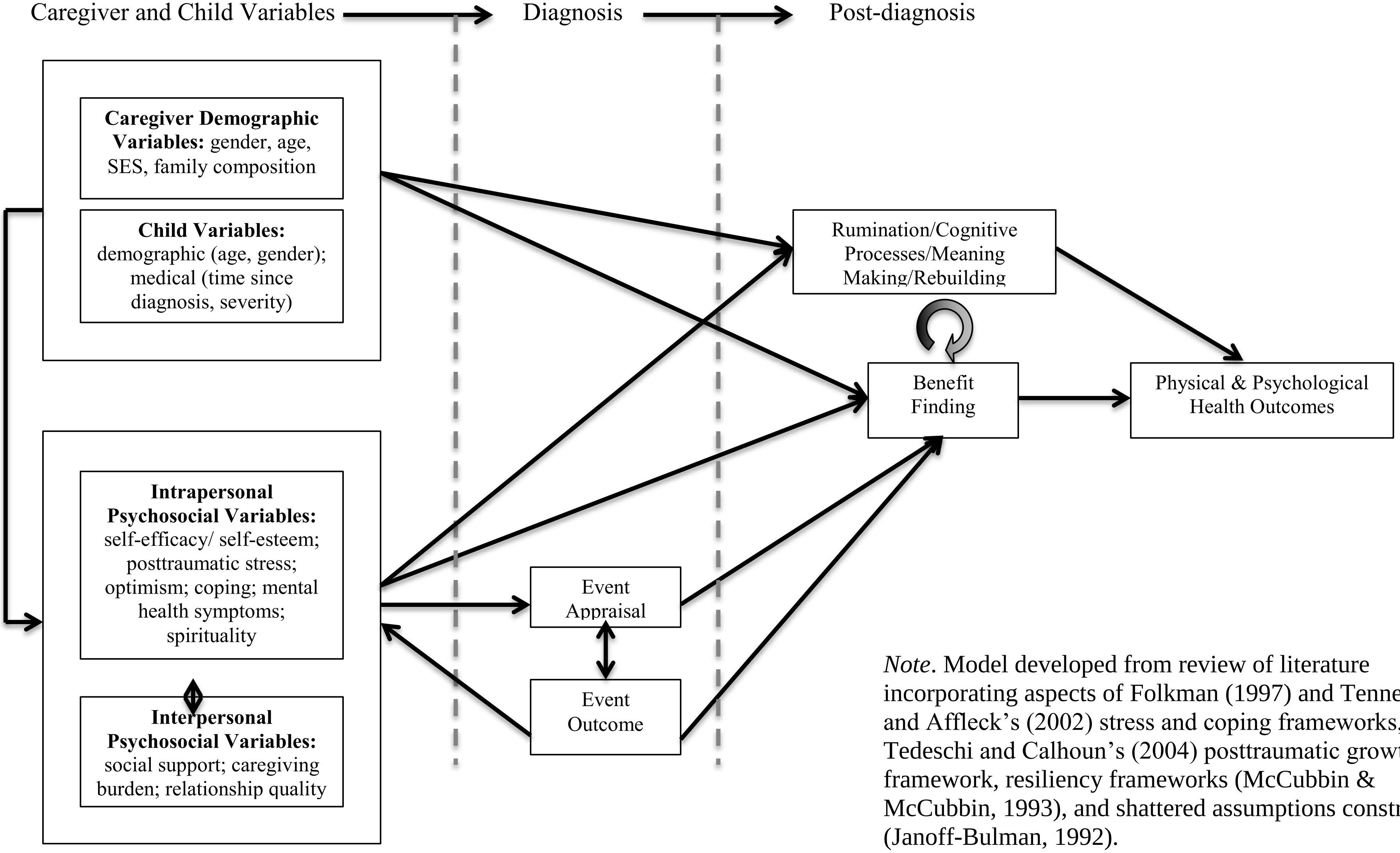
A second factor which could potentially explain discrepancies in several variables' relations with benefit finding includes characteristics of the child's illness, such as severity of the illness (mentioned earlier as potentially leading to differences in benefit finding among caregivers), functional limitation due to the illness, and length of treatment/illness (e.g., Wallander & Thompson, 1998). Investigation of these medical variables in this review was difficult due to many studies grouping several illness groups together, which makes parsing out specific characteristics of individual illness groups difficult. In this review, the domain of New Possibilities was found to be among the highest areas of benefit finding in studies of children with life-limiting illnesses but among the lowest area in studies of children with chronic but not necessarily life-threatening and generally curable conditions (e.g., gastrointestinal illnesses). Therefore, it could be that more severe illnesses that potentially shorten a child's life lead caregivers to search for meaning in their experience, particularly a focus on betterment of their lives and seeking meaning-oriented opportunities, thus promoting benefit finding.

Additionally, although child functional limitation due to their disease was not studied as a predictor of caregiver benefit finding in any study, it could be that caregiver burden or demand is affected by a child’s level of disability, thus affecting benefit finding. Length of time caring for a child with an illness could potentially affect benefit finding as well, particularly with caregiving burden experienced when providing ongoing care for a child. There are no longitudinal studies that assess the long-term nature of benefit finding to determine if benefit finding increases linearly after a child’s diagnosis, or if benefit finding has a curvilinear relationship with time, increasing initially after a child’s diagnosis and then either stabilizing or decreasing. Future studies would prove beneficial in this regard.

Conceptual Model

A conceptual model summarizing the literature is presented in Figure 2. The literature on benefit finding among caregivers of children with chronic conditions suggests that numerous factors are important in determining one’s level of benefit finding, including caregiver gender, time since child’s diagnosis, and both intra- and interpersonal psychosocial variables. Importantly, the predictors of benefit finding are likely related to one another, and therefore it would be important to identify these links as well as potential mediation or moderation effects among these variables. For example, as mentioned above it is likely that a child’s disease severity and functional disability affect the caregiving demands and caregivers’ involvement with the child, which may in turn affect their benefit finding and other facets of adjustment. Several other hypotheses can be made about the process of benefit finding drawing from other theoretical frameworks of positive adjustment. For instance, the outcome of a child’s disease (e.g., remission, cure) and how the caregiver appraises their child’s illness interact to promote or inhibit positive outcomes, such as benefit finding. These relationships could be bidirectional in that a child’s diagnosis and the outcome of that illness affect the way in which caregivers cope with their situation or may affect the level of burden they feel caring for their child. It is likely that other aspects of caregivers (e.g., demographic variables such as gender or age; psychosocial variables such as coping strategies and optimism) affect one’s appraisal of the event as well. Furthermore, rumination, cognitive processing, and rebuilding/making meaning after one’s pre-existing worldview is disrupted (likely impacted by caregivers’ demographic and psychosocial variables) and benefit finding interact in a feedback loop to promote each other. Specifically, individuals hold beliefs about the world in terms of predictability and controllability, which guide their attributions for the cause of events. When a child is diagnosed with a chronic illness, these beliefs are disrupted, and benefit finding may result from trying to “rebuild” and make sense of their situation. These attempts to make meaning and re-conceptualize one’s beliefs may potentially not only have indirect links to physical or psychological health outcomes through benefit finding, but directly impact one’s health as well. Furthermore, there are likely interactions among variables that either promote or inhibit benefit finding. As an illustration, it could be that certain psychosocial variables such as parental depression are more important in predicting benefit finding for caregivers of children with negative health outcomes than for caregivers of children with positive outcomes (e.g., cure). Finally, evidence suggests that benefit finding relates to other physical and psychological health outcomes, although these links necessitate further exploration.

Figure 2. Proposed conceptual model of benefit finding.



Note. Model developed from review of literature incorporating aspects of Folkman (1997) and Tennen and Affleck's (2002) stress and coping frameworks, Tedeschi and Calhoun's (2004) posttraumatic growth framework, resiliency frameworks (McCubbin & McCubbin, 1993), and shattered assumptions constructs (Janoff-Bulman, 1992).

Implications

The present review has several clinical implications. Overall, findings suggest specific groups of caregivers who may be at greater risk for decreased benefit finding following the diagnosis of a child with a chronic condition (e.g., males, those with low optimism, and those with limited coping resources or social support). Further, this review suggests various avenues for increasing positive outcomes among caregivers following the diagnosis of a child with a chronic illness. Specifically, helping families access their support networks or develop adaptive, active ways of coping may prove helpful. Researchers in the adult literature have also suggested that cognitive-behavioral stress management interventions promote benefit finding for women being treated for breast cancer (Antoni et al., 2001). Regarding temporal associations with benefit finding, available literature suggests that benefit finding increases over time and then stabilizes, perhaps suggesting a “critical period” for targeting this construct (e.g., between 6 months-2 years post-diagnosis). Further, given the link between female gender and benefit finding, perhaps male caregivers may benefit to a greater degree than females from strategies to promote benefit finding. Also, given self-efficacy’s link with benefit finding, interventions aimed at promoting confidence in caregivers’ ability to manage their child’s medical condition may be helpful. Interestingly, caregivers who experienced greater posttraumatic stress actually found greater benefits. It could be that experience of the illness as more stressful promotes benefit finding.

Limitations and Future Directions

Limitations of studies included in this review are several. Due to small sample sizes, many studies investigated only one or a small number of variables in relation to benefit finding, making it difficult to discern the most important factors for positive adjustment among caregivers. In light of the proposed conceptual model developed from existing frameworks, it is likely that multiple variables interact in complex ways to impact benefit finding although most studies have yet to investigate some important proposed relationships. For example, it is unclear how one's appraisal of a child's diagnosis or the outcome of the child's medical condition predict benefit finding, or whether caregivers engage in ruminative processes which either promote or inhibit positive outcomes. Further, no one variable was included in the majority of studies, so it is difficult to make strong conclusions about the effect of these factors on benefit finding. Future larger scale studies should address this limitation by investigating multiple predictors in the same study to determine their unique contributions to benefit finding. Further, examining associations and interactions among predictor variables would help elucidate the complex relationships among the variables involved in benefit finding. A second limitation of the majority of included studies is the cross-sectional design, which makes it difficult to determine directionality of the studied relationships. For example, it is likely that adaptive coping strategies promote benefit finding, but it could also be that benefit finding leads to the use of better coping strategies. Finally, future research should explore outcomes of benefit finding. It would be important to determine if benefit finding leads to other health outcomes, such as improved quality of life or physical health improvement, as suggested in the adult literature (e.g., Affleck et al., 1987; Bower et al., 1998).

Conclusions

In sum, there is a growing body of literature on benefit finding among individuals facing adversity, yet a limited number of studies addressed benefit finding among caregivers generally, and among caregivers of children with chronic conditions specifically. This systematic literature review documented high prevalence of benefit finding among caregivers of children with chronic medical conditions and identified several variables that could help providers identify caregivers at greatest risk for decreased positive outcomes following a child's diagnosis. There are many areas of future research that remain to be explored, such as interactions among variables that may impact benefit finding or physical/psychological health outcomes, cognitive processes that promote benefit finding, and physical and psychological health outcomes linked with benefit finding.

