Activism as a coping strategy among parents of children with cancer

Alexandra Neenan

Follow this and additional works at: https://commons.emich.edu/theses

Part of the Psychology Commons

Recommended Citation

This Open Access Thesis is brought to you for free and open access by the Master's Theses, and Doctoral Dissertations, and Graduate Capstone Projects at DigitalCommons@EMU. It has been accepted for inclusion in Master's Theses and Doctoral Dissertations by an authorized administrator of DigitalCommons@EMU. For more information, please contact lib-ir@emich.edu.
Activism as a Coping Strategy Among Parents of Children with Cancer

by

Alexandra Neenan

Thesis

Submitted to the College of Arts and Sciences

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Clinical Psychology

Thesis Committee:

Michelle Byrd, Ph.D., Chair

Flora Hoodin, Ph.D.

Angela D. Staples, Ph.D.

October 16, 2020

Ypsilanti, Michigan
Abstract

Childhood cancer is a lifelong, whole-family diagnosis. The coping strategies employed by parents of children with cancer have implications for the family system both during and after their diagnosed child’s treatment. The current study found that activism, or actions taken on behalf of the greater childhood cancer community by individual parents, is an activity that parents ($N = 67$) universally engaged in after their child was diagnosed with cancer. Consistent with study hypotheses, activism was positively associated with aspects of well-being such as hope and resilience, and it was also positively associated with an active coping style. Activism was not associated with depression in this sample. Notably, participants qualitatively reported acute stressors related to activism alongside rich benefits. The current study contributes significantly to understanding the role of childhood-cancer-related activism as a coping strategy for parents whose children have been diagnosed with the disease.
# Table of Contents

Abstract .............................................................................................................................. ii
List of Tables ....................................................................................................................... vii
List of Figures .................................................................................................................... viii
Introduction .......................................................................................................................... 1
  Childhood Cancer ................................................................................................................ 1
  Children’s Experience of Childhood Cancer ...................................................................... 3
  Parents’ Experience of Childhood Cancer ........................................................................ 4
  Coping with Pediatric Cancer ............................................................................................ 7
  Activism as a Coping Strategy ............................................................................................ 9
    Activism as a Form of Active Coping ............................................................................. 10
    Activism as It Relates to Socially Supported/Emotion-Focused Coping ...................... 11
  Conceptualizing Emotional Well-Being .......................................................................... 12
    Hope ............................................................................................................................... 13
    Resilience ..................................................................................................................... 14
    Meaning in Life ............................................................................................................. 15
  Conceptual Model of Relationships Between Activism, Treatment Variables, and Well-
  Being ............................................................................................................................... 16
  The Current Study ............................................................................................................ 18
  Hypotheses ....................................................................................................................... 19
  Primary Hypothesis 1 ....................................................................................................... 19
  Primary Hypothesis 2 ....................................................................................................... 19
  Primary Hypothesis 3 ....................................................................................................... 19
Appendix B: IRB Approval Letter.................................................................................................................82
Appendix C: Demographics..........................................................................................................................83
Appendix D: Activism Orientation Scale – Conventional Subscale .....................................................87
Appendix E: Revised Activism Orientation Scale – Childhood Cancer Activism..........................89
Appendix F: The Hope Scale .....................................................................................................................90
Appendix G: Measure of Hope for Other Children with Cancer......................................................91
Appendix H: Connor Davidson Resilience Scale – 10 Item.................................................................92
Appendix I: Meaning in Life Questionnaire.............................................................................................93
Appendix J: The COPE...........................................................................................................................94
Appendix K: Patient Health Questionnaire-9 .........................................................................................97
Appendix L: Open-Ended Comments on Childhood-cancer-related activism.........................98
Appendix M: Table of Means and Standard Deviations Across Treatment Phases .................105
Appendix N: Correlations for Primary Hypotheses-Posttreatment Parents Only................106
Appendix O: Correlations for Planned Regression Analyses-Posttreatment Parents Only ....107
Appendix P: Selected Quotes from Qualitative Data ..........................................................................108
List of Tables

Table 1: Sample Demographics ........................................................................................................32
Table 2: Correlation Analyses for Primary Hypothesis 1, Primary Hypothesis 2, and Exploratory
       Hypothesis 3 ..............................................................................................................................36
Table 3: Preliminary Correlation Analyses Between Hierarchical Regression Variables ..........37
Table 4: Predicting Activism from Treatment Types and Active Coping ....................................45
Table 5: Predicting Hope from Demographics and Activism .......................................................47
Table 6: Sample Sizes for Pre-Diagnosis General Activism Groups ...........................................52
Table 7: Sample Sizes for Pre-Diagnosis Cancer-Related Activism Groups ...............................50
Table 8: Means, Standard Deviations, and Analysis of Variances for Key Study Variables Across
       Treatment Phases ......................................................................................................................105
Table 9: Correlations for Primary Hypotheses-Posttreatment Parents Only ...............................100
Table 10: Correlations for Regression Analyses-Posttreatment Parents Only ............................101
Table 11: Emergent Themes from Qualitative Data ......................................................................103
List of Figures

Figure 1: Conceptual Model of Relationships Between Activism, Treatment Variables, and Emotional Well-Being ................................................................. 17

Figure 2: CONSORT Flow Diagram .................................................................................................................. 34

Figure 3: Frequency of Childhood-Cancer-Related Activism Behaviors Before and After Diagnosis........................................................................................................ 42

Figure 4: Proposed Model of Activism, Treatment Variables, and Aspects of Well-Being with Results............................................................................................................. 58
Introduction

Parents of children with cancer are at risk of experiencing a variety of negative mental health outcomes (Warmerdam et al., 2019). Additionally, many parents of children with cancer eventually develop both a sense of gratitude for the support they receive and a desire to help others (Molinaro & Fletcher, 2018; Patterson et al., 2004). Parents’ efforts to both cope with their own experiences and assist others who have been affected by childhood cancer may manifest in the form of activism. The current study defines activism as collective action taken to further a social or political cause (Corning & Myers, 2002). Relatively little is known about how activism behaviors, such as leading fundraisers and awareness campaigns, relate to the psychological functioning of parents who have faced pediatric cancer. Thus, the goal of the current study is two-fold: (a) to clarify how activism relates to previously defined coping styles and (b) to explore the relationships between activism, positive well-being, and depression.

Childhood Cancer

There are approximately 15,000 new diagnoses of pediatric cancer within the United States each year (Ward et al., 2014). The diagnosis rate of childhood cancer has slowly increased throughout the last several decades (National Cancer Institute, 2016). The causes of childhood cancer and this increase in prevalence are unknown, but improved diagnostic practices are believed to contribute at least partially to the increase in documented incidence (Ward et al., 2014). Since 1975, the death rate for childhood cancer has fallen 2.1% per year on average, leading to an overall decrease of 50% in that time. Currently, the overall five-year survival rate is 80%, although this varies by subtype (Ward et al., 2014). Specifically, retinoblastoma has a survival rate of 98%, while diffuse intrinsic pontine glioma is nearly always fatal (Ward et al.,
2014; Hargrave et al., 2006). Thus, some children enter treatment facing a much greater life threat than others.

The variance in survival rates by cancer type can be attributed to differences in the nature and availability of treatment options (Ward et al., 2014). Uncertainty regarding the existence of appropriate medical interventions contributes to the overall cancer burden, which impacts all aspects of daily living (Canter et al., 2018). Waiting for clinical trial availability is a common experience among families whose child has cancer, and knowledge of new available treatments is considered primary among the types of “good” news that a parent can receive (Feraco et al., 2017, p. 833). Similarly, learning that one’s child does not qualify for a potential new treatment is a predominant type of “bad” news (p. 833). New treatments are made available through clinical trials, and an estimated 30-60% of diagnosed children enroll in at least one clinical trial during the course of treatment (Children’s Oncology Group, 2019; National Cancer Institute, 2018).

Clinical trials are often funded by grants from the federal government, research institutions, and—importantly—charitable foundations (Bender et al., 2013; Kriesmann et al., 2013). Parents of childhood cancer patients have established a variety of foundations that serve to increase research funding, some of which have raised millions of dollars. These foundations and others provide grants directly to researchers to support clinical trials. By supporting clinical trials, these foundations contribute to the overall search for effective treatments for childhood cancers. The current study proposed that directly supporting efforts to improve medical treatments, such as raising funds for or increasing public knowledge of clinical trials, constitutes a type of activism that relates to healthy coping for parents whose children are or have been diagnosed with cancer.
Regardless of the type of treatment that children receive for their cancer, families face many issues during and after treatment with which it is difficult to cope (Canter et al., 2018). Although the experiences and emotions of children and their parents are intertwined (Bakula et al., 2019), specific concerns relating to each group will be discussed separately here.

**Children’s Experience of Childhood Cancer**

A cancer diagnosis leads to a variety of physical, social, and emotional challenges for children. For children who receive chemotherapy, nausea, hair loss, fatigue, and sleep disturbance are typical side effects (Canter et al., 2018; Hildenbrand et al., 2011). Many children also undergo invasive surgery to remove tumors or place medication delivery ports, which can entail pain, recovery, and a risk for infection. Even simple procedures, such as shots and blood draws, require needle insertions; these frequent procedures are often preceded by significant fear and anxiety (Di Battista et al., 2017). Children must be largely separated from their friends and families during treatment due to their immunocompromised state, which can cause a sense of isolation (Hildenbrand et al., 2011; Sandeberg et al., 2013). Young children may become overwhelmed by their experiences and withdraw or otherwise exhibit significant alterations in personality (Darcy et al., 2014). School-age children and adolescents report depression and anxiety symptoms approximately half a standard deviation above normative samples (Compas et al., 2014). They also often experience significant social and educational disruption. More than 30% of children with cancer have reported being bullied at school, and a similar portion repeat at least one grade in school (Bonneau et al., 2011; Collins et al., 2019; Lahteenmaki et al., 2002).

The challenges of pediatric cancer continue after the conclusion of treatment. After treatment, children must reintegrate their sense of self as being a “survivor” rather than a “patient” (Wakefield et al., 2009, p. 262). Although ending treatment may be exciting for
children, reintegration to school and other routines is also often accompanied by anxiety (Wakefield et al., 2009). As with children undergoing treatment, pediatric cancer survivors are at elevated risk for developing depression (Li et al., 2013). Childhood cancer survivors also routinely suffer physical late effects, or effects that either emerge or persist after treatment ends. These late effects can affect virtually every body system, but issues with growth, heart functioning, kidney functioning, and liver functioning are noted most often (McClellan et al., 2013). Motor functioning is also often impacted for years after treatment ends (Hartman et al., 2008). Perhaps most concerning, cancer treatment can lead to relapse of the original cancer type as well as secondary cancers (McClellan et al., 2013). All of these issues underscore the fact that children and families must cope indefinitely with evolving challenges that stem from the cancer experience.

Parents’ Experience of Childhood Cancer

For parents, the difficulties that accompany childhood cancer usually begin prior to diagnosis. Parents recognize that their child is experiencing medical symptoms, but they often do not know the cause of these issues, which leads to anxiety about the possible outcomes (Canter et al., 2018). When parents are informed of the cancer diagnosis, they frequently experience a state of shock (Schweitzer et al., 2011). In a single meeting, parents are often informed of both the threat to their child’s life and that intensive, long-term medical treatment will begin immediately (Björk et al., 2005). Thus, parents too are overwhelmed by the childhood cancer experience from its earliest moments. Indeed, the experience has been poignantly described as a “broken life world” (Björk et al., 2005, p. 269).

Loss of control is a primary feature of the parental experience of childhood cancer. On a practical level, parents must immediately rearrange their lives after receiving the diagnosis to
accommodate the needs of their critically ill child (McCubbin et al., 2002). In families with two working parents, one parent frequently must leave their job or reduce their workload in order to be with the child receiving treatment at the hospital (James et al., 2002). A large financial burden may be associated with this loss of income, in addition to the numerous medical costs that may or may not be covered by medical insurance. During treatment, parents routinely witness their child experiencing painful treatments and struggle to comfort them (Darcy et al., 2014). Many parents must also address the needs of other children, who will lose attention from their caregivers during their sibling’s treatment (Long & Marsland, 2011). These challenges often pose an unreasonable burden for the family to manage on their own, so parents may need to seek outside assistance with tasks that would typically be managed within the family unit (McCubbin et al., 2002). This assistance, which allows parents to focus their attention to the child with cancer, also represents a loss of control over both their own lives and their children’s lives. One goal of the current study was to investigate the ways in which activism may restore a sense of control in the lives of parents following a child’s cancer diagnosis. For example, although parents may experience frustration with the uncertainty of treatment availability (Feraco et al., 2017), parents can help accelerate the rate at which new medical treatments are developed by generating funding for research.

Because approximately 25% of pediatric cancer patients die within 15 years of diagnosis (Ward et al., 2014), bereavement is common among families of children with cancer. When faced with the loss of a child, many parents struggle to see purpose in their lives (Barrera et al., 2009). Families characterize grief as both eternal and evolutionary, which sometimes leads to a sense of agency regarding the role that grief will ultimately play in their lives (Snaman et al.,
2016). This agency may be expressed through actions that support other childhood cancer families, and this possibility was explored in the current study.

Many parents of children with cancer do not develop psychological disorders. However, as Van Warmerdam et al. (2019) recently discussed in a meta-analysis, a sizable subset of parents develops clinically significant symptoms. Rates of depression, anxiety, and posttraumatic stress disorder (PTSD) among parents at any time after diagnosis are approximately 28%, 21%, and 26%, respectively; among the general population, the lifetime prevalence rates of anxiety and PTSD are approximately 9% (American Psychiatric Association, 2013). However, research findings in parents of children with cancer have been highly variable; for example, PTSD rates range from 4% to 75% (Van Warmerdam et al., 2019). Time since diagnosis can also influence the course of psychological symptoms. Specifically, subclinical posttraumatic stress is most frequently elevated among parents with recently diagnosed children (Phipps et al., 2015). Notably, depression rates are similar among bereaved parents and parents of children in active treatment (Van Warmerdam et al., 2019).

It is important to note that many families report that they are able to derive meaningful positive outcomes from their experience with pediatric cancer, which often occur alongside significant distress (Molinaro & Fletcher, 2018; Nakayama et al., 2016). Posttraumatic growth, or positive growth in the face of trauma, has been found in both parents and children following treatment for pediatric cancer (Barakat et al., 2006; Nakayama et al., 2016). In one study, a majority of parents of survivors endorsed seeing improvement in how they treat others and how they think about their lives (Barakat et al., 2006). Parents have specifically described experiencing both gratitude for the support they receive and the desire to give back to other childhood cancer families (Schweitzer et al., 2011).
Coping with Pediatric Cancer

Several coping categories have been used in previous research to describe the ways in which parents cope with pediatric cancer (Norberg et al., 2005; Turner-Sack et al., 2016). The current study used the categorical labels of avoidant coping, social support and emotion-focused coping, and active coping to describe various coping strategies (Carver et al., 1989). Avoidant coping refers to attempts to distract or otherwise avoid directly confronting feared events and outcomes such as relapse or worsening prognosis (Carver et al., 1989). Social support involves giving to and receiving support from others via friendship or in formal contexts such as support groups. Emotion-focused coping, as the name suggests, involves focusing on the emotions that arise during cancer treatment, rather than addressing specific events (Carver et al., 1989). For example, feelings of uncertainty can be a significant concern (Fletcher et al., 2010). Because emotion-focused coping and social support seeking often occur in tandem, these strategies will be measured as one coping style (Carver et al., 1989). Active coping refers to parental problem-solving efforts that address specific needs (Carver et al., 1989), such as using numbing agents during children’s medical procedures, seeking education on their child’s disease, and collaborating with the medical team (Blount, 2019; Patterson et al., 2004). These actions serve to minimize their child’s suffering, which in turn lowers parental distress (Bakula et al., 2019).

Although the strategies that comprise active coping and social support and emotion-focused coping could be grouped according to other criteria, other models are insufficient for investigating activism behaviors specifically. One alternative categorization of coping styles proposes that specific coping strategies should be separated into independent and socially supported coping clusters (Wang et al., 2018). Another proposes that coping strategies are best grouped according to whether they address controllable versus uncontrollable stressors (Compas
et al., 2014). Both of these alternative categorizations have demonstrated that, in aggregate, strategies that comprise active coping and socially supported/emotion-focused coping are associated with lower distress (Compas et al., 2014; Wang et al., 2018). However, these categorical methods do not adequately assess the nature of activism as a coping mechanism, which is inherently socially supported (not self-sufficient) and focused on controllable (not uncontrollable) outcomes.

When used alongside active coping strategies, higher usage of social support and emotional coping strategies is associated with reduced distress for parents of children in active treatment (Compas et al., 2014), but not for parents of survivors (Turner-Sack et al., 2016). Turner-Sack et al. (2016) noted that they may have failed to detect significant effects due to lack of power ($N = 30$). Although avoidant coping is contraindicated as a general approach to coping with the cancer experience, some medical professionals propose that it may be a preferred method of coping with acute issues such as procedural pain and anxiety (Blount, 2019). Blount (2019) argued that distracting children and their parents from the child’s emotional and physical experiences of a medical procedure may reduce distress more effectively than efforts to deal with these issues directly. This claim is supported by evidence indicating that child distress increases when parents and medical providers attempt to initiate active coping prior to a painful procedure (Blount et al., 1989; Blount et al., 1991). Thus, contextual factors influence the effectiveness of coping approaches.

Active, social support and emotion-focused, and avoidant coping are all used by parents of children in treatment and survivors, although parents report using avoidant coping less than the others (Compas et al., 2014; Turner-Sack et al., 2016). When asked in a focus group setting about coping, only 7% of parents of survivors endorsed using avoidant coping strategies, such as
“hiding difficult feelings” and “denying what is happening” (Patterson et al., 2004, p. 402). In contrast, 73% described using at least one active coping method (Patterson et al., 2004). The extremely low percentage of parents who disclosed avoidant coping is likely an underestimate (e.g., parents likely avoided talking about avoidance). Still, the rates reported by Patterson et al. (2004) suggest that parents employ coping strategies in a manner that minimizes distress (Compas et al., 2014; Turner-Sack et al., 2016).

**Activism as a Coping Strategy**

For the purpose of this study, activism is defined as actions that serve to improve conditions for children with cancer and their families, particularly by advancing medical treatments and cures. Emphasis was placed on “collective, social-political, problem-solving behaviors” (Corning & Myers, 2002, p. 704). Therefore, actions that parents take that solely benefit their own child (e.g., creating a personal crowdfunding page) were excluded from the current study. Although activism has not been formally investigated as a coping strategy for parents of children with cancer, limited qualitative evidence suggests that it may align with several of the previously mentioned coping styles. As Patterson et al. (2004) noted,

> It is a paradox of social support that giving it can be as helpful as receiving it, or perhaps, it is the reciprocity of informal social connections that makes it beneficial. As one mother said, “When we see a fundraiser for someone with cancer, we’ll go...we don’t know the people, but we still go, just for the support.” (p. 403)

In this example, activism encompasses material financial support (active coping) alongside the stated goal of social support.