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DEMOGRAPHIC, MEDICAL, AND PSYCHOSOCIAL PREDICTORS OF BENEFIT FINDING AMONG CAREGIVERS OF CHILDHOOD CANCER SURVIVORS

by

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Abstract

Objective. There is a growing body of literature examining benefit finding, or finding positive outcomes in the face of adversity, among both adults and children with chronic conditions, and to some degree among caregivers. This study examined demographic, medical, and psychosocial predictors of greater benefit finding among caregivers of childhood cancer survivors.

Methods. Caregivers of childhood cancer survivors (*n*=83) completed measures assessing child and caregiver demographic information, child internalizing/externalizing problems, and caregiver coping, optimism, social support, caregiving demand, post-traumatic stress, illness impact, and benefit finding. We explored six domains of benefit finding (acceptance, empathy, appreciation, family, positive self-view, and reprioritization).

Results. Regression analyses indicated that positive spiritual coping, optimism, and illness impact uniquely predicted overall benefit finding. Most benefit finding domains were uniquely predicted by positive spiritual coping and at least one other psychosocial variable.

Conclusions. Results point to adaptive tendencies that are associated with finding benefits when caring for a childhood cancer survivor and suggest potential avenues for intervention among this population. Investigating several domains of benefits reveals how specific personal factors may contribute to the various domains.

Background

Approximately 10,400 children are diagnosed with cancer every year in the United States [1]. Although cancer is the second leading cause of pediatric death [2], advances in medical treatment have led to improved prognosis for youth diagnosed with cancer. Overall cure rates for children with cancer are approaching 85%, with 5-year survival rates near 80% [3]. Consequently, most children diagnosed with cancer survive well into adulthood. With increased survival rates focus has shifted to examining long-term physical and psychological outcomes for childhood cancer survivors and their adult caregivers. In particular, caregivers of child cancer survivors experience extraordinary practical and psychological difficulties during treatment that may continue post-completion of their child's medical therapy.

The challenges associated with caring for a child with cancer include managing complex in-home medical treatment regimens [4], taking time off work to care for children, managing diagnosis and treatment-related medical effects [5], and continued involvement in their child's medical care into survivorship [6]. Together, these challenges increase distress among caregivers [7]. Accordingly, many studies on psychological adjustment of caregivers focus on negative outcomes including emotional distress and trauma symptoms [8].

Less studied in relation to caregiver's experience with childhood cancer are positive outcomes, termed benefit finding [9]. Benefit finding is an important determinant of physical and psychological health among adults, such as increased happiness [10]; thus, it is important to investigate which factors contribute to benefit finding among caregivers of children with cancer. Research among adults and children with chronic conditions points to several psychosocial variables that may influence benefit finding among individuals with chronic health conditions: optimistic world-view [11-13], active and acceptance coping [10,14], practicing of religion [10,14], and greater perceived impact of the illness [12,15].

Only a few studies have examined benefit finding among caregivers, and fewer studies have included caregivers of children with cancer. These studies show that 90% of mothers and 80% of fathers find at least one benefit in having a child diagnosed with cancer [15]. Domains of benefit are similar to those endorsed by other adult and child populations and include changed life perspective, emotional growth, family integration, and healthier lifestyle [16]. Personality traits such as optimism (among mothers and fathers) and spirituality (among mothers) are associated with greater perception of benefit among caregivers of children with chronic health conditions [17]. Mental health symptoms, conceptualized as posttraumatic stress symptoms, also are associated with greater benefit finding among caregivers of children with cancer [18]. Parenting and caregiving responsibilities also are associated with benefit finding. Specifically, those with greater caregiving demand, especially among mothers of children with cancer, report greater benefit finding [19]. Finally, the perception of better quality family relationships contributed prospectively to benefit finding among caregivers of children with cancer or Type 1 diabetes [20].

The present study was designed to better understand demographic, disease, and psychosocial predictors of benefit finding among caregivers of childhood cancer survivors. Based on findings among adult and pediatric cancer patients, we hypothesized greater benefit finding would be associated with greater child disease severity, and the following caregiver variables: use of problem-focused and religious coping, post-traumatic stress symptoms, optimism, perceived social support, increased caregiver demand, and greater illness impact. We also explored whether the survivor's current emotional/behavioral difficulties were associated with caregivers' benefit finding, hypothesizing that caregivers dealing with difficulties in their children would find fewer benefits. To provide a more refined view of benefit finding, we also considered its subdomains of acceptance, empathy, appreciation, family, positive self-view, and reprioritization, hypothesizing that different aspects of benefit finding would be associated differently with predictors.

Methods

Participants

Eighty-three caregivers of childhood cancer survivors participated. Demographic data for children and caregivers are presented in Table 1. Inclusion criteria included (1) child off-treatment for cancer for at least one year; and (2) caregiver speaks English.

Procedure

Caregivers of childhood cancer survivors from a large tertiary care facility in the southeast U.S. were recruited during their child's routine outpatient follow-up oncology clinic visit. Eligible families were mailed a letter describing the purpose of the study and approached in person during their child's clinic appointment. After providing informed consent, caregivers completed the questionnaires. Participants were compensated for their time. The study was approved by the university Institutional Review Board (IRB).

Measures

Caregivers completed 10 questionnaires, detailed below.

Benefit Finding. Caregivers completed the Benefit Finding Questionnaire [21], a 17-item self-report measure of perceived benefits from a having a child with cancer (e.g., brought my family closer together; helped me become a stronger person). Responses were recorded using a 5-point scale ranging from “not at all” (1) to “extremely” (5), and averaged to create a total benefit finding score, with higher scores indicating greater benefit finding (α = .96). The scale also yields six domains of benefits: acceptance, empathy, appreciation, family, positive self-view, and reprioritization [22], each with 2-4 items (α=.79-.90).

Coping. Caregivers completed 52 items from the COPE [23], which assesses how people deal with challenges. Caregivers were asked how they coped with having had a child with cancer (e.g., I try to get advice from someone about what to do; I refuse to believe that it happened), rated on a four-point scale from “I don’t do this at all” (1) to ”I do this a lot” (4). The items load onto four factors: Active Coping, Emotion-Focused Coping, Avoidant Coping, and Acceptance Coping, each with 8-16 items (α=.75–.88) [24]. Higher scores indicate greater use of each strategy.

Spiritual Coping. Caregivers completed the Brief RCOPE [25], a self-report measure of positive and negative religious/spiritual coping strategies. Seven items represent positive spiritual coping (seeking spiritual support/collaboration from God; benevolent religious reappraisals) and 7 items represent negative spiritual coping (interpersonal spiritual discontentment; negative reappraisals of God’s powers). Participants described how frequently they use different strategies to respond to a specific stressor (e.g., Looked for a stronger connection with God; Felt punished by God for my lack of devotion), rated on a four-point scale from “not at all” (1) to “a great deal” (4).

Items from positive (α=.87) and negative (α=.77) spiritual coping domains were averaged to form the two scales. Higher scores indicate higher levels of positive and negative spiritual coping, respectively.

Caregiving Burden. Caregivers completed the Caregiving Burden Inventory [26], a 24-item measure that assesses five domains of caregiving burden: time-dependence burden (e.g., I have to help my child with many basic functions), developmental burden (e.g., I feel that I am missing out on life), physical burden (e.g., I'm not getting enough sleep), social burden (e.g., I don't get along as well as I used to with others), and emotional burden (e.g., I feel angry about my interactions with my child). Caregivers rated items on a five-point scale ranging from "never" (1) to "always" (5). Responses were averaged for a total caregiving burden score with higher scores indicating greater burden (α=.91).

Illness Impact. Caregivers completed the Impact of Illness Scale [27], a 9-item measure exploring limitations in the caregiver's daily roles due to having a child with cancer. Domains assessed include impact on personal care, fulfilling family obligations, and recreational activities. Participants rated how much having had a child with cancer has impacted their functioning over the past several months in these domains (e.g., To what extent has your capacity to take part in enjoyable recreational activities been reduced by having had a child with cancer?) Items were rated on a four-point scale ranging from "not at all" (1) to "fully" (4). Responses were averaged for an overall impact score (α=.91), with higher scores representing greater negative impact of their child's illness.

Post-traumatic Stress. Caregivers completed the Post-Traumatic Stress Disorder Checklist-Civilian Version (PCL-C) [28], a 17-item measure covering the three primary clusters of symptoms: re-experiencing, avoidance, and hyperarousal. Participants rated the extent to which they have been bothered by problems/complaints in the last month due to having had a child with cancer (e.g., Repeated, disturbing memories, thoughts, or images of a stressful experience in the past). Items were rated on a five-point scale ranging from "not at all" (1) to "extremely" (5), and averaged for a total severity score (α=.95).

Optimism. Caregivers completed the Life-Orientation Test-Revised (LOT-R) [29], a 6-item self-report instrument measuring individual differences in generalized optimism. Participants rated statements reflecting their level of optimism (e.g., In uncertain times, I usually expect the best). Questions were answered on a five-point rating scale ranging from "I disagree a lot" (1) to "I agree a lot" (5). After reversing negatively worded items, responses were averaged with higher scores representing higher levels of optimism (α=.83).

Child Behavior. Caregivers completed the Strengths and Difficulties Questionnaire (SDQ) [30], a 25-item parent-report of child emotional and behavioral difficulties. Participants rated their child's behavior/emotions in the last six months (e.g., Often unhappy, depressed, or tearful). Items were answered on a three-point scale ranging from "not true" (1) to "certainly true" (3) and averaged for a total difficulties score with higher scores representing greater behavioral/emotional symptoms (α=.85).

Social Support. Caregivers completed the Social Provisions Scale (SPS) [31], a 24-item measure assessing six supportive functions, including attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance. Participants were asked to consider their current relationships with friends, family, community, and coworkers and rate their agreement with how much support they receive (e.g., There are people I can depend on to help me if I really need it). Responses were rated on a four-point scale ranging from “strongly disagree” (1) to “strongly agree” (4). After reversing negatively worded items, responses were averaged for a total social provisions score (α=.84).

Demographic and disease variables. Caregivers provided demographic information, including the child’s age, gender, and ethnicity. Caregivers also reported on their own age, relationship to child, ethnicity, education level, religious preference, family’s annual income, family composition, marital status, and zip code from which urban/rural designation was determined. Ethnicity was recoded into a dichotomous variable representing minority vs. White. Education level was recoded into a dichotomous variable representing completed college/higher education vs. completion of high school/lower education. Marital status was recoded into a dichotomous variable representing married vs. not married.

Medical information was extracted from the child’s medical chart and included diagnosis (coded as leukemia, brain tumor [BT], or other non-CNS solid tumor/lymphoma), age at diagnosis (years), treatment length (months), number of treatment modalities (coded as 1 modality vs. ≥ 2 modalities), relapse (coded as relapsed vs. did not relapse), and time since treatment ended (years). The child’s treatment intensity was measured with the Intensity of Treatment Rating-2 (ITR-2) [32]. This scale assesses the intensity of disease and treatment modality ranging from “least intensive” (1) to “most intensive” (4) based on diagnosis, stage or risk level, and treatment modality. After establishing initial reliability with an oncology nurse practitioner (25% of participants; κ=.93) and resolving differences through discussion, the first author completed these ratings for participants.