Activism is unique in that it provides an outlet for the parental desire to prevent other children from suffering to the same extent as their own child. It provides both a conceptual
framework of a desired future and specific actions that parents can take to work toward that future. Activism behaviors themselves encompass active coping as well as socially supported/emotion-focused coping. Importantly, maintaining the desire to improve outcomes for children with cancer represents an additional style of coping that encompasses overall emotional well-being. All three of these aspects of activism as a coping strategy will be discussed below.

**Activism as a Form of Active Coping**

Historically, parental activism has been defined as actions that parents would take to improve their own child’s medical treatment (Chesler, 1987; Chesney & Chesler, 1993). In decades past, parents routinely reported issues with even basic aspects of care, with 41% of parents in one study reporting that they did not feel their medical providers demonstrated empathy for their child (Chesler, 1987). In contrast, although the intensity of childhood cancer treatment still leads to some conflict in the present, families now largely report that their medical team is a beloved and indispensable source of support (Moules et al., 2016; Wilford et al., 2018). Thus, the primary problem being solved currently by activism is the suffering caused by cancer treatments (or lack of available treatments).

Evidence indicates that some parents fundraise for treatment research and patient support programs, especially when their child has died (Barrera et al., 2009; Meert et al., 2015; Rehman et al., 2018). Parents have described their efforts to develop community fundraisers as a means of maintaining an emotional connection to a child who is no longer alive, but this function and other potential functions of this type of behavior have not been investigated quantitatively (Barrera et al., 2009). A recent qualitative study of parents’ online behavior indicated that parents in various stages of treatment develop online awareness and fundraising campaigns that seek to improve conditions for children with cancer (Rehman et al., 2018). Parents also appear to
consider activist objectives even when making choices that significantly affect their own child. Parents have cited their hope of improving cancer treatment as a motivating factor to consent to children’s clinical trial participation, both while their child is alive and posthumously through tumor donation (Baker et al., 2013; Eder, 2006). The current study was the first to use quantitative methods to address possible functions of activism behaviors among parents of children with cancer.

**Activism as It Relates to Socially Supported/Emotion-Focused Coping**

Socially supported/emotion-focused coping primarily consists of expressing emotions and seeking or giving social support (Carver et al., 1989). Given the highly social and passionate nature of activism, it is especially well-suited to foster each of these activities. For example, when working on an advocacy project, parents can express among like-minded peers their feelings of anger about their child’s suffering and the lack of treatments for children with cancer. Organizing fundraisers and awareness campaigns that serve to benefit children with cancer provides opportunities to connect with others who have been affected by pediatric cancer. These social connections may then create additional opportunities to receive social support that may or may not be activism related. Activism may also support positive identity changes among parents of children with cancer, as this outcome has been seen in both community samples and childhood cancer survivors themselves (Klar & Kasser, 2009; Yi & Nam, 2017). These changes have included increases in perceived motivation and alertness for college students (Klar & Kasser, 2009) and improved ability to relate to others among childhood cancer survivors (Yi & Nam, 2017). Thus, a variety of social and emotional coping strategies can occur within the context of activism.
Conceptualizing Emotional Well-Being

The psychological impact of activism on parents of children with cancer has not been directly investigated. However, the related concept of self-transcendence has demonstrated a positive association with both resilience and emotional well-being in this population (Bajjani-Gebara et al., 2018). Self-transcendence is defined as the ability to see beyond one’s present stressful circumstances (Bajjani-Gebara & Reed, 2016). Bajjani-Gebara et al. (2018) named “volunteering/helping others” as one type of self-transcendence intervention (p. 11). Thus, the current study proposed that, since self-transcendence and well-being are positively associated, activism would also be associated with well-being in this population.

The definition of well-being used in Bajjani-Gebara et al. (2018) focuses on an individual’s perceived positive and negative feelings at one point in time without accounting for factors that influence one’s ability to maintain a positive state. A more robust definition of well-being requires the presence of “psychological, social and physical resources [people] need to meet a particular psychological, social and/or physical challenge” and balance in the fluctuation of these challenges and resources (Dodge et al., 2012, p. 230). This definition acknowledges that well-being is contextual, as the nature of the challenge that one is facing will influence the necessary resources for coping effectively. Additionally, the definition from Dodge et al. (2012) deemphasizes the importance of lacking distress in a given moment, so it can be applied more appropriately to parents whose children are facing a life-threatening illness.

The current study highlighted three emotional resources that may comprise well-being among parents of children with cancer: hope, resilience, and perceived meaning in life. Although each of these emotional resources has distinct elements, conceptual and empirical relationships exist between them. Notably, hope and resilience have been used interchangeably to describe
coping in this population (Germann et al., 2015). In community samples, the statistical association between hope and meaning in life is high \( r = .62 \), supporting the claim that these two resources are connected (Hedayati & Khazaei, 2014). The current study measured hope, resilience, and perceived meaning in life to explore the possibility of these three variables representing a construct of well-being among parents of children with cancer.

Hope, resilience, and perceived meaning in life are each conceptualized as encompassing aspects of fluctuation and balance (Dodge et al., 2012). Hope has been defined as the perceived presence of both goals and concrete paths of how to reach those goals (Kwong, 2018). Resilience emphasizes taking initiative to effectively handle situations in which resources are insufficient (Rosenberg & Yi-Frazier, 2016). Meaning in life has been conceptualized as involving both an individual’s present meaning and their continuous search to derive meaning from their experiences (Steger et al., 2006). Collectively, these three assets may encompass a wide span of well-being that appropriately captures how parents of children with cancer are able to cope with their experiences. Previous research has addressed potential empirical and conceptual links between these three resources and activism, and these links are explored further below.

**Hope**

The importance of hope for parents of children with cancer cannot be overstated; one study on factors that affect the decision to pursue palliative chemotherapy found that parents consider hope to be the most important, ranking above quality of life (Tomlinson et al., 2011). Parents of children with cancer express hope for future outcomes (i.e., cure, comfort, and happiness) in a variety of ways in nearly all stages of treatment, often adapting the content of their hopes to the current circumstances (Barrera et al., 2013; Conway et al., 2017; Granek et al., 2013). Early in treatment, nearly all parents hope that their child will be cured. When children
are in an acutely difficult phase of treatment, hope for a cure is accompanied by hope for comfort and joy (Barrera et al., 2013; Kamihara et al., 2013). Some parents express hope that better treatments will someday be available for other children, particularly when their own child’s prognosis is poor or uncertain (Kamihara et al., 2013).

Among parents of children with cancer, higher levels of hopefulness are associated with greater quality of life (Germann et al., 2015). This finding indicates that hope represents one element of well-being in this population. The current study will be the first to address whether hope is associated with activism. Presumably, having hope or belief that activism will make an impact on the problem of childhood cancer predisposes parents to engage in collective action. Similarly, working with others on activism projects may strengthen one’s hope that these improvements are indeed possible. Thus, the current study proposes that activism and hope are positively associated among parents of children with cancer. In community samples, this association has been demonstrated previously (Klar & Kasser, 2009).

**Resilience**

For the purpose of this study, resilience is defined as “identifying and harnessing new and existing resources to maintain well-being,” a definition that has been recommended for use with parents of children with cancer (Rosenberg & Yi-Frazier, 2016, p. 507). This process-based (as opposed to outcome-based) definition allows for flexibility in recognizing that, although resilience is positively associated with well-being in this population, some parents endorse experiencing both resilience and distress (Bajjani-Gebara et al., 2018). Still, studies of resilience among childhood cancer families that are more outcome-focused have shown that families are generally able to maintain strong functioning, particularly in the domain of family cohesion (Eilertsen et al., 2016; Van Schoors et al., 2015). Because evidence demonstrates that families
are able to harness internal and external resources to ensure that needs are met (McCubbin et al., 2002; Van Schoors et al., 2015), activism is one resource that families may use to maintain high levels of functioning.

Activism and resilience are conceptually related in that activism represents a resource that can be harnessed long-term. As a child’s condition either improves or deteriorates, families can adapt the focus of their activism (e.g., adjusting the amount of effort involved or the degree to which parents focus on projects that could help save their own child). Previous research has found that resilience relates to the construct of self-transcendence among parents of children with cancer (Bajjani-Gebara et al., 2018). This suggests that resilience likely also relates to activism, since activism and self-transcendence are similar constructs (Bajjani-Gebara & Reed, 2016).

Although measuring resilience within the family unit as a whole is outside the scope of this study, activism has many unique strengths as a coping strategy that may serve to promote family functioning. All members of a family can attend a fundraising event together; in contrast, many other coping mechanisms are not inclusive of parents and siblings. Additionally, advocating for children with cancer can provide family members with opportunities for leadership within the greater childhood cancer community. These actions may also serve to remind the diagnosed child that their parents and siblings acknowledge their struggles and wish to reduce their burden. Thus, while the current study only addresses parental resilience, future research should address how activism relates to overall family functioning.