Data Analysis Plan

Missing data were examined (<1% of data points) and imputed using the EM algorithm. Univariate descriptive statistics identified three outliers which were truncated to 3.5 standard deviations from the mean.

Then, correlations among all variables were examined. Predictors that were correlated with overall benefit finding at $p < .10$ were entered into a hierarchical multiple regression predicting benefit finding. Medical and demographic variables were entered in Step 1 of the regression model. To test the predictive utility of each psychosocial variable over medical and demographic factors, psychosocial variables were entered in Step 2 in separate regression models. Then, all psychosocial variables were entered together at Step 2 to examine the unique predictive utility of each variable over all other variables.

Secondary analyses examined predictors of the six domains of benefit finding, following a similar analytic sequence. Only predictors that were correlated with each domain of benefit finding at p < .10 were entered. Step 1 included demographic and medical variables; all psychosocial predictors were entered simultaneously in Step 2. Assumptions of multiple regressions were evaluated for all regression models, and no violations were found.

Results

Preliminary Analyses

As shown in Table 1, caregivers on average reported that they experienced posttraumatic stress symptoms a little bit to not at all and caregiving burden rarely to never; utilized negative spiritual coping somewhat to not at all; and felt their child's disease currently impacted them a little to not at all. In contrast, caregivers reported that they utilized positive spiritual coping quite a bit to a great deal; agreed or strongly agreed that they received social support; agreed they had an optimistic world view; and felt that their child's cancer experience made contributions to their lives quite a bit to extremely. The highest levels of benefit finding were reported for the empathy domain and the lowest for the family domain.

Table 1. Descriptive statistics of demographic, medical, and psychosocial variables and correlations with benefit finding.

Variable	Descriptives		Correlations with Benefit Finding						
	M (%)	SD	Overall Benefit Finding	Accept -ance	Empathy	Appreci -ation	Family	Positive self-view	Repriori -tization
Child Variables									
Age	14.01	5.19	.00	-.02	.04	.01	.00	.01	-.03
Female	48%	-	-.08	-.03	-.08	-.03	-.05	-.14	-.07
Minority	33%	-	-.04	-.07	-.01	-.03	-.12	.00	-.05
Diagnosis of leukemia	42%	-	.24*	.20†	.23*	.18	.13	.17	.29*
Diagnosis of BT	16%	-	-.15	-.07	-.10	-.12	-.08	-.03	-.23*
Multiple treatment modalities	52%	-	-.25*	-.27*	-.21†	-.17	-.15	-.23*	-.24*
Age at diagnosis (years)	5.93	4.76	-.08	-.02	-.06	-.10	-.07	-.09	-.12
Time since treatment (years)	5.71	4.31	.07	-.04	.10	.10	.13	.06	.06
Treatment length (months)	19.82	13.60	.07	.13	.16	.01	-.06	.06	.15
Treatment intensity	2.55	0.77	-.05	.01	.07	-.04	-.09	-.09	-.05
Experienced relapse	13%	-	-.18†	-.14	-.05	-.16	-.20†	-.15	-.12
Caregiver Variables									
Age	43.39	8.01	-.02	-.09	-.06	.08	-.02	.01	-.08
Female	86%	-	-.01	.05	.03	-.04	.02	-.06	-.07
Minority	25%	-	.01	.07	-.04	-.02	.08	-.02	.03
Rural location	28%	-	-.09	-.06	.05	-.08	-.05	-.16	-.08
Mother completed college	39%	-	.12	.10	.04	.10	.07	.18	.15
Father completed college	33%	-	.14†	.09	.04	.20†	.16	.16	-.02
Family annual income	3.83	1.75	.20	.16	.05	.27*	.24*	.15	.10
Married	80%	-	.03	.00	-.01	.03	.06	.11	.00
Psychosocial Variables									
Active coping[a]	2.78	0.55	.22*	.30*	.15	.19†	.14	.15	.14

Emotion coping[a]	2.46	0.67	.29*	.38*	.33*	.22*	.24*	.11	.26*
Avoidant coping[a]	1.23	0.32	.00	.02	.10	-.02	.01	-.07	.05
Acceptance coping[a]	2.79	0.39	.19†	.43*	.19†	.09	.06	.07	.17
Positive Spiritual Coping[a]	3.34	0.66	.53*	.46*	.53*	.48*	.51*	.47*	.31*
Negative Spiritual Coping[a]	1.33	0.42	-.02	.01	.03	-.09	-.05	-.01	.00
Social support[a]	3.57	0.37	.47*	.44*	.33*	.39*	.38*	.40*	.32*
Optimism[b]	3.85	0.85	.36*	.29*	.26*	.39*	.27*	.34*	.30*
Caregiving burden[b]	1.64	0.52	-.17	-.13	-.10	-.23*	-.07	-.26*	-.09
Illness impact[a]	1.28	0.39	-.30*	-.12	-.16	-.42*	-.28*	-.19	-.25*
Post-traumatic stress[b]	1.53	0.68	-.16	-.01	-.07	-.23*	-.14	-.12	-.15
Child behavior[c]	1.43	0.31	-.12	-.06	-.04	-.12	-.11	-.13	.01
Benefit Finding									
Overall benefit finding[b]	4.03	0.79	--						
Acceptance[b]	3.99	0.78	.80*	1.00					
Empathy[b]	4.19	0.89	.89*	.71*	1.00				
Appreciation[b]	3.90	0.96	.89*	.64*	.70*	1.00			
Family[b]	3.83	1.02	.87*	.61*	.73*	.78*	1.00		
Positive Self-View[b]	4.09	0.88	.89*	.69*	.76*	.79*	.71*	1.00	
Reprioritization[b]	4.14	0.93	.81*	.62*	.71*	.72*	.66*	.68*	1.00

Note. †p<.10; **p* < .05. ALL=Acute lymphocytic leukemia; BT=brain tumor. [a]Scale range 1-4; [b]Scale range 1-5; [c]Scale range 1-3

Benefit finding was unrelated to demographic variables. Associations between benefit finding and the three diagnosis groups were examined, and only diagnosis of leukemia was associated with benefit finding; therefore, this variable was coded as diagnosis of leukemia versus other diagnoses. Additionally, receiving only one treatment modality (i.e., surgery, chemotherapy, or radiation) was associated with greater benefit finding. Higher levels of active, emotion, and positive spiritual coping, social support, and optimism were related to greater benefit finding. Illness impact was associated with less benefit finding, contrary to predictions. Table 2 presents a correlation matrix of all predictors correlated with benefit finding at $p<.10$. Evaluation of multicolinearity risk yielded one correlation of concern, between child diagnosis of leukemia and receiving multiple treatment modalities (r = -.79). Thus, diagnosis of leukemia was omitted from the regression analyses, because it was deemed less general than treatment modalities.

Table 2. Intercorrelations among variables retained for multiple regression analyses.

Predictor Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Child Variables														
1. Diagnosis of leukemia	1.00													
2. Diagnosis of BT	-.34*	1.00												
3. Multiple treatment modalities	-.79*	.28*	1.00											
4. Experienced relapse	-.26*	.32*	.31*	1.00										
Caregiver Variables														
5. Father completed college	-.08	-.01	.07	-.03	1.00									
6. Family annual income	-.05	-.17	.01	-.04	.43*	1.00								
Psychosocial Variables														
7. Active coping	.14	-.16	-.05	.08	.25*	.29*	1.00							
8. Emotion coping	.14	-.07	-.06	.13	.02	.19†	.46*	1.00						
9. Acceptance coping	.00	-.15	.02	-.04	.02	.14	.51*	.50*	1.00					
10. Positive Spiritual Coping	.12	-.16	-.11	-.06	.04	.15	.12	.39*	.22*	1.00				
11. Social support	.06	-.14	-.07	-.23*	.26*	.43*	.23*	.17	.23*	.33*	1.00			
12. Optimism	-.03	-.11	-.02	-.04	.11	.22*	.21†	-.10	.11	.14	.43*	1.00		
13. Caregiving burden	-.05	.17	.06	.01	-.10	-.25*	.01	.16	.22*	-.09	-.21†	-.21†	1.00	
14. Illness impact	-.11	.23*	.00	.20†	-.08	-.24*	.08	.07	.19	-.06	-.27*	-.22†	.53*	1.00
15. Post-traumatic Stress	-.13	.31*	.14	.27*	.02	-.17	.01	.18	.20†	.04	-.32*	-.31*	.49*	.57*

Note. †p<.10; *p* < .05.

Primary Analyses

Multiple regressions predicting benefit finding appear in Table 3. At Step 1, multiple treatment modalities, experiencing relapse, and family income explained 11% of variance in benefit finding, but no variable was a unique predictor. When each psychosocial variable was entered by itself ('Step 1 adjusted models' in Table 3), emotion-focused coping, positive spiritual coping, social support, optimism, and illness impact each uniquely predicted benefit finding above the demographic and medical variables (ΔR^2 range from .07-.24, *p*s < .05). In the fully adjusted model where all psychosocial variables were entered together at Step 2, positive spiritual coping, optimism, and illness impact emerged as unique significant predictors of benefit finding. This fully adjusted model explained 46% of the variance in benefit finding.

Table 3. Multiple regressions predicting overall benefit finding.

Predictor	Step 1 Adjusted		Fully adjusted	
	β	ΔR^2	β	ΔR^2
Step 1		.11*		.11*
Multiple treatments	-.22		-.22	
Experienced relapse	-.11		-.11	
Family annual income	.20		.20	
Step 2				.42*
Active coping	.21	.04	.09	
Emotion coping	.28*	.07*	.13	
Acceptance Coping	.18	.03	.00	
Positive spiritual coping	.49*	.24*	.35*	
Social support	.47*	.17*	.19	
Optimism	.37*	.13*	.23*	
Illness Impact	-.27*	.06*	-.22*	

Note. *$p<.05$. Step 1 adjusted values indicate the beta and ΔR^2 for each predictor variable separately after adjusting for Step 1 variables. Fully adjusted values indicate beta and ΔR^2 for variables after adjusting for Step 1 and including other Step 2 variables in the model.

Secondary Analyses

Correlations among the six domains of benefit finding ranged from .61 to .79 (Table 1), suggesting that these domains may represent somewhat unique but related aspects of benefit finding. Brain tumor diagnosis was associated with finding fewer benefits in reprioritization. Receiving multiple treatment modalities was correlated with finding fewer benefits in acceptance, positive self-view, and reprioritization. Family annual income was positively associated with the appreciation and family domains. Several psychosocial variables were consistently correlated with most or all of the domains, including emotion-focused and positive spiritual coping, social support and optimism.

Table 4 presents the results of regression models predicting the domains of benefit finding. Together, the predictor variables explained between 22% (Reprioritization) and 42% (Appreciation) of the variance in the benefit finding domains. In Step 1, family annual income uniquely predicted greater the appreciation and family domains (Table 4), although these variables were no longer significant after entering psychosocial predictors in Step 2. Receiving multiple treatment modalities uniquely predicted lower acceptance and positive self-view domains, but only remained a significant predictor after Step 2 for acceptance. After controlling for demographic and medical variables, positive spiritual coping uniquely predicted greater acceptance, empathy, appreciation, family, and positive self-view domains. Social support uniquely predicted greater acceptance. Greater optimism and lower illness impact uniquely predicted more appreciation. Emotion-focused coping predicted greater reprioritization.

Table 4. Multiple regressions predicting domains of benefit finding.

	Acceptance		Empathy		Appreciation		Family		Self		Reprioritization	
Variable	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2	β	ΔR^2
Step 1		.05*		.04		.11*		.10*		.05*		.08*
Child diagnosis-BT	-		-		-		-		-		-.19	
Child Multiple Treatments	-.23*		-.21		-		-		-.23*		-	
Child Relapse	-		-		-		-.19		-		-	
Father completed college	-		-		.04		-		-		-	
Family annual income	-		-		.31*		.24*		-			
Step 2		.39*		.33*		.39*		.30*		.32*		.21*
Active Coping	-.02		-		.06		-		-		-	
Emotion-focused Coping	.13		.18		.06		.12		-		.22*	
Avoidant Coping	-		-		-		-		-		-	
Acceptance Coping	.26*		-.03		-		-		-		-	
Positive Spiritual Coping	.24*		.40*		.34*		.39*		.36*		.12	
Negative Spiritual Coping	-		-		-		-		-		-	
Social Support	.21*		.09		.05		.06		.16		.08	
Optimism	.15		.18		.29*		.18		.19		.22	
Caregiving Burden	-		-		.06		-		-.14		-	
Illness Impact	-		-		-.40*		-.18		-		-.18	
Post-traumatic stress	-		-		.08		-		-		-	
Total R^2		.39		.32		.42		.34		.32		.22

Note. *$p < .05$. BT = brain tumor. Only variables correlated $p < .10$ with each domain were entered into regression analyses.

Conclusions

This study investigated multiple predictors of benefit finding among caregivers of childhood cancer survivors. The results suggest that despite the stressors associated with caring for a child with cancer, caregivers of childhood cancer survivors generally report finding positive changes from having endured this experience. Their perceived benefits extend across multiple domains, and include greater empathy for others, appreciation of others' support, acceptance of life's circumstances, feeling more capable to handle difficulties, a reprioritization of one's values, and feeling closer with family. Caregivers of children who received only one treatment modality, did not experience a relapse, and had a higher family annual income tended to report somewhat greater benefits from their experience. However, these variables did not uniquely predict benefit finding after accounting for psychosocial variables. Optimism, positive spiritual coping, and lower illness impact emerged as unique psychosocial predictors of benefit finding after controlling for demographic, medical, and psychosocial factors. In the secondary analyses, positive spiritual coping also uniquely predicted all domains of benefit finding, with the exception of the reprioritization domain. Optimism, emotion-focused coping, acceptance coping, social support, and lower illness impact uniquely predicted specific domains of benefit finding.

Predictors of Benefit Finding

The results of this study resonate with previously reported inconsistent associations between benefit finding and demographic and medical variables [33]. Thus, benefit finding seems to extend across many demographic groups and medical populations. Our findings extend previous results of greater benefit finding among childhood survivors of leukemia compared to other cancers [12], suggesting that this association may be explained by lower number of treatment modalities among patients with leukemia. Specifically, leukemia survivors in our sample typically received only one treatment modality (chemotherapy), and receiving only one treatment modality was associated with greater benefit finding. However, it may also be that parents of children with leukemia experience greater benefits due to the better prognosis and greater survival rate of leukemia compared to other diagnoses [3].

Interestingly, benefit finding was more consistently related to a number of positive psychosocial factors, including optimism, positive spiritual coping, emotion-focused coping, and social support, but was typically unrelated to the use of negative strategies such as negative spiritual coping, avoidant coping, caregiving burden, and negative child behavior. These results point to the nature of benefit finding as an active experience in which one arrives at positive adaptation through the use of positive strategies [34], but not necessarily through the absence of negative factors. In fact, past research among other populations suggests that benefit finding can occur even in the presence of significant negative psychological adjustment [35], although negative psychological adjustment was generally not related to benefit finding among caregivers in our study.

Although this cross-sectional study does not elucidate the mechanisms that lead to benefit finding, some have suggested that optimism may contribute to finding benefits indirectly through greater use of adaptive coping strategies [36]. Additionally, spiritual or religious coping has consistently been related to making meaning of one’s experience and finding benefits among different populations including adult breast cancer survivors and caregivers of children with Asperger's Syndrome [14,37]. Researchers speculate that optimism, spiritual coping, and social support all promote interpretation of a difficult situation in a favorable light by helping to make sense of the event and encouraging the use of positive coping strategies [38]. Cotton and colleagues [39] suggested greater optimism predicts greater use of spiritual coping strategies, and this strategy may be particularly important for promoting positive psychological adaptation after a stressful experience. Taken together, it seems likely that optimism, positive spiritual coping, and benefit finding are interrelated. Potential mediating causal paths should be elucidated in longitudinal research.

Surprisingly, social support did not uniquely predict benefit finding in the fully adjusted models, possibly because of its association with spiritual coping (r = .33). Those who engage in positive spiritual coping may have access to additional sources of social support, such as someone in their spiritual community, which may facilitate positive adaptation. Further, it has been suggested that spirituality promotes a sense of community [38], and therefore, the overlap between the two constructs may mask the individual effect of social support that emerged in bivariate and partially-adjusted analyses.

Contrary to past research [12,15], greater illness impact was related to finding not more but *fewer* benefits. However, caregivers in our sample reported that their child's illness impacted them a little to not at all in the present day, likely because their children had been off treatment for several years. The link between impact and benefit finding has been found among childhood cancer survivors, and not specifically among caregivers [12], so possibly the impact of a child's illness differentially predicts finding benefits for children and caregivers. Another possible explanation is that past research has utilized varied measures of the impact of the cancer experience (e.g., emotional impact of illness compared to global impact including physical, social, and cognitive impact) [12].

Benefit Finding Domains

Secondary analyses indicated that most domains of benefit finding were predicted by positive spiritual coping, underscoring the importance of this strategy for positive adaptation in the face of stress. However, each domain was also predicted by one or two other positive psychosocial variables, suggesting some specificity in the links between psychosocial resources and particular domains of finding benefit. Acceptance coping and social support uniquely predicted greater acceptance, for example, indicating that striving to accept life’s challenges and receiving support from others may be instrumental in better adjustment to change and acceptance of life’s circumstances. Additionally, lower illness impact and optimism uniquely predicted greater appreciation, perhaps as a function of comparison with others (who may have experienced greater impact of illness) and optimism-driven focus on the positive. Finally, emotion-focused coping was the only unique predictor of reprioritization, perhaps because seeking emotional support from others helps people realize how important others are in their lives. In summary, these analyses provide a more nuanced view of how different psychosocial strengths may contribute to specific domains of benefit finding, and suggest the utility both of using multi-dimensional measures of benefit finding in future studies and of specifying which aspect of benefit finding is of interest to the clinician or researcher.

Limitations

One study limitation was the use of a cross-sectional design, which does not allow inferences about the directionality of the associations. For example, psychosocial resources may improve benefit finding as hypothesized, but finding greater benefits in the cancer experience could also influence optimism, positive spiritual coping, and seeking/accepting support. Future research should utilize longitudinal designs to elucidate the directionality of the associations among the variables. Additionally, caregivers were the only informant for this study and therefore shared method variance could contribute to the observed relationships. Despite this limitation, we still found differential prediction of benefit finding, supporting the validity of the findings. There is also the possibility that the relatively small sample size and breadth of variables studied led to increased type I error. Given this is one of the first studies to examine multiple variables together, future studies should include larger samples and validate the observed relationships. Further, the sample included primarily female caregivers of children with cancer, so the findings may not generalize to male caregivers. Future research should address predictors of benefit finding in different caregivers. The generalizability of the results also may be limited by recruiting families from a cancer survivorship clinic. It could be that families who do not attend such a clinic experience fewer positive outcomes following their child's diagnosis. Recruiting families of cancer survivors outside of a clinic may increase the generalizability of the findings.

Implications and Conclusions

Despite these limitations, this study has several clinical implications. Many interventions for families of children with cancer focus on lowering distress (anxiety, depression) [40]. These aspects of the cancer experience are important to address, but they may not represent the only way to improve caregivers' positive adaptation. Our results suggest that helping caregivers learn to cope more adaptively with their child's diagnosis, especially through strategies that lessen the perceived impact of the illness and promote optimism and positive spiritual coping, may promote finding benefits among families. Further, helping caregivers develop more acceptance and emotion-focused coping and increase their support may ultimately lead to finding benefits in specific domains.

In summary, several factors may be important to the development of benefit finding among caregivers of childhood cancer survivors, including perceived illness impact, optimism, adaptive coping skills, and receiving support from others. Future research should extend these results longitudinally and evaluate interventions targeting these constructs in families of children with cancer.

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BENEFIT FINDING AND QUALITY OF LIFE IN CAREGIVERS OF CHILDHOOD CANCER SURVIVORS: THE MODERATING ROLES OF DEMOGRAPHIC AND PSYCHOSOCIAL FACTORS

by

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Abstract

Objective: Benefit finding, or finding positive outcomes in the face of adversity, may play a role in predicting quality of life (QoL) among caregivers, but mixed results suggest that other factors may moderate this relationship. This study examined demographic and psychosocial moderators of the association between benefit finding and QoL among caregivers of childhood cancer survivors.

Methods: Caregivers of childhood cancer survivors (*n*=83) completed measures of benefit finding, QoL, coping, optimism, social support, caregiving demand, posttraumatic stress, and demographics.

Results: The relationship between benefit finding and QoL was moderated by caregiver age, marital status, socioeconomic status, geographic location, acceptance and emotion-focused coping, optimism, caregiving demand, and posttraumatic stress. Benefit finding was more strongly related to QoL among caregivers with fewer demographic/psychosocial resources.

Conclusions: Results have implications for research investigating the complex nature of QoL among caregivers. Finding benefits may lead to greater QoL among caregivers having fewer coping resources.