**Meaning in Life**

Meaning making, or integrating one’s past experiences into an evolved understanding of themselves and the world, is a common process that occurs following a traumatic event (Park, 2010). Many families report that finding meaning in their child’s cancer journey is highly
important to them, particularly if they are bereaved (Meert et al., 2015). One type of meaning making that is noteworthy is benefit finding. Benefit finding refers to acknowledgment of growth processes that can be attributed to having endured adversity (Meert et al., 2015). Benefit finding has been documented among survivors of childhood cancer and their caregivers (Michel et al., 2010; Parry & Chesler, 2005). These individuals perceive themselves as more empathetic and able to help others with cancer and other life threats as a result of their own experiences. Meaning making was relevant to the current study because of the role that activism can play in defining the meaning of a child’s cancer experience. Both bereaved caregivers and caregivers of survivors have cited the importance of situating their child’s experience within the context of a larger cultural fight against cancer (Barrera et al., 2009; Molinaro & Fletcher, 2018). The implication of connecting one child’s experiences to those of other children is that families may experience a continuing desire to advance the cause of curing cancer, which could be fulfilled through activism behaviors. The current study proposed that, because parents have emphasized the importance of both finding meaning in the cancer experience and their desire to give back to others, activism would be significantly associated with perceived meaning in this population.

**Conceptual Model of Relationships Between Activism, Treatment Variables, and Well-Being**

The separate dimensions of well-being described above can be integrated into a cohesive model that addresses the relationships between well-being, activism, and child treatment variables. Among parents of deceased children, activism has been described as a mechanism for deriving meaning from their experiences (Barrera et al., 2009; Meert et al., 2015; Rosenberg et al., 2013). Time since diagnosis is associated with parental usage of various coping styles in this population (Turner-Sack et al., 2016). Since activism may be one of many coping strategies
parents employ, time since diagnosis may relate to engagement in activism in addition to other coping approaches. Parents have previously reported that hope for other children with cancer is important to them when their own child’s prognosis is poor (Kamihara et al., 2015).

Conceptually, it follows that hopeful parents will seek out specific opportunities to act in a way that increases the likelihood of positive outcomes, such as improved treatment options (Kamihara et al., 2015; Snyder et al., 1991). Resilience has been characterized as a predictor of selfless coping behaviors in previous research (Bajjani-Gebara et al., 2018). Taken in aggregate, these relationships suggest that various aspects of emotional well-being may be intertwined with parental activism. Figure 1 displays these relationships visually.

**Figure 1**

*Conceptual Model of Relationships Between Activism, Treatment Variables, and Emotional Well-Being*

Despite poignant qualitative findings on this topic, the current literature on engagement in childhood-cancer-related activism among parents of diagnosed children is limited. The directionality of the relationships shown in Figure 1 is based on conceptual understandings of the relevant variables rather than experimental investigation. The temporal relevance of hope,
resilience, and perceived meaning in life is a key aspect of this model. The bidirectional relationship between hopefulness and activism is based on an understanding of hope as a future-oriented construct, with hopefulness and activism mutually increasing over time. Resilience is predictive of engagement in positive behaviors, and activism is the positive behavior of interest in this model. Similarly, meaning is derived from past experiences, so activism would need to occur prior to meaning making. The temporally unique aspects of hope, resilience, and meaning in life allow each of these three variables to contribute a distinct element to the construct of emotional well-being that was proposed within the current study.

The Current Study

Existing literature has documented that some parents participate in childhood-cancer-related activism after their own children are diagnosed with the disease. Additionally, evidence suggests that both active and emotional coping mechanisms can mitigate parental distress. The purpose of the current study was to clarify how activism functions as a coping mechanism for parents of children with cancer. Notably, this study was the first to investigate activism in this population using both qualitative and quantitative methods.

This study also sought to simultaneously address activism among families in treatment, those whose children are in remission, and those whose children are no longer alive. Previous literature has documented that all three of these groups engage in activism, with activism among families of deceased children being mentioned most often. In addition to addressing the relationship between a child’s treatment phase and parental activism, other aspects that comprise a parent’s exposure to the stresses of childhood cancer were measured. These include the number of treatment types given to the child, the number of perceived side effects the child had endured, and time since diagnosis. The current study also addressed the extent to which possessing a
general interest in activism impacts parental activism on behalf of children with cancer. Previous literature has demonstrated that an individual’s general interest in activism and cause-specific activism are related. However, because some families have indicated that they began engaging in activism following their child’s death, it is possible that the cancer experience is the impetus for those actions in this population.

**Hypotheses**

**Primary Hypothesis 1.** It was predicted that greater post-diagnosis childhood-cancer-related activism would be significantly associated with treatment variables that indicate exposure to cancer-related stress (i.e., longer time since diagnosis, higher number of treatment types, higher number of reported side effects, and status as a parent of a deceased child), higher levels of hope, resilience, present meaning in life, active coping, and socially supported/emotion-focused coping.

**Primary Hypothesis 2.** It was predicted that greater post-diagnosis childhood-cancer-related activism would be significantly associated with lower levels of avoidant coping and depression.

**Primary Hypothesis 3.** It was predicted that higher levels of post-diagnosis childhood-cancer-related activism would be uniquely predicted by treatment variables, higher levels of active coping, and higher levels of socially supported/emotion-focused coping.

**Primary Hypothesis 4.** It was predicted that higher levels of emotional well-being would be uniquely predicted by level of post-diagnosis childhood-cancer-related activism after accounting for parental demographic factors, pre-diagnosis general activism, pre-diagnosis childhood-cancer-related activism, and post-diagnosis childhood general activism.
The following exploratory hypotheses were intended to investigate concepts that have not been explored in any prior research:

**Exploratory Hypothesis 1.** It was predicted that, in general, parents would retrospectively report maintaining or decreasing their general activism behaviors post-diagnosis and increasing their childhood-cancer-related activism behaviors post-diagnosis.

**Exploratory Hypothesis 1a.** It was predicted that parents would display different patterns of change in post-diagnosis activism behaviors (general and childhood cancer related) depending on their pre-diagnosis levels of activism (general and childhood cancer related).

**Exploratory Hypothesis 2.** It was predicted that hope for other children with cancer would account for unique variance in post-diagnosis childhood-cancer-related activism beyond that which could be explained by general hope.

**Exploratory Hypothesis 3.** It was predicted that search for meaning in life would be negatively associated with depression among parents of children with cancer.
Method

Recruitment

Adult, English-speaking parents and caregivers who had a child diagnosed with cancer under the age of 18 were recruited via Facebook and Instagram posts on accounts managed by the primary investigator (see Appendix A for full recruitment materials). The link to the research study was publicly accessible via both social media platforms that were used for recruitment. As a participation incentive, advertisements indicated that two dollars would be donated to a childhood cancer charity for each survey response that was completed. Parents completed the following measures: child and parent demographics surveys, measures of activism behaviors, measures of psychological variables, and open-ended questions regarding activism experiences. Caregivers were eligible regardless of their child’s treatment, remission, or deceased status. The consent form indicated that only one caregiver per family could complete the study.

Procedure

The Eastern Michigan University Human Subjects Research Committee approved all study materials prior to study recruitment (see Appendix B). Recruitment took place during February and March 2020. Participants who followed the survey link from a social media posting were directed to a webpage containing the consent form. Prior to proceeding to the survey, caregivers were required to consent by clicking “agree” and indicating that they had read the relevant information. No identifying information was collected. Caregivers completed the study in approximately 30-45 minutes via REDCap online survey software, which is compatible with both computers and mobile devices (Harris et al., 2009).
Measures

Demographics. The primary investigator developed demographic questionnaires that included questions regarding caregiver age, gender, race/ethnicity, education, and income, for general descriptive purposes. Current child age, age at diagnosis, child race/ethnicity, and child gender were also collected for general descriptive purposes. The following child medical treatment variables were collected: time since diagnosis, treatment/remission/deceased status, cancer type, type(s) of treatment received, type(s) of side effects reported, and satisfaction with treatment. See Appendix C for the demographic questionnaire.

Activism Orientation Scale-Conventional Subscale. General activism was assessed using the Activism Orientation Scale-Conventional subscale (AOS-C). The AOS-C is a self-report measure that assesses whether an individual has engaged in a variety of social or political activism behaviors during a specified time period or plans to do so in the future (Corning & Myers, 2002). The full Activism Orientation Scale also includes a subscale for risky behaviors (e.g., illegal behavior) that was not appropriate for use in the current study (Corning & Myers, 2002). The AOS-C is not a cause-specific scale, so the items included are applicable to any collective action cause. Internal reliability of the AOS-C is strong (α = .88-.96) (Corning & Myers, 2002; Klar & Kasser, 2009). Among self-identified activists, a shortened version of the conventional subscale has shown convergent validity with measures of cause-specific activism, hope, and sense of agency (Klar & Kasser, 2009). The current study was the first to use the AOS-C with caregivers of children with cancer. The AOS-C demonstrates stronger psychometric properties than other, similar measures, supporting its use in the current study (Feitzer & Ponerotto, 2015).
The current study used a modified version of the 28-item AOS-C as a measure of general activism among parents of children with cancer. On the original measure, responders are asked to indicate the likelihood that they will participate in the action in the future (0 = extremely unlikely to 3 = extremely likely). Because the current study asked about past actions, responders were simply asked to indicate whether they had previously engaged in the activity at all. The items on both the original measure and the modified measure are identical. Possible scores on the modified AOS-C ranged from zero to 28, with higher scores indicating participation in more activism behaviors. Parents completed this measure as a retrospective report of activism behaviors they engaged in both before and after their child’s cancer diagnosis. This allowed for exploration of relationships between both pre-diagnosis activism and post-diagnosis activism as well as between general activism and cancer-related activism. See Appendix D for the modified AOS-C.

**Study-Specific Measure of Activism.** Childhood-cancer-related activism was measured with an adapted version of the AOS-C (Corning & Myers, 2002) that was created for the current study. The scale has 15 items, with possible scores ranging from zero to 15. Higher scores indicate engagement in more types of childhood-cancer-related activism behaviors (see Appendix E for the full list of items). As mentioned before, the relationship between pre-diagnosis activism (general or cancer-related) and post-diagnosis activism that centers on helping other children with cancer was investigated. Thus, parents were asked to retrospectively report actions they took before and after their child’s diagnosis.