Introduction

Caregivers of children with cancer face numerous challenges throughout treatment and into survivorship, including managing complex in-home medical treatment regimens (Anderson, 1990), taking time off work, managing lasting medical effects from treatment (Oeffinger et al., 2006), and continued involvement in children’s medical care (Ressler, Cash, McNeill, Joy, & Rosoff, 2003). These responsibilities may lead to increased distress even into the survivorship period (Kazak, Alderfer, Rourke, Simms, Streisand, & Grossman, 2004; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Pai et al., 2007). In addition, caregivers of children with cancer generally experience decreased quality of life (QoL) compared to normative samples and mothers of children without cancer (Eiser, Eiser, & Stride, 2005; Klassen et al., 2008; Yamazaki, Sokejima, Mizoue, Eboshida, & Fukuhara, 2005). With increasing childhood cancer survival rates due to improved medical treatment (Howlader, Noone, & Krapcho, 2013), focus on the QoL of children and caregivers is of great importance to ensure positive well-being following a cancer diagnosis, particularly considering that greater well-being is associated with longevity and reduced mortality among healthy adults, and a weaker but positive association among adults with diseases, including cancer (Diener & Chan, 2011).

Although little is known about factors that contribute to better QoL among caregivers of children who survived cancer, benefit finding appears to play an important role. Benefit finding is conceptualized as experiencing positive outcomes in the face of adversity and is a way of finding meaning and adapting to adversity, in particular to medical conditions (Antoni et al., 2001). Researchers suggest that benefit finding involves a cognitive reorganization of one’s world-view following an adverse event (Calhoun & Tedeschi, 1998). This construct has been posited to be similar to posttraumatic growth and stress-related growth (Park, Cohen, & Murch, 1996; Tedeschi & Calhoun, 1996). Benefit finding is common among adults and children with cancer, as well as caregivers of childhood cancer survivors and includes domains of changed life perspective, emotional growth, and family integration (Barakat, Alderfer, & Kazak, 2006; Hensler, Katz, Wiener, Berkow, & Madan-Swain, 2013). It is possible that appreciating the benefits of having a child with cancer helps parents cope with the challenges of survivorship and attain higher QoL. Interestingly, however, empirical evidence of benefit finding and QoL with varied populations is mixed. Some studies found positive associations between benefit finding and QoL among cancer survivors (Carver & Antoni, 2004; Lelorain, Bonnaud-Antignac, & Florin, 2010; Mols, Vingerhoets, Coebergh, & Van de Poll-Franse, 2009), caregivers of children in the intensive care unit (Affleck, Tennen, & Gershman, 1985), and caregivers of adults with cancer (Kim, Schulz, & Carver, 2007). However, other studies found no associations between benefit finding and QoL among breast cancer survivors (Cordova, Cunningham, Carlson, & Andrykowski, 2001) and parents of childhood cancer survivors (Michel, Taylor, Absolom, & Eiser, 2010). One explanation for these discrepancies is that benefit finding may not translate into better QoL for all survivors or their caregivers, but that other factors moderate this relationship. In other words, benefit finding may be more important for enhanced QoL among some individuals than others. Support for this hypothesis was provided by McMillen and colleagues, who reported a stronger relationship between benefit finding and well-being among those who experienced more severe disasters (McMillen, Smith, &

Fisher, 1997), suggesting that individuals who are more vulnerable to poor QoL may profit more from finding benefits in challenging situations.

Because little research to date has examined moderators of the association between benefit finding and QoL, we examined two types of moderators – demographic and psychosocial variables. Researchers investigating these variables as predictors of QoL achieve inconsistent results, further suggesting the presence of moderating relationships. For example, low caregiver education was associated with low QoL among caregivers of brain tumor survivors (Chien, Lo, Chen, Chen, Chaing, & Chao, 2003), but others found no associations between caregiver education/income and QoL (Eyigor, Karapolat, Yesil, & Kanta, 2011). Other demographic characteristics of caregivers such as younger age, being single, or living in a rural area may make caregivers more vulnerable to poor QoL and moderate the relationship between benefit finding and QoL. Several psychosocial variables may increase vulnerability to poor QoL and increase the importance of benefit finding including caregiving stress, ineffective coping strategies, low social support, and low optimism (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Klassen et al., 2011; Mellon, Northouse, & Weiss, 2006; Miller, Manne, Taylor, Keates, & Dougherty, 1996; Witt et al., 2010).

In summary, benefit finding may be an important predictor of QoL among caregivers of childhood cancer survivors, but its role may vary based on caregivers' demographic and psychosocial characteristics. We investigated the moderating roles of caregiver age, marital status, socioeconomic status (SES), geographic location, optimism, coping strategies, posttraumatic stress symptoms, caregiving burden, and social support. We hypothesized stronger positive relationships between benefit finding and QoL among caregivers more vulnerable to poor QoL – those who were younger, single, with lower SES, residing in rural locations, less optimistic, used less effective coping strategies, experienced more posttraumatic stress symptoms or caregiving burden, and received less social support.

Methods

Participants

Eighty-three caregivers of childhood cancer survivors participated. Demographic data for both children and caregivers are presented in Table 1. Inclusion criteria included (1) child off-treatment for cancer for ≥ 1 year; and (2) caregiver speaks English.

Procedure

Caregivers of childhood cancer survivors treated at a large tertiary care facility in the southeast U.S. were recruited during outpatient follow-up oncology clinic visits at the same facility. Eligible families were mailed a letter describing the purpose of the study prior to their clinic appointment and were provided the opportunity to participate during the appointment. After providing informed consent, caregivers completed the questionnaires. Study completion took approximately 30 minutes, and participants were compensated modestly for their time. The study was approved by the university Institutional Review Board (IRB).

Measures

Caregivers completed 8 questionnaires, detailed below.

Quality of Life. QoL was measured by World Health Organization Quality of Life BREF (WHOQOL Group, 1998), a 26-item measure assessing four domains: physical, psychological, social, and environmental QoL. Participants rated the frequency/intensity of items within the past month (e.g., Do you have enough energy for everyday life?) on 5-point scales ranging from “very poor” (1) to “very good” (5), “very dissatisfied” (1) to “very satisfied” (5), “not at all” (1) to “an extreme amount” (5) and “never” (1) to “always” (5). The scales were averaged for overall QoL score (Cronbach’s alpha=.95).

Benefit Finding. Caregivers completed the Benefit Finding Questionnaire (Antoni et al., 2001), a 17-item measure of perceived benefits from a having a child with cancer (e.g., brought my family closer together; helped me become a stronger person). Responses were recorded using a 5-point scale ranging from “not at all” (1) to “extremely” (5), and averaged to create a total benefit finding score, with higher scores indicating greater benefit finding (Cronbach’s alpha=.96).

Coping. Caregivers completed 52 items from the COPE (Carver, Scheier, & Weintraub, 1989) assessing how people manage challenges. Caregivers were asked how they coped with having had a child with cancer (e.g., I try to get advice from someone about what to do), rated on a four-point scale from “I don’t do this at all” (1) to ”I do this a lot” (4). The items load onto four factors: Active, Emotion-Focused, Avoidant, and Acceptance Coping, each with 8-16 items (Cronbach’s alpha=.75-.88; Turner-Sack, Menna, & Setchell, 2012). Higher scores indicate greater use of each strategy.

Caregiving Burden. Caregiver burden was measured using the Caregiving Burden Inventory (Novak & Guest, 1989), a 24-item measure assessing five domains of caregiving burden: time-dependence, developmental, physical, social, and emotional burden. Caregivers rated items on a 5-point scale ranging from “never” (1) to “always” (5). Responses were averaged for a total burden score with higher scores indicating greater burden (Cronbach’s alpha=.91).

Post-traumatic Stress. Caregivers completed the Post-Traumatic Stress Disorder Checklist-Civilian Version (Weathers, Huska, & Keane, 1991), a 17-item measure covering re-experiencing, avoidance, and hyperarousal symptoms. Participants rated the extent to which they have been bothered by problems/complaints in the last month due to having had a child with cancer (e.g., Repeated, disturbing memories, thoughts, or images of a stressful experience in the past). Items were rated on a five-point scale ranging from "not at all" (1) to "extremely" (5), and averaged for a total severity score (Cronbach's alpha=.95).

Optimism. Caregivers completed the Life-Orientation Test-Revised (Scheier, Carver, & Bridges, 1994), a 6-item instrument measuring individual differences in generalized optimism. Participants rated statements reflecting their level of optimism (e.g., In uncertain times, I usually expect the best). Questions were answered on a five-point rating scale ranging from "I disagree a lot" (1) to "I agree a lot" (5). After reversing negatively worded items, responses were averaged with higher scores representing higher levels of optimism (Cronbach's alpha=.83).

Social Support. Caregivers completed the Social Provisions Scale (Cutrona & Russell, 1987), a 24-item measure assessing six supportive functions: attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance. Participants considered their current relationships and rated their agreement with how much support they receive (e.g., There are people I can depend on to help me if I really need it). Responses were rated on a four-point scale ranging from "strongly disagree" (1) to "strongly agree" (4). After reversing negatively worded items, responses were averaged for a total social provisions score (Cronbach's alpha=.84).

Demographic and disease variables. Caregivers provided demographic information, including the child's age, gender, and ethnicity. Caregivers reported on their own age, relationship to the child, ethnicity, education level, family's annual income, family composition, marital status, and zip code from which urban/rural designation was determined by US Census data. Ethnicity was recoded into a dichotomous variable (minority/White). Education level was used as a continuous variable ranging from did not complete high school to completed advanced degree. Mother and father education were averaged, and standardized education was averaged with standardized family income (r = .68, p<.001) to yield a composite measure of SES. Marital status was recoded into a dichotomous variable (married/not married).

Medical information was extracted from the child's medical chart, including diagnosis (coded as leukemia/lymphoma, brain tumor, or other non-CNS solid tumor), age at diagnosis (years), treatment length (months), number of treatment modalities (dichotomized into 1 modality vs. ≥ 2 modalities), relapse (coded as relapsed vs. did not relapse), and time since treatment ended (years). The child's disease/treatment intensity was measured with the Intensity of Treatment Rating-2 (Werba, Hobbie, Kazak, Ittenbach, Reilly, & Meadows, 2007), ranging from "least intensive" (1) to "most intensive" (4) based on diagnosis, stage/risk level, and treatment modality. After establishing initial reliability with an oncology nurse practitioner (25% of participants; κ = .93) and resolving differences through discussion, the first author completed these ratings for all participants.

Data Analysis Plan

Missing data were examined (<1% of data points) and imputed using the EM algorithm. Univariate descriptive statistics identified three outliers which were truncated to 3.5 standard deviations from the mean. Correlations among variables were examined. Prior to the main analyses, interaction terms were computed as products of benefit finding with each demographic and psychosocial variable; all variables were first centered to mean of 0.

Main analyses involved a series of multiple regressions predicting QoL from benefit finding, each demographic or psychosocial variable, and their interaction. Benefit finding was entered in Step 1 with SES, which was the only demographic variable correlated with QoL. Because some demographic and psychosocial variables were modestly correlated with one another and due to the modest sample size, remaining demographic and psychosocial variables and their moderating effects were tested in separate regressions in Step 2. Significant interactions were followed with tests of simple slopes for benefit finding at high vs. low levels of the moderator (±1SD for continuous variables). Assumptions of multiple regressions were evaluated, and no violations of normality, linearity or homoscedasticity were found.

Results

Preliminary Analyses

As shown in Table 1, children were on average 14.01 years (SD=5.19) at the time of study, included about equal proportions of males and females, and slightly less than half had a diagnosis of leukemia. On average, children were 5.93 years old (SD=4.76) at the time of diagnosis and 5.71 years past completing medical treatment (SD=4.31). The average treatment intensity was moderate. Caregivers were mostly females from nonrural geographic locations. Median family annual income was $70,000. Most caregivers were married.

Table 1. Descriptive statistics of demographic, medical, and psychosocial variables, and correlations with QoL.

	M (%)	SD	Correlation with QoL
Child Variables			
Age	14.01	5.19	0.05
Female	48%	-	-0.07
Minority	33%	-	-0.09
Diagnosis of leukemia/lymphoma	42%	-	0.16
Diagnosis of brain tumor	16%	-	-0.34*
Multiple treatment modalities	52%	-	-0.21
Age at diagnosis (years)	5.93	4.76	-0.01
Time since treatment (years)	5.71	4.31	-0.01
Treatment length (months)	19.82	13.60	0.00
Treatment intensity	2.55	0.77	-0.17
Experienced relapse	13%	-	-0.16
Caregiver Variables			
Age	43.39	8.01	0.01
Female	86%	-	-0.05
Minority	25%	-	0.10
Rural location	28%	-	-0.03
Socioeconomic status^c	0.00	0.92	0.27*
Married	80%	-	0.02
Psychosocial Variables			
Benefit Finding^b			0.50*
Active coping^a	2.78	0.55	0.20
Emotion coping^a	2.46	0.67	0.01
Avoidant coping^a	1.23	0.32	-0.38*
Acceptance coping^a	2.79	0.39	-0.02
Optimism^b	3.85	0.85	0.44*
Caregiving burden^b	1.64	0.52	-0.53*
Post-traumatic stress^b	1.53	0.68	-0.62*
Social support^a	3.57	0.37	0.58*
QoL^a	4.01	0.66	--

Note. **p* < .05. QoL = quality of life. ^{a}Scale range 1-4; ^{b}Scale range 1-5; ^{c}Created by averaging z-scored education and income.

Correlations between QoL and demographic, medical, and psychosocial variables are presented in Table 1. Caregivers of childhood cancer survivors generally reported lower levels of QoL compared to normative samples. Higher SES was correlated with better QoL. Among medical variables, child diagnosis of brain tumor was associated with lower QoL. Among psychosocial variables, greater benefit finding, social support, and optimism were related to higher QoL; avoidant coping, caregiving burden, and post-traumatic stress were associated with lower QoL. Table 2 presents correlations of all predictor variables that were included in the main analyses, including benefit finding and all demographic variables and psychosocial factors hypothesized to moderate the link between benefit finding and QoL.

Table 2. Intercorrelations among variables retained for multiple regression analyses.

Predictor Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
Caregiver Variables													
1. Age	1.00												
2. Married	.16	1.00											
3. Socioeconomic status	.37*	.11	1.00										
4. Rural location	-.19	.07	-.27*	1.00									
Psychosocial Variables													
5. Benefit finding	-.02	.03	.21	-.09	1.00								
6. Active coping	.24*	-.18	.29*	-.10	.22*	1.00							
7. Emotion coping	.10	-.15	.16	.10	.29*	.46*	1.00						
8. Avoidant coping	-.03	-.13	-.18	.08	.00	.06	.27*	1.00					
9. Acceptance Coping	.01	-.27*	.18	.03	.19	.51*	.50*	.20	1.00				
10. Optimism	.16	.09	.22*	-.11	.36*	.21	-.10	-.16	.11	1.00			
11. Caregiving burden	-.04	-.25*	-.18	-.05	-.17	.01	.16	.39*	.22*	-.21	1.00		
12. Posttraumatic stress	-.05	-.08	-.15	-.11	-.16	.01	.18	.50*	.20	-.31*	.49*	1.00	
13. Social Support	.03	.07	.44*	-.11	.47*	.23*	.17	-.30*	.23*	.43*	-.21	-.32*	1.00

Note. *$p < .05$. Marital status (1=married, 0=not married). Geographic location (1=rural, 0=urban).

Main Analyses

A series of multiple regressions predicting QoL are presented in Table 3. At Step 1 (same for all models), benefit finding and SES explained a significant proportion of variance in QoL ($R^2 = .28$, $p < .05$), and benefit finding uniquely predicted higher QoL. In Steps 2, age, marital status, rural location and SES interacted with benefit finding to predict QoL. Emotional and avoidant coping, optimism, caregiving burden and post-traumatic stress symptoms also interacted with benefit finding, whereas active coping, acceptance coping and social support did not. Social support predicted higher QoL over and above benefit finding and SES, but active and acceptance coping did not. Most groups of variables entered at Steps 2 predicted QoL above SES and benefit finding (ΔR^2 ranged from .04-.33, $ps < .05$), with the exception of the analyses involving caregiver age, active coping, and acceptance coping.

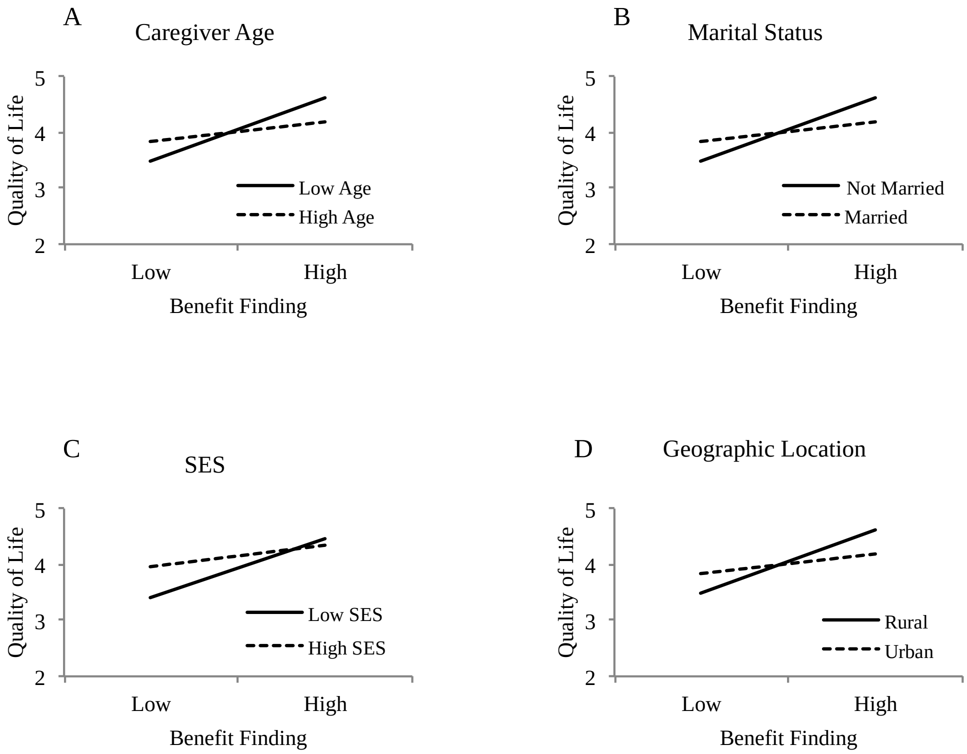
Table 3. Multiple regressions predicting QoL.

Predictors	β	ΔR^2
Step 1		.28*
Socioeconomic status	.18	
Benefit finding	.47*	
Step 2a		.04
Caregiver age	.00	
Caregiver age X benefit finding	-.21*	
Step 2b		.06*
Married	-.02	
Married X benefit finding	-.25*	
Step 2c		.08*
Rural location	-.08	
Rural location X benefit finding	.29*	
Step 2d		.04*
Socioeconomic status X benefit finding	-.19*	
Step 2e		.03
Active coping	.05	
Active coping x benefit finding	.16	
Step 2f		.11*
Emotion coping	-.15	
Emotion coping X benefit finding	.31*	
Step 2g		.18*
Avoidant coping	-.38*	
Avoidant coping X benefit finding	.24*	
Step 2h		.03
Acceptance coping	-.14	
Acceptance coping x benefit finding	.08	
Step 2i		.11*
Optimism	.28*	
Optimism X benefit finding	-.22*	
Step 2j		.24*
Caregiving burden	-.44*	
Caregiving burden X benefit finding	.24*	
Step 2k		.33*
Post-traumatic stress symptoms	-.51*	
Post-traumatic stress symptoms X benefit finding	.23*	
Step 2l		.12*
Social support	.43*	
Social support x benefit finding	-.03	

Note. *$p < .05$. QoL = quality of life.

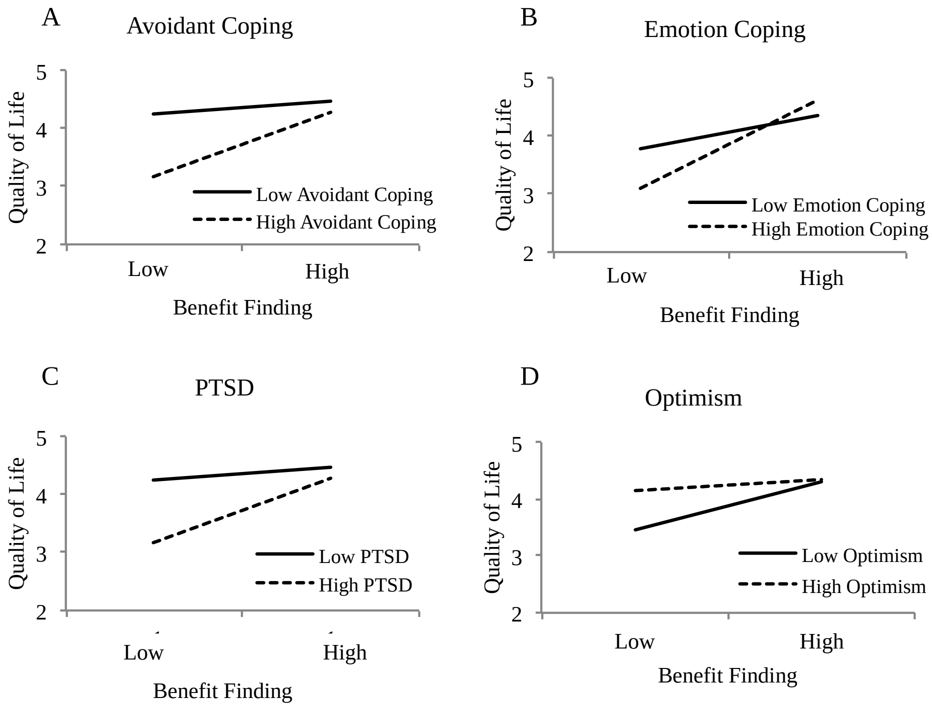
The significant interactions between benefit finding and demographic and psychosocial variables are depicted in Figures 1 and 2, respectively. Finding greater benefits was associated with higher QoL more strongly among younger compared to older caregivers ($\beta = .56$, $p < .001$, vs. $\beta = .21$, $p = .009$). Additionally, benefit finding was related to higher QoL among single but not married caregivers ($\beta = .57$, $p < .001$, vs. $\beta = .18$, $p = .11$), among those with low but not high SES ($\beta = .53$, $p < .001$, vs. $\beta = .20$, $p = .10$), and those residing in rural but not urban locations ($\beta = .67$, $p < .001$, vs. $\beta = .17$, $p = .11$).