**The Hope Scale.** Hope was measured in the current study using the Hope Scale, which measures hope as a two-factor construct containing both agency and pathways (Snyder et al., 1991). Items are rated on a four-point scale (1 = definitely false, 2 = mostly false, 3 = mostly true,
4 = definitely true; Snyder et al., 1991). Higher scores indicate greater perceived hopefulness.

The Hope Scale has shown strong internal and test-retest reliability, consistently demonstrating $\alpha > .75$ in both domains (Hellman, Pitman, & Munoz, 2012). When used with parents of children with cancer, the Hope Scale has shown convergent validity with family functioning (Popp et al., 2015) and discriminant validity with depression and anxiety (Germann et al., 2015). In the current study, the Hope Scale was used as a general measure of dispositional hope. See Appendix F for the full Hope Scale.

**Measure of Hope for Children With Cancer.** Hope is a key form of emotional coping among parents of children with cancer, as mentioned previously (Kamihara et al., 2013; Tomlinson et al., 2011). Hoping for better outcomes for other children with cancer was a particularly relevant type of hope for the current study. Previous research has not directly addressed how parents experience hope for better outcomes for other children with cancer. This construct was measured with two items that were created for the current study. The first measured perceived strength of hope (How strong is your belief that there will be cures for all childhood cancers someday?) using a seven-point Likert scale (1 = extremely weak, 7 = extremely strong). The second measured perceived importance of hope (How important is that belief to you and your family?), also using a seven-point Likert scale (1 = not at all important, 7 = extremely important). Higher scores indicate greater perceived hopefulness. The word “belief” was used rather than “hope” to maintain consistency with feedback from a qualitative study of hope in which some parents reported that “belief” captured their feelings more accurately (Conway et al., 2017). The purpose of this measure was to gather exploratory data on how parents characterize the hope that they have for other children with cancer. See Appendix G for the full measure.
**Connor-Davidson Resilience Scale.** Resilience was measured in the current study using the Connor-Davidson Resilience Scale (CD-RISC). The CD-RISC was originally developed as a 25-item measure that loaded onto five separate factors of resilience (Connor & Davidson, 2003). A refined measure, the CD-RISC-10, consists of ten items that load onto a single resilience factor (Campbell-Sills & Stein, 2007). In both measures, items are scored using a scale that ranges from 0 (*not true at all*) to 4 (*true nearly all the time*; Campbell-Sills & Stein, 2007; Connor & Davidson, 2003). Higher scores indicate greater perceived resilience. The shortened measure was initially validated using a sample of adult survivors of childhood abuse and demonstrated strong reliability with that sample (α = .85; Campbell-Sills & Stein, 2007). In the same study, abuse survivors with high CD-RISC-10 scores endorsed fewer symptoms of anxiety and PTSD than abuse survivors with low CD-RISC-10 scores, which supports the construct validity of this measure. In a community sample, approximately half of whom were adult female breast cancer survivors, CD-RISC-10 scores were negatively associated with the presence of current psychiatric disorder and positively and independently associated trauma history (including, but not limited to, breast cancer; Scali et al., 2012). This study also found that the CD-RISC-10 demonstrates strong reliability (α = .88).

The current study used the CD-RISC-10 as a measure of resilience among parents who have had a child diagnosed with cancer. Although this measure of resilience has not previously been used with parents of children with cancer, it includes a greater range of items than the six-item Brief Resilience Scale that has been used with this population (Bajjani-Gebara et al., 2018). Thus, the CD-RISC-10 is favorable due to its greater content validity. See Appendix H for the full CD-RISC-10.
**Meaning In Life Questionnaire.** The Meaning In Life Questionnaire (MLQ) contains 10 items that map onto two factors: presence and search (Steger et al., 2006). The presence subscale (MLQ-P) investigates the degree to which participants feel their life currently has meaning, and the search subscale (MLQ-S) represents the degree to which participants perceive themselves as searching for meaning. Items are scored on a Likert scale that ranges from 1 (*absolutely untrue*) to 7 (*absolutely true*; Steger et al., 2006). Higher scores indicate greater perceived life meaning. The measures have demonstrated strong internal reliability for both the MLQ-P ($\alpha = .82-.86$) and the MLQ-S ($\alpha = .86-.87$; Steger et al., 2006). Additionally, the MLQ-P has shown convergent validity with measures of life satisfaction and joy while the MLQ-S has shown convergent validity with measures of depression and sadness (Steger et al., 2006). Additionally, both subscales demonstrated discriminant validity from social desirability in the same study.

In the current study, both MLQ subscales were used to investigate the degree to which parents endorse the presence of and search for meaning in their own lives. It was predicted that parents who engage in activism of any kind would score higher on the MLQ-P, as parents have qualitatively reported deriving meaning from engaging in activism following their child’s cancer diagnosis (Barrera et al., 2009; Meert et al., 2015). Although searching for meaning has been positively associated with distress in community populations, the current study proposed that this finding will not be replicated among parents of children with cancer due to parental reports that seeking meaning in traumatic cancer-related experiences is a key coping process (Meert et al., 2015; Parry & Chesler, 2005). Rather, the current study proposed that searching for meaning would be negatively associated with depression, just as presence of meaning was expected to be negatively associated with depression. See Appendix I for the full list of items.
The COPE. The COPE comprises 14 scales that measure various aspects of coping, 12 of which load onto a four-factor structure of active coping, socially supported/emotion-focused coping, acceptance coping, and avoidant coping (Carver et al., 1989). The thirteenth and fourteenth scales measure substance use and religious coping, respectively (Carver et al., 1989). Each scale includes four items, and item scores range from 1 (I usually don’t do this at all) to 4 (I usually do this a lot). Higher scores indicate more usage of the coping style. The reliability of active coping ($\alpha = .62-.80$), socially supported and emotional coping $\alpha = (.75-.85)$, and acceptance coping ($\alpha = .65-.72$) is somewhat higher than the reliability of avoidant coping ($\alpha = .45-.71$; Carver et al., 1989). The reliability of avoidant coping when measured among parents of children with cancer ($\alpha = .52$) is also lower than that of the other scales (Turner-Sack et al., 2016). Lower levels of avoidant coping and higher levels of active coping are both associated with reduced distress among parents of childhood cancer survivors (Turner-Sack et al., 2016). Higher levels of the same types of coping strategies that are categorized as emotional coping on the COPE have been related to reduced distress among parents of children in active treatment when measured using alternative methods (Compas et al., 2015). The current study included scales from the COPE to measure three types of coping: active coping, socially supported/emotion-focused coping, and avoidant coping. Because the current study proposed that there are distinct active and emotional components of activism, the COPE was the most appropriate measure available. On this measure, higher scores indicate greater usage of a certain coping style. See Appendix J for the full list of COPE questionnaires that were used.

Patient Health Questionnaire-9. The nine-item depression screen on the Patient Health Questionnaire (PHQ-9) is a valid self-report measure of patient depression that has demonstrated concordance with mental health provider interviews with test-retest reliability of $\alpha = .84$.
(Kroenke et al., 2001). Similarly, the measure has demonstrated strong reliability in both primary care and specialist settings (α = .86-.89; Kroenke et al., 2001). For each symptom, scores from 0 (not at all) to 3 (nearly every day) indicate how often the symptom occurred during the prior two weeks (Kroenke et al., 2001). A final question asks respondents to report how difficult they find daily functioning tasks using a range from not difficult at all to extremely difficult (Kroenke et al., 2001). Higher scores indicate greater depression. The PHQ-9 has been used in a variety of contexts to briefly assess for both the presence of depression symptoms and their severity (Manea, Gilbody, & McMillan, 2012). Additionally, it has demonstrated similar diagnostic accuracy as other well-established measures, such as the Hospital Anxiety and Depression Scale (HADS; Hartung et al., 2017). As noted in Hartung et al. (2017), the HADS is generally used with ill patients; thus, the PHQ-9 is more appropriate for use with healthy parents whose children are ill. The PHQ-9 was used as a continuous scale score to assess parental depression in the current study. See Appendix K for the full PHQ-9.

Open-Ended Comments on Childhood-Cancer-Related Activism. A series of open-ended questions were included at the end of the overall battery for parents who endorse at least one childhood-cancer-related activism behavior. Because the benefits of activism have not previously been directly investigated among parents of children with cancer, the qualitative items served to capture aspects of parents’ experiences that the other measures may not have adequately addressed. These include perceived benefits of activism and perceived motivations for engaging in activism. See Appendix L for a full list of items.
Analyses

All study hypotheses were analyzed using IBM SPSS Statistics 27 software (IBM Corp). The initial analysis included descriptive statistics to assess the normality distribution among study variables and a Pearson’s $r$ correlation matrix between all study variables. Internal reliability was also assessed for all measures. The necessary sample size for this study was found to be 153, based on a power analysis conducted using G*Power 3.1.4.9 statistical software ($f^2 = .15$, alpha = .05). All $p$ values reported are of two-tailed tests, with $p < .05$ significance.

A correlation matrix was constructed as the means of analyzing several study hypotheses. One correlation table (Table 2) served as the means of analyzing Primary Hypothesis 1, Primary Hypothesis 2, and Exploratory Hypothesis 3. The other (Table 3) served as the preliminary means of analyzing Primary Hypothesis 3, Primary Hypothesis 4, and Exploratory Hypothesis 2.

Primary Hypothesis 4 refers to the construct “emotional well-being.” The intended analyses for evaluating emotional well-being included z-scoring and combining the data for measures of hope, resilience, and present well-being. This plan required each of the three variables to be moderately correlated with the other two ($0.40 < r < 0.70$) and significantly correlated with post-diagnosis childhood-cancer-related activism ($p < .05$). In the event that either of those assumptions were not met, the alternative was to substitute the single variable that had the strongest association with post-diagnosis childhood-cancer-related activism in the place of emotional well-being. In actuality, because meaning in life was not associated with post-diagnosis childhood-cancer-related activism, hope was substituted in place of the proposed composite variable emotional well-being, as shown in Results.

There were three planned hierarchical regression analyses. The first, for Primary Hypothesis 3, included post-diagnosis childhood-cancer-related activism as the outcome variable.
and involved three steps: treatment variables (all that were correlated with post-diagnosis childhood-cancer-related activism at the $p < .05$ significance level), active coping, and socially supported/emotion-focused coping. The second planned hierarchical regression, for Primary Hypothesis 4, included hope as the outcome variable and involved three steps. Step 1 included demographics (age, race/ethnicity, and gender); Step 2 included pre-diagnosis childhood-cancer-related activism, pre-diagnosis general activism, and post-diagnosis general activism; and Step 3 included post-diagnosis childhood-cancer-related activism. The third planned hierarchical regression, for Exploratory Hypothesis 2, included post-diagnosis childhood-cancer-related activism as the outcome variable and involved two steps. Step 1 included hope, and Step 2 included strength of hope for other children with cancer and importance of hope for other children with cancer. Variables were removed from planned regression analyses if they were either not correlated with the outcome variable at the $p < .05$ significance level or if they were highly correlated with other predictors ($r > .70$).

Exploratory Hypotheses 1 and 1a served to compare participants’ reported change in activism following their child’s cancer diagnosis. For Exploratory Hypothesis 1, paired-samples t-tests were used to compare mean levels of engagement in pre-diagnosis and post-diagnosis general and cancer-related activism. For Exploratory Hypothesis 1a, participants were cleaved into low and high pre-diagnosis childhood-cancer-related activism groups as well as low and high pre-diagnosis general activism groups (described in detail in Results). Each group’s pre- and post-diagnosis engagement in both general and childhood-cancer-related activism was then compared using paired-samples t-tests.
Results

Participants

The final sample included 67 parents of children who have been diagnosed with cancer. Recruitment took place over a five-week period between February and March 2020. Study recruitment was suspended following the onset of the COVID-19 pandemic due to ethical concerns surrounding recruitment of a population that is highly vulnerable to illness and economic disruption. Additionally, the challenges posed by the COVID-19 pandemic may have introduced a methodological confound by impacting parent reports on measures of psychological well-being. As a result, slightly less than one-half of the proposed sample size of 153 was achieved. Sample demographics are included in Table 1.
Table 1

Sample Demographics

<table>
<thead>
<tr>
<th>Measure</th>
<th>n (Percent)</th>
<th>M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62 (92.5)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5 (7.5)</td>
<td></td>
</tr>
<tr>
<td>Parent Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>65 (95.6)</td>
<td></td>
</tr>
<tr>
<td>Non-Caucasian</td>
<td>5 (4.4)</td>
<td></td>
</tr>
<tr>
<td>Parent Age</td>
<td>43.36 (7.34)</td>
<td></td>
</tr>
<tr>
<td>Parent Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>59 (88.1)</td>
<td></td>
</tr>
<tr>
<td>Not Currently Married</td>
<td>8 (11.9)</td>
<td></td>
</tr>
<tr>
<td>Parent Financial Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than enough for basic needs</td>
<td>55 (82.1)</td>
<td></td>
</tr>
<tr>
<td>Struggling to meet basic needs</td>
<td>12 (17.9)</td>
<td></td>
</tr>
<tr>
<td>Child Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>32 (47.8)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>35 (52.2)</td>
<td></td>
</tr>
<tr>
<td>Child Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>61 (91.0)</td>
<td></td>
</tr>
<tr>
<td>Non-Caucasian</td>
<td>8 (9.0)</td>
<td></td>
</tr>
<tr>
<td>Biracial or Multiracial</td>
<td>2 (2.9)</td>
<td></td>
</tr>
<tr>
<td>Current Child Age</td>
<td>11.98 (5.87)</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute Lymphoblastic Leukemia</td>
<td>38 (56.7)</td>
<td></td>
</tr>
<tr>
<td>Other Diagnosis</td>
<td>29 (43.3)</td>
<td></td>
</tr>
</tbody>
</table>

Note. a Some parents selected multiple race or ethnicity categories. None of these parents selected the option for “Biracial or Multiracial.” b One parent entered their age as 5, and that likely error was excluded from this analysis.

Preliminary Analyses

The distribution of study variables was assessed for normality and homoscedasticity, and several exhibited a non-normal distribution (e.g., the absolute value of the skew statistic was greater than twice the standard error; Field et al., 2012). Raw data for the following variables violated the normality assumption: present meaning in life, avoidant coping, pre-diagnosis cancer-related activism, pre-diagnosis general activism, post-diagnosis general activism, depression, side effects, treatment types, and importance of hope for other children with cancer.
With the exception of present meaning in life and importance of hope for other children with cancer, all skewed variables were positively skewed. The positively skewed distribution of pre-diagnosis general and childhood-cancer-related activism was consistent with the predicted (and actual) low engagement in these behaviors among participants. Results for all study hypotheses were analyzed using both raw data and data that was transformed to correct violations of the normality assumption. Exploratory Hypothesis 2 was not supported when using raw data and partially supported when using transformed data (discussed in detail in Results). Because there were no other significant differences in results between the two sets of analyses, all results presented use raw data to for the sake of clarity and to present the most conservative estimate of true effect sizes.

All measures except for demographics required participants to respond to all items before proceeding. Thus, attrition was the only cause of missing non-demographic data. Of the 93 participants who completed the consent form, 53 completed the entire survey. Partial responses were included in the analyses if parents completed cancer-related demographic questions, childhood-cancer-related activism measures, and at least one other measure (N = 67). See Figure 2 for CONSORT (CONsolidated Standards Of Reporting Trials) inclusion flow chart.
Note. Because recruitment took place exclusively online, it is unknown how many parents viewed the advertisements or consent forms but chose not to participate.

Mean scores across all study variables were compared between complete responders ($n = 53$) and partial responders using paired-samples $t$-tests. No significant differences were found.

There were far more diagnosed children who were posttreatment ($n = 53$) than in treatment ($n = 8$) or deceased ($n = 6$). In light of this discrepancy, a one-way ANOVA was used to analyze potential differences between these groups and determine whether the full sample or posttreatment parents only would be included in subsequent analyses. Levene’s Test for Equality of Variances indicated that the assumption of equal variance was not violated for any variable except for time since diagnosis. Given the nature of cancer treatment, it is unsurprising that equal variances could not be assumed between groups regarding time since diagnosis (e.g., a child can only reach the posttreatment phase after months or years of treatment, while the other two groups could potentially include children within weeks of diagnosis). There were significant differences between groups on hope ($\eta^2 = .20; p = .001$), search for meaning in life ($\eta^2 = .10; p = .045$), active coping ($\eta^2 = .17; p = .006$), and time since diagnosis ($\eta^2 = .29; p < .001$). See Appendix M
for mean scores of each group. None of the hypotheses that include the variables hope, search for meaning in life, active coping, or time since diagnosis had different results when including the full sample compared to posttreatment parents only. However, when comparing the whole sample to posttreatment parents only across all variables, three significant differences emerged. Number of side effects was positively correlated with post-diagnosis cancer-related activism among the whole sample, but not among the posttreatment parents only. Avoidant coping was positively correlated with post-diagnosis childhood-cancer-related activism among the whole sample, but not among posttreatment parents only. Strength of hope for children with cancer was positively correlated with post-diagnosis childhood-cancer-related activism among posttreatment parents, but not among the whole sample. Because there were no significant differences between treatment phase groups regarding these three variables, treatment phase cannot explain the difference in results between the posttreatment parents and the full sample. Accordingly, the full sample was used to preserve power. Primary results are reported for the full sample, with pairwise deletions where necessary. See Tables 2 and 3 for correlations among the full sample and Appendices N and O for correlations among posttreatment parents only.
Table 2

*Correlation Analyses for Primary Hypothesis 1, Primary Hypothesis 2, and Exploratory Hypothesis 3.*