Figure 1. Interactions of benefit finding and demographic moderators on QoL.



Additionally, finding greater benefits was associated with higher QoL more strongly among caregivers who utilized more avoidant coping than those using less (β = .61, *p* < .001 vs. β= .23, *p* = .014) and among those using more emotion-focused coping than less (β= .77, *p* < .001 vs. β= .30, *p* = .001). Additionally, benefit finding was related to higher QoL among those with low but not high levels of optimism (β = .42, *p* < .001 vs. β = .10, *p* = .45), those with high but not low caregiving burden (β = .52, *p* < .001 vs. β = .11, *p* = .28), and those experiencing high but not low posttraumatic stress (β = .56, *p* < .001 vs. β = .12, *p* = .21).

Figure 2. Interactions of benefit finding and psychosocial moderators on QoL.



Conclusions

Because previous research found inconsistent relationships between benefit finding and QoL among cancer survivors and their caregivers, and to more clearly elucidate these relationships, this study explored under what conditions benefit finding may be related to QoL by examining demographic and psychosocial characteristics of caregivers of childhood cancer survivors as potential moderators. We hypothesized that the relationship may be stronger among individuals more vulnerable to poor QoL due to their demographic and psychosocial characteristics. The results generally supported our hypotheses and showed that benefit finding was related to QoL more strongly or only among caregivers who were younger, unmarried, had low SES, and lived in rural areas, and those with greater posttraumatic stress and caregiving burden, utilized more emotional and avoidant coping strategies, and experienced less optimism. The results suggest that finding benefits may play a more important role in the well-being of caregivers with relatively low psychosocial and demographic resources (i.e., demographic profiles previously associated with worse QoL), consistent with research suggesting that lower demographic resources may put caregivers at risk for reduced QoL.

Specifically, among caregivers of children with cancer and among cancer patients themselves, younger caregivers were at increased risk for worse QoL (Klassen et al., 2008; Parker, Baile, de Moor, & Cohen, 2003), potentially because older caregivers utilize more adaptive forms of coping. Similarly, caregivers with higher SES and those who were married also reported higher QoL in other studies (Mellon et al., 2006), suggesting that these caregivers possess greater resources to foster QoL, such as more disposable income and stable social support. These findings also are in line with personality literature suggesting that individuals who possess greater resources utilize more active forms of coping strategies (Holahan & Moos, 1987), which may enhance QoL. Furthermore, our results show that caregivers who are single, have low SES, and reside in rural locations (i.e., caregivers with fewer resources) may profit more from benefit finding, perhaps helping them appreciate and make the most of the resources they have, increasing QoL. By contrast, QoL of caregivers who were married, had high SES, and lived in urban settings was not affected by benefit finding.

Among psychosocial variables, benefit finding was related to higher QoL for those who were less optimistic, experienced more caregiving burden, and reported more posttraumatic stress, groups with relatively fewer psychosocial resources which may put them at increased risk for poor QoL. Indeed, relationships between reduced QoL or worse general adjustment and high burden, more posttraumatic stress, decreased optimism and reduced satisfaction with life have been shown among caregivers of adults with cancer (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Fotiadou, Barlow, Powell, & Langton, 2008; Wagner, Bigatti, & Storniolo, 2006). Thus, benefit finding may help compensate for lower levels of psychosocial resources by increasing awareness and appreciation of resources and what they gained through the cancer experience. However, benefit finding was unrelated to QoL for caregivers with high optimism, low burden, and low stress, perhaps because they already possessed sufficient resources to manage their experiences.

Furthermore, finding benefits was more strongly associated with better QoL for caregivers who used avoidant and emotion-focused coping. Compared to more active types of coping, avoidant and emotion-coping strategies put caregivers of children with cancer and other chronic conditions at risk for poor well-being (Norberg, Lindblad, & Boman, 2005; Sales, Fivush, & Teague, 2008). Our results suggest that finding benefits helps buffer against the negative outcomes of using ineffective strategies, perhaps through compensatory mechanisms of providing more useful ways of coping. In fact, coping skills interventions have been shown to improve QoL among caregivers of cancer patients (McMillan et al., 2006), and it is possible that similar effects could be achieved through interventions focused on benefit finding.

Contrary to predictions, active coping and acceptance coping did not moderate the relationship between benefit finding and QoL, and were unrelated to QoL. Others have found that QoL is negatively affected by the use of maladaptive strategies, but is unrelated to the use of adaptive coping strategies (Klein, Turvey, & Pies, 2007; Sales et al., 2008). Together, these results suggest that the use of negative coping strategies leads to worse QoL, perhaps through ineffectively managing difficulties, but that using adaptive strategies may not necessarily enhance QoL. Thus, benefit finding may help caregivers regardless of their use of effective coping strategies, but may further buffer against negative QoL outcomes among those who utilize maladaptive strategies (e.g., emotion-focused and avoidant coping).

Similar to effective coping, benefit finding did not moderate the relationship between social support and QoL in our sample. Instead, benefit finding and social support made unique contributions to QoL. Indeed, Kim and colleagues (2007) found that benefit finding and social support were independently important in adult caregivers' well-being. It could be that benefit finding and social support uniquely promote QoL, such that caregivers who are able to make meaning of the cancer experience and feel supported in this endeavor experience the greatest outcomes.

There are several limitations of the present study. The sample size is modest and therefore it was not possible to examine all main effects and interactions in a single model. The multiple analyses did not account for overlap among the predictors and may have inflated Type I error. However, given the paucity of research on the role of benefit finding in QoL and factors that may moderate this relationship, this analytic approach allowed us to examine multiple demographic and psychosocial variables that may affect the role of benefit finding in well-being, shedding light on previous mixed results and providing valuable directions for future research. Additionally, the cross-sectional design does not support causal inferences about the relationships among the studied variables. It is likely that finding benefits predicts increased QoL over time, as shown among caregivers of adults with cancer (Carver & Antoni, 2004). However, it is also possible that QoL influences perceptions of benefit finding. Longitudinal or intervention research is necessary to more clearly elucidate the temporal sequencing and causal associations among the variables. Our sample included mostly female caregivers recruited from a single cancer survivorship clinic, so the results may not generalize to other types of caregivers, medical populations, and geographic locations. Furthermore, the study was not designed to examine child characteristics in relation to benefit finding and caregivers' QoL, which should be addressed in future research. Finally, restricting participants to English speakers limits the generalizability of the findings, and a more heterogeneous sample should be recruited in future research.

Despite these limitations, the results of the study have several implications. From a clinical standpoint, our results suggest that benefit finding may be particularly important for caregivers who utilize maladaptive coping strategies or have fewer demographic resources. Thus, clinicians may identify caregivers at increased risk for poor QoL and counsel these caregivers to find benefit in their experiences or help strengthen their coping or social support to seek improvement in their QoL. In some cases, motivational interviewing to determine readiness for cognitive restructuring or help with making meaning from their experiences with cancer may be appropriate. From a research standpoint, the results suggest that QoL has a complex relationship with risk and protective factors, and that benefit finding is differentially important for caregivers with varied resource levels. Future research should utilize heterogeneous samples to increase the generalizability of the observed relationships. Further, larger sample sizes would improve exploration of which factors and interactions with benefit finding make the strongest unique contributions to QoL.

In conclusion, this study is among the first to address the complex interplay of benefit finding with other variables in relation to QoL. Caregivers with relatively low demographic and psychosocial resources (i.e., younger, unmarried, rural, and of low SES; with low optimism, more distress and maladaptive coping) report higher QoL when they are able to find benefits in their experience. By contrast, caregivers who have relatively greater demographic and psychosocial resources do not appear to gain better QoL from benefit finding. Future research should further explore the relationships among these variables and potentially target benefit finding or other factors promoting well-being among low-resource caregivers to improve their QoL.

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CONCLUSIONS

A growing body of research has explored benefit finding among caregivers of children with chronic health conditions. Despite the numerous challenges associated for caring for a child with cancer, even into the survivorship period, evidence suggests that many caregivers experience positive outcomes as well. In a systematic review, we found that caregivers indeed find benefits in several domains. Furthermore, benefit finding was associated with female gender, increased child illness severity, use of active coping strategies, optimism, self-efficacy, social support, and posttraumatic stress symptoms. Little research addressed other physical or psychological health outcomes of benefit finding (e.g., quality of life).

Extending findings from the literature review to focus specifically on caregivers of childhood cancer survivors, two empirical investigations were pursued exploring benefit finding and quality of life among caregivers. Caregivers of children who received fewer treatment modalities while they were on-treatment for cancer and those of children who did not experience a relapse found greater benefits in their experience, suggesting that perhaps increased severity of a child’s illness impacts caregivers’ ability to find benefits in their experience. Caregivers with higher family income reported somewhat greater benefits, perhaps suggesting the role of family resources in promoting benefits or the lack of family resources in restricting benefits. Generally, however, benefit finding spanned across many demographic groups and medical populations.

However, caregiver psychosocial variables had the most prominent effects on finding benefits among caregivers. Specifically, optimism, positive spiritual coping, and lower perceived impact of a child's illness led to finding greater benefits among caregivers. The different domains of benefit finding (greater empathy for others, appreciation of others' support, acceptance of life's circumstances, feeling more capable of handling difficulties, reprioritization of values, and feeling closer with family) were each uniquely predicted by varied psychosocial factors (e.g., optimism, coping strategies, social support) but were mostly all affected by positive spiritual coping, suggesting a strong contribution of this coping resource for families. Importantly, benefit finding was impacted by numerous positive psychosocial factors but generally unrelated to the use of negative strategies, such as negative spiritual coping and other maladaptive coping strategies, supporting the view of benefit finding as an active process through which positive strategies promote adaptation. Further, the literature review identified that benefit finding can occur even in the face of negative adjustment (e.g., depressive symptoms).

To extend research on the link between benefit finding and other psychological health outcomes, in particular quality of life, we examined under what conditions benefit finding played a role in promoting better quality of life among caregivers. Benefit finding was only related to or more strongly related to quality of life among caregivers who were younger, not married, of low socioeconomic status, and lived in rural areas. Furthermore, finding benefits was more strongly or only related to quality of life for caregivers who were less optimistic, experienced greater posttraumatic stress and caregiving burden, and those who utilized more emotional and avoidant coping strategies. Taken together, these findings suggest that benefit finding may be most important for caregivers who may be at greatest risk for poor quality of life due to lower demographic and psychosocial resources. Interestingly, however, the use of positive coping resources (e.g., active coping) did not moderate the relationship between benefit finding and quality of life, perhaps due to the particular role of the use of maladaptive strategies in quality of life (Klein, Turvey, & Pies, 2007; Sales et al., 2008), which could be due to ineffective management of difficulties. Taken together, results suggest a buffering effect of benefit finding on quality of life for caregivers who may be more susceptible to experiencing worse psychological health outcomes.