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDCRA (n = 67)</td>
<td>10.18</td>
<td>3.18</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. AHS (n = 67)</td>
<td>24.72</td>
<td>3.78</td>
<td>.46***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. CD-RISC (n = 65)</td>
<td>27.08</td>
<td>6.77</td>
<td>.37**</td>
<td>.81***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. MLQ-P (n = 62)</td>
<td>20.56</td>
<td>5.35</td>
<td>.17</td>
<td>.57***</td>
<td>.44**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. MLQ-S (n = 62)</td>
<td>17.73</td>
<td>5.46</td>
<td>.10</td>
<td>-.03</td>
<td>.08</td>
<td>-.37**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Active Coping (n = 60)</td>
<td>35.22</td>
<td>6.14</td>
<td>.50***</td>
<td>.60***</td>
<td>.43**</td>
<td>.25</td>
<td>.06</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. SSEFC (n = 60)</td>
<td>32.10</td>
<td>7.62</td>
<td>.13</td>
<td>.18</td>
<td>.23</td>
<td>.01</td>
<td>.21</td>
<td>.31*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Avoidant Coping (n = 60)</td>
<td>20.58</td>
<td>5.37</td>
<td>-.27*</td>
<td>-.45***</td>
<td>-.52***</td>
<td>-.51***</td>
<td>.12</td>
<td>-.26*</td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PHQ-9 (n = 53)</td>
<td>9.02</td>
<td>6.48</td>
<td>-.19</td>
<td>-.46***</td>
<td>-.53***</td>
<td>-.57***</td>
<td>.34*</td>
<td>-.02</td>
<td>.01</td>
<td>.58***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Treatment Types (n = 67)</td>
<td>2.36</td>
<td>1.16</td>
<td>.29*</td>
<td>.06</td>
<td>.09</td>
<td>-.07</td>
<td>.18</td>
<td>.04</td>
<td>-.20</td>
<td>.18</td>
<td>.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Side Effects (n = 67)</td>
<td>1.57</td>
<td>1.34</td>
<td>.32**</td>
<td>.15</td>
<td>.08</td>
<td>-.13</td>
<td>.21</td>
<td>.31*</td>
<td>-.08</td>
<td>.04</td>
<td>.16</td>
<td>.33**</td>
<td></td>
</tr>
<tr>
<td>12. TSD (Months) (n = 65)</td>
<td>59.04</td>
<td>40.6</td>
<td>.17</td>
<td>-.01</td>
<td>-.12</td>
<td>-.03</td>
<td>.05</td>
<td>-.06</td>
<td>-.32*</td>
<td>.12</td>
<td>.10</td>
<td>.32**</td>
<td>.17</td>
</tr>
</tbody>
</table>

*Note.* PDCRA = Post-Diagnosis Cancer-Related Activism. AHS = Adult Hope Scale. CD-RISC = Connor Davidson Resilience Scale – 10 Item. MLQ-P = Meaning In Life Questionnaire, Presence Subscale. MLQ-S = Meaning In Life Questionnaire, Search Subscale. SSEFC = Socially Supported/Emotion-focused Coping. PHQ-9 = Patient Health Questionnaire – 9 Item. TSD = Time Since Diagnosis. *p < .05, two tailed. **p < .01, two-tailed. ***p < .001, two-tailed.
Table 3

Preliminary Correlation Analyses Between Hierarchical Regression Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDCRA (n = 67)</td>
<td>10.07</td>
<td>3.25</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. AHS (n = 67)</td>
<td>24.82</td>
<td>3.86</td>
<td>.46***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Active Coping (n = 60)</td>
<td>35.10</td>
<td>6.16</td>
<td>.50***</td>
<td>.60***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. SSEFC (n = 60)</td>
<td>31.92</td>
<td>7.69</td>
<td>.13</td>
<td>.18</td>
<td>.31*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Avoidant Coping (n = 60)</td>
<td>20.58</td>
<td>5.37</td>
<td>-.27*</td>
<td>-.45**</td>
<td>-.26*</td>
<td>.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Side Effects (n = 67)</td>
<td>1.54</td>
<td>1.34</td>
<td>.32**</td>
<td>.15</td>
<td>.31*</td>
<td>-.08</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Treatment Types (n = 67)</td>
<td>2.32</td>
<td>1.19</td>
<td>.29*</td>
<td>.06</td>
<td>.04</td>
<td>-.20</td>
<td>.18</td>
<td>.33**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. PrDCRA (n = 67)</td>
<td>4.01</td>
<td>4.08</td>
<td>.30*</td>
<td>.12</td>
<td>.29*</td>
<td>.04</td>
<td>-.38**</td>
<td>.01</td>
<td>.09</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PrDGA (n = 55)</td>
<td>8.98</td>
<td>7.58</td>
<td>.20</td>
<td>.31*</td>
<td>.15</td>
<td>.10</td>
<td>-.01</td>
<td>.09</td>
<td>.18</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. PDGA (n = 55)</td>
<td>9.93</td>
<td>8.91</td>
<td>.35**</td>
<td>.39**</td>
<td>.28*</td>
<td>.08</td>
<td>-.04</td>
<td>.12</td>
<td>.28*</td>
<td>-.05</td>
<td>.75**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Strength of Hope</td>
<td>4.43</td>
<td>1.38</td>
<td>.05</td>
<td>.08</td>
<td>-.06</td>
<td>-.35**</td>
<td>-.06</td>
<td>-.32*</td>
<td>-.09</td>
<td>-.10</td>
<td>.01</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Importance of Hope</td>
<td>5.75</td>
<td>1.68</td>
<td>.07</td>
<td>.14</td>
<td>-.08</td>
<td>-.08</td>
<td>-.02</td>
<td>-.20</td>
<td>-.05</td>
<td>.09</td>
<td>-.20</td>
<td>-.07</td>
<td>.35*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Age (n = 67)</td>
<td>43.36</td>
<td>7.34</td>
<td>.10</td>
<td>.02</td>
<td>-.03</td>
<td>-.13</td>
<td>-.20</td>
<td>-.01</td>
<td>.08</td>
<td>-.14</td>
<td>-.05</td>
<td>.17</td>
<td>-.05</td>
<td>.18</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Female (n = 67)</td>
<td>NA</td>
<td>NA</td>
<td>-.06</td>
<td>-.05</td>
<td>-.15</td>
<td>.27*</td>
<td>.06</td>
<td>.01</td>
<td>-.06</td>
<td>.01</td>
<td>-.06</td>
<td>.07</td>
<td>-.09</td>
<td>-.24</td>
<td>-.33</td>
<td></td>
</tr>
<tr>
<td>15. Non-Hispanic White (n = 67)</td>
<td>NA</td>
<td>NA</td>
<td>.29*</td>
<td>.08</td>
<td>.08</td>
<td>-.07</td>
<td>-.04</td>
<td>.03</td>
<td>.21</td>
<td>-.01</td>
<td>.12</td>
<td>.22</td>
<td>-.16</td>
<td>.13</td>
<td>.09</td>
<td>-.04</td>
</tr>
</tbody>
</table>

Note. PDCRA = Post-Diagnosis Cancer-Related Activism. AHS = Adult Hope Scale. SSEFC = Socially Supported/Emotion-focused Coping. PrDCRA = Pre-Diagnosis Cancer-Related Activism. PrDGA = Pre-Diagnosis General Activism. PDGA = Post-Diagnosis General Activism. *p < .05, two tailed. **p < .01, two-tailed. ***p < .001, two-tailed.
All multi-item study measures were assessed for internal reliability. Overall, reliability was high (α = .77-.96). Internal reliability for the cancer activism measure that was created for this study was higher for pre-diagnosis cancer-related activism (α = .91) than post-diagnosis cancer-related activism (α = .79). The modified AOS-C also had strong internal reliability for both pre-diagnosis general activism (α = .94) and post-diagnosis general activism (α = .96). Notably, internal reliability for the avoidant coping measure in this sample (α= .77) was higher than that found in previous research with parents of children with cancer (α = .52; Turner-Sack et al., 2016). Both the measure of strength of hope for other children with cancer and the measure of importance of hope for children with cancer consisted of a single item, so there were no reliability analyses for these measures.

**Descriptive Statistics**

Tables 2 and 3 display means, standard deviations, and correlations relative to interpreting the results discussed in subsequent sections of this document.

Parents generally reported moderate satisfaction with their child’s treatment (M = 3.12, SD = 1.39; range 1-5), and children generally received multiple treatment modalities (M = 2.32, SD = 1.19). Most parents (76.1%) reported that their child had experienced at least one long-term physical, cognitive, or emotional side-effect from cancer treatment (M = 1.54, SD = 1.34). The high reported rate of long-term side effects is consistent with evidence documenting near-universal chronic health concerns among adult survivors of pediatric cancer (Bhakta et al., 2017).

Parents’ PHQ-9 scores (M = 9.02, SD = 6.48) indicated that parents were generally moderately depressed (Manea et al., 2012). A significant minority of parents (38.7%) endorsed clinically significant depression on the PHQ-9 as evidenced by scores of at least 10 (Manea et al., 2012). Additionally, 10 parents (18.9%) endorsed experiencing thoughts of suicide or self-
harm at least once during the two weeks prior to completing the survey. Links to mental health resources were provided at the end of the anonymous survey, but there was no way to contact parents directly to provide resources.

Parents generally reported moderate to high levels of general hopefulness on the AHS, with scores ranging from 15 to 32 (possible scores ranged from eight to 32; Snyder et al., 1991). The current sample mean was similar to that observed among a college student community sample, $t(404) = 1.30$, $p = .194$ (Snyder et al., 1991).

A similar pattern of moderate to high scores was found for resilience on the CD-RISC-10 with scores ranging from 11 to 40 (possible scores ranged from 0 to 40; Campbell-Sills & Stein, 2007). Higher scores indicate greater resilience on this measure (Campbell-Stills & Stein, 2007). Compared to a community sample of adults of similar age to the parents in the current study, the current sample had lower CD-RISC-10 scores, $t(609) = 5.35$, $p < .001$ (Campbell-Sills et al., 2009).

Regarding perceived life meaning, scores on the MLQ-P which ranged from five to 28, were slightly higher than those for the MLQ-S which ranged from four to 28 (possible scores ranged from four to 28 for both measures; Steger et al., 2006). This finding indicates that parents reported higher present meaning than search for meaning (Steger et al., 2006). The current sample’s scores for both subscales were lower than previous reports from a college student community sample on presence, $t(214) = 3.12$, $p < .002$, and search, $t(214) = 5.67$, $p < .001$ (Steger et al., 2006).