Taken together, these studies extend past literature by including a specific sample of caregivers of childhood cancer survivors, exploration of several variables simultaneously to document the unique and potentially most important contributions to benefit finding and quality of life, and investigating the complex relationships among benefit finding and other child and caregiver factors in impacting quality of life. Despite these findings, there are several limitations of these studies. The literature review was limited by the varied use of predictor variables and measures of positive adjustment, making comparison among the studies difficult. Most studies also included only one or a small number of variables, leading to difficulties assessing the relative importance of various factors’ role in benefit finding. With respect to the empirical studies, both studies were cross-sectional in nature, which does not allow for inferences about the directionality of the associations. For example, it is plausible that benefit finding and psychosocial resources interact in a bi-directional nature to promote each other, and that quality of life and benefit finding also promote each other. Further, as is a limitation of many studies of pediatric illness populations, female caregivers served as the majority of participants, making it difficult to generalize the results to fathers and other male caregivers, particularly given the unique experiences of each member of the family. Another limitation is the difficulty examining all effects between benefit finding and quality of life in the same model due to the small sample size.

Despite these limitations, the results have several clinical implications, particularly with regard to identifying caregivers who may be at increased risk for lower levels of benefit finding or quality of life. For example, connecting caregivers with spiritual leaders to promote their use of positive spiritual coping, or working with pediatric psychologists to help families access their social support networks, develop adaptive coping strategies, and lower the perceived impact of a child's medical journey are potential targets for intervention. Furthermore, these studies elucidated some of the complex relationships among adjustment variables among caregivers. Further, for caregivers with profiles consistent with poorer quality of life, interventions aimed at increasing their awareness of benefits from their situation may also prove important in overall outcomes. In fact, interventions targeting benefit finding have been shown to be effective in the adult literature.

Given the importance of caregiver adjustment when caring for a child with a chronic health condition, identification of caregivers who are at particular increased risk for worse outcomes following a diagnosis of a child with cancer, and establishing effective interventions for positive adjustment are important goals. Based on the findings of the present study, future areas of research include longitudinal investigations to explore the temporal nature of benefit finding, especially as it relates to time after completion of treatment, including fathers in future research to understand their unique experiences, and utilization of larger sample sizes to more clearly understand the important unique contributions of caregiver and child factors to psychological adjustment.

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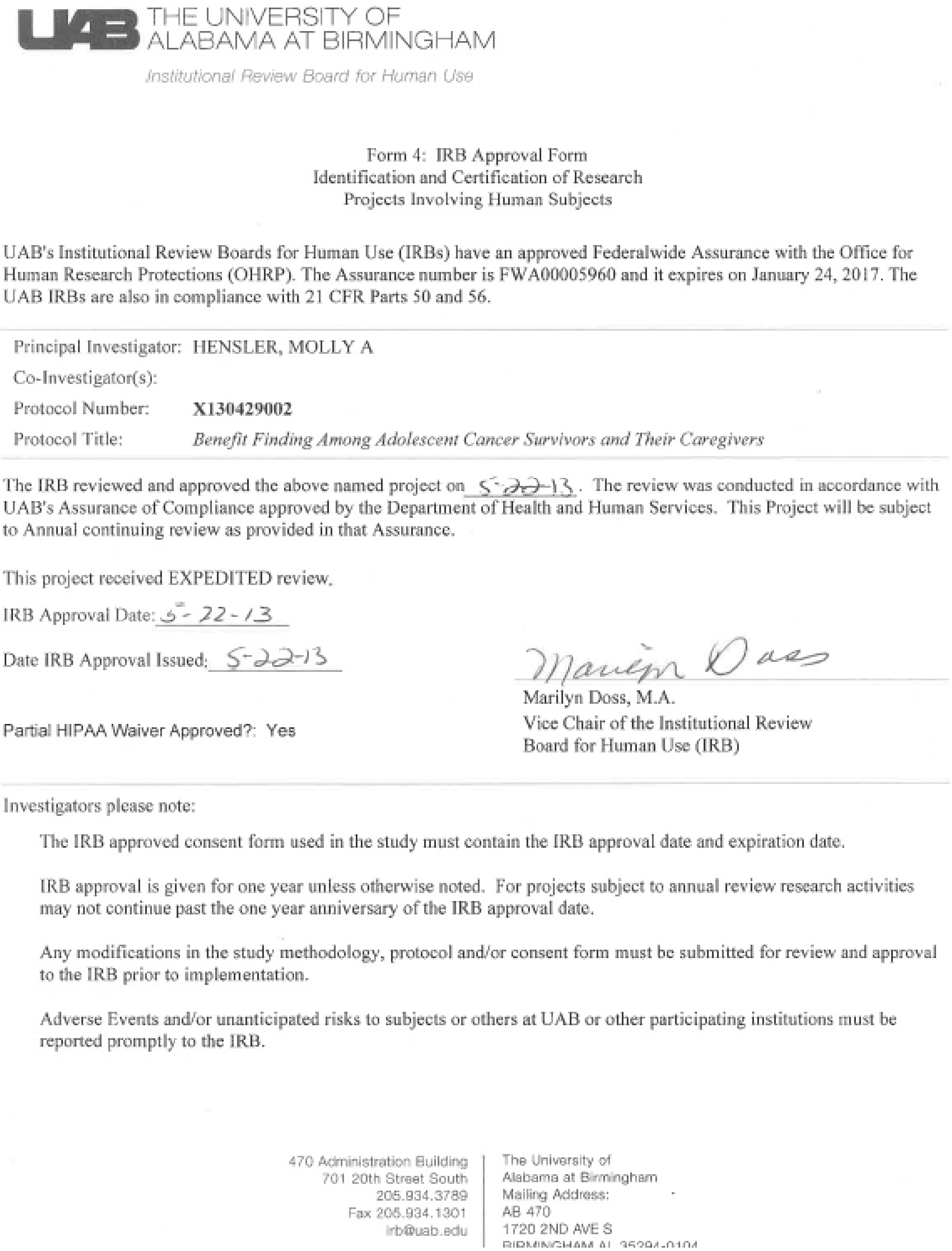
APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL



UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on January 24, 2017. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator:	HENSLER, MOLLY A
Co-Investigator(s):	
Protocol Number:	**X130429002**
Protocol Title:	*Benefit Finding Among Adolescent Cancer Survivors and Their Caregivers*

The IRB reviewed and approved the above named project on 5-22-13. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: 5-22-13

Date IRB Approval Issued: 5-22-13

Marilyn Doss
Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Partial HIPAA Waiver Approved?: Yes

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

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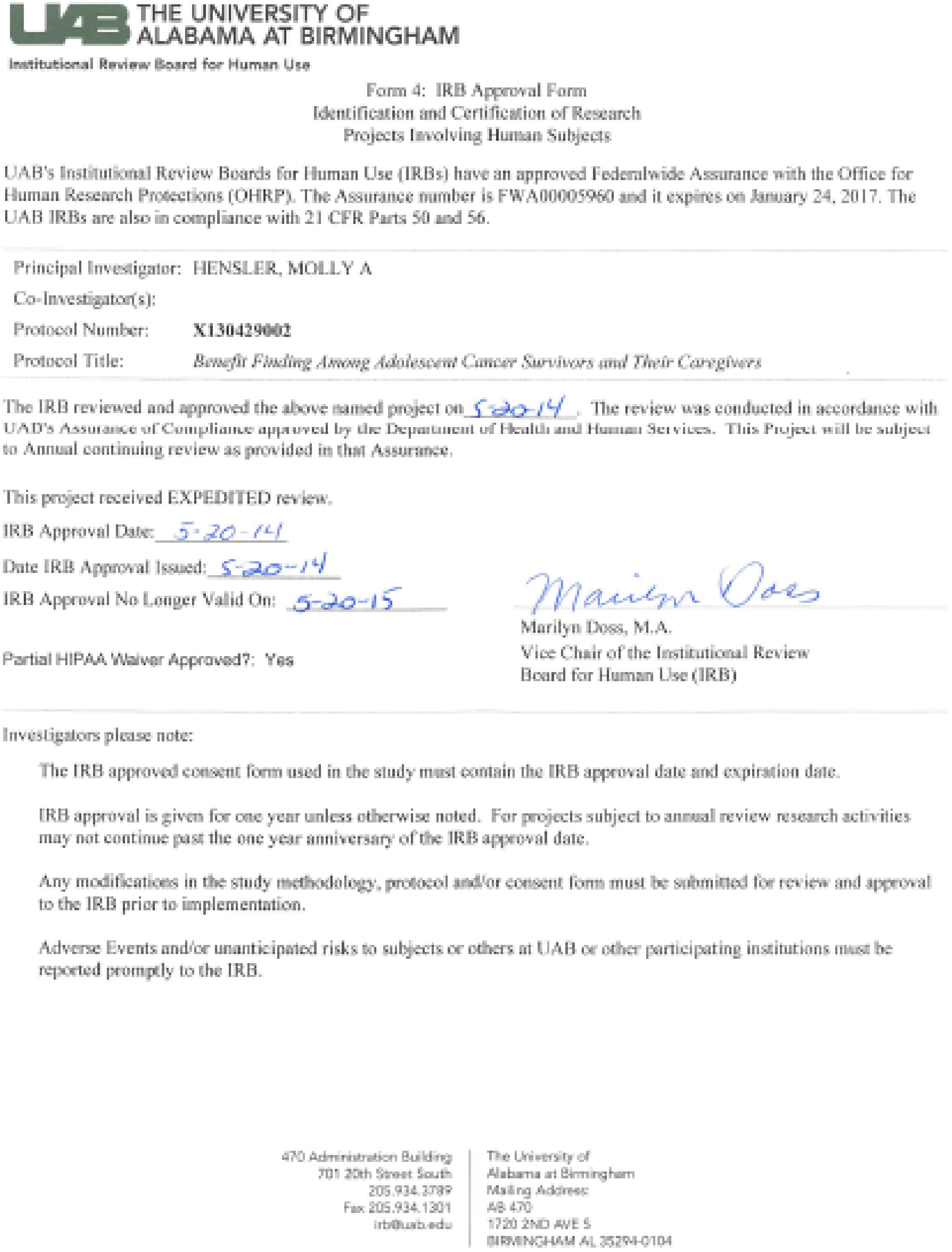

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This project received EXPEDITED review.

IRB Approval Date: 5-20-14

Date IRB Approval Issued: 5-20-14

IRB Approval No Longer Valid On: 5-20-15

Marilyn Doss

Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Partial HIPAA Waiver Approved?: Yes

Investigators please note:

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