Within this sample, hope, resilience, and perceived meaning in life were all positively associated. Hope was highly intercorrelated with resilience and hope was moderately correlated with present meaning in life). Resilience and present meaning in life were also moderately
correlated. Additionally, all three of these variables were negatively associated with depression, providing convergent validity that they do in fact represent constructs of positive emotional well-being. Because hope and resilience were highly intercorrelated, these two variables may, in fact, represent a single construct within this population. As proposed in the analysis plan, hope was substituted for emotional well-being due to the lack of association between presenting meaning in life and post-diagnosis childhood-cancer-related activism as well as the high degree of intercorrelation between hope and resilience.

Of the three coping styles measured with the COPE, parents reported using active coping the most with scores ranging from 22 to 47 (possible scores ranged from 12 to 48 on the coping measures) (Carver et al., 1989). Socially supported/emotion-focused coping which had scores ranging from 19 to 48, was used more than avoidant coping, which had scores ranging from 12 to 33. These findings are similar to previously reported findings on how parents of children with cancer employ various coping styles; active coping is used the most, followed by socially supported/emotion-focused coping, and then avoidant coping (Turner-Sack et al., 2016).

Parents were asked to rate the strength of their hope for other children with cancer. Parents generally reported moderate strength of hope with scores ranging from 1 (extremely weak) to 7 (extremely strong). Of the 53 parents who answered this question, 12 (22.6%) reported having either a “very strong” or “extremely strong” belief that childhood cancer will eventually be cured. Parents were also asked to rate the importance of their hope for other children with cancer from 1 (extremely weak) to 7 (extremely strong), and they generally reported that their hope is highly important to them. Of the 53 parents who answered this question, 39 (74.6%) reported that their belief that childhood cancer will be cured is “very important” or “extremely important” to them. Overall, there were few significant associations
between hope for children with cancer and other study variables. Strength of hope was positively associated with present meaning in life \( (r = .30, p = .028) \) and negatively associated with search for meaning in life \( (r = -.37, p = .006) \). In other words, parents who reported high levels of hope for other children with cancer also reported having a resolved sense of meaning in their lives.

Participation in general activism as measured with the modified AOS-C varied widely both pre-diagnosis and post-diagnosis covering the full range from zero to 28 behaviors at both time points (Corning & Myers, 2002). Although the scoring of the modified measure differed from the original measure, college student community samples have also exhibited wide variation in their participation in activism behaviors, suggesting some similarities between parents of children with cancer and the broader community regarding their engagement in general activism (Corning & Meyers, 2002).

Engagement in pre-diagnosis childhood-cancer-related activism was relatively low \( (M = 4.01, SD = 4.08) \), with a range of zero to 15 behaviors. In contrast, parents universally engaged in childhood-cancer-related activism following their own child’s diagnosis. Parents generally reported moderate to high levels of engagement in post-diagnosis childhood-cancer-related activism \( (M = 10.18, SD = 3.18) \), ranging from three to 15 behaviors. Regarding post-diagnosis cancer-related activism, the most common behavior was purchasing items that referenced supporting childhood cancer or for which a portion of proceeds were donated to a childhood cancer-related cause \( (92.5\%) \). A vast majority of parents had also shared information about childhood cancer online \( (91.0\%) \) or donated directly to a childhood cancer-related organization \( (91.0\%) \). The least common behavior was serving as a leader in an organization that seeks to support children with cancer \( (23.9\%) \), followed by giving a speech \( (43.3\%) \) and contacting a
celebrity or public official (43.3%). See Figure 3 for a bar graph displaying the frequency of each cancer-related activism behavior pre-diagnosis and post-diagnosis.

**Figure 3**

*Frequency of Childhood-Cancer-Related Activism Behaviors Before and After Diagnosis*

![Bar graph showing frequency of childhood-cancer-related activism behaviors before and after diagnosis.](image)

**Hypotheses**

**Primary Hypothesis 1**

It was predicted that greater post-diagnosis childhood-cancer-related activism would be significantly associated with treatment variables that indicate greater exposure to cancer-related stress (i.e., longer time since diagnosis, higher number of treatment types, higher number of reported side effects, status as a parent of a deceased child), as well as higher levels of hope, resilience, present meaning in life, active coping, and socially supported/emotion-focused coping.
A correlation matrix was constructed to analyze associations between the relevant variables. See Table 2 for all correlations and sample sizes for each. Greater post-diagnosis childhood-cancer-related activism was significantly associated with higher number of reported treatment types, higher number of reported side effects as well as higher levels of hope, resilience, and active coping. Post-diagnosis cancer-related activism was not associated with longer time since diagnosis, greater present meaning in life or higher levels of socially supported/emotion-focused coping. The association between status as parent of a deceased child and activism was not investigated due to low sample size of such parents. As such, Primary Hypothesis 1 was partially supported.

**Primary Hypothesis 2**

It was predicated that greater post-diagnosis childhood-cancer-related activism would be significantly associated with lower levels of avoidant coping and depression.

As in Primary Hypothesis 1, the correlation table was used to analyze associations between relevant variables. Greater post-diagnosis childhood-cancer-related activism was significantly associated with lower levels of avoidant coping but not with lower levels of depression. Results indicate that Primary Hypothesis 2 was partially supported. These results are also reported in Table 2.

**Primary Hypothesis 3**

It was predicted that higher levels of post-diagnosis childhood-cancer-related activism would be uniquely predicted by treatment variables that indicate exposure to cancer-related stress, higher levels of active coping, and higher levels of socially supported/emotion-focused coping.
A hierarchical regression model was used to determine the predictors of post-diagnosis childhood-cancer-related activism. The two treatment variables that were positively associated with post-diagnosis cancer-related activism (number of treatment types and number of side effects) were positively associated. Because the degree of intercorrelation was well below the proposed $r > .70$ level for excluding redundant variables, both variables were included when accounting for the amount of variance in activism that could be attributed to treatment variables. It was originally proposed that socially supported/emotion-focused coping would be significantly associated with post-diagnosis cancer related activism, but this was not the case. Therefore, according to the proposed analysis plan, socially supported/emotion-focused coping was not included in the regression analyses. Side effects and treatment types were entered as one step, and active coping was entered as a second step, with post-diagnosis cancer-related activism as the outcome variable.

Parents who completed the COPE ($n = 60$) were included in the regression analysis. Higher levels of post-diagnosis childhood-cancer-related activism were uniquely predicted by treatment variables (side effects and treatment types, collectively) and higher levels of active coping. Overall, results indicate that Primary Hypothesis 3 was partially supported. See Table 4 for the results of the regression analyses for Primary Hypothesis 3. The $R^2$ variance in activism accounted for by the entire model was $.31$. 
Table 4

Predicting Activism from Treatment Types and Active Coping

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>95% CI for B</th>
<th>SE B</th>
<th>β</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>8.47</td>
<td>[6.62, 10.28]</td>
<td>0.92</td>
<td>.20</td>
<td>.10</td>
<td>.10*</td>
</tr>
<tr>
<td>Number of Side Effects</td>
<td>0.45</td>
<td>[-0.15, 1.05]</td>
<td>0.30</td>
<td>.20</td>
<td>.10</td>
<td>.10*</td>
</tr>
<tr>
<td>Number of Treatment Types</td>
<td>0.52</td>
<td>[-0.17, 1.21]</td>
<td>0.34</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.31</td>
<td>.21***</td>
</tr>
<tr>
<td>Constant</td>
<td>0.48</td>
<td>[-3.72, 4.68]</td>
<td>2.10</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Side Effects</td>
<td>0.09</td>
<td>[-0.47, 0.65]</td>
<td>0.28</td>
<td>.04</td>
<td>.10</td>
<td>.10*</td>
</tr>
<tr>
<td>Number of Treatment Types</td>
<td>0.60</td>
<td>[-0.01, 1.21]</td>
<td>0.31</td>
<td>.23</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active Coping</td>
<td>0.24</td>
<td>[0.12, 0.35]</td>
<td>0.60</td>
<td>.48</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. CI = confidence interval. *p < .05, **p < .01, ***p < .001.

Primary Hypothesis 4

It was predicted that higher levels of emotional well-being would be uniquely predicted by level of post-diagnosis childhood-cancer-related activism after accounting for parental demographic factors, pre-diagnosis general activism, pre-diagnosis childhood-cancer-related activism, and post-diagnosis general activism.

The proposed analyses for this hypothesis included z-scoring and computing a combined variable for hope, resilience, and present meaning in life. However, this analysis required significant associations between each variable and post-diagnosis cancer-related activism; this assumption was not met. Specifically, present meaning in life was not significantly associated with post-diagnosis cancer-related activism. See Table 3 for all correlations.

To address the issue of meaning in life not being associated with activism, hope was substituted in place of emotional well-being since it shared the strongest association with post-diagnosis cancer-related activism out of the three well-being variables. Hope alone was used due to a high degree of intercorrelation between hope and resilience (r > .70) Then, a hierarchical regression analysis was used to determine the predictors of hope, with participants who completed all activism measures (n = 55) being included. There was significant multicollinearity
between pre-diagnosis general activism and post-diagnosis general activism ($r > .70$), two of the proposed predictors. Because post-diagnosis general activism was a significant predictor of hope, but pre-diagnosis general activism was not, pre-diagnosis general activism was removed from the analyses to ensure that all significant findings were presented. Higher levels of hope were uniquely predicted by level of post-diagnosis childhood-cancer-related activism after accounting for parental demographic factors (age, gender, and ethnicity), pre-diagnosis childhood-cancer-related activism, and post-diagnosis general activism. Results indicate that Primary Hypothesis 4 was supported and are shown in Table 5. The $R^2$ variance in activism accounted for by the entire model was .33.
Table 5

Predicting Hope from Demographics and Activism

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>95% CI for B</th>
<th>SE B</th>
<th>B</th>
<th>R²</th>
<th>ΔR²</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant</td>
<td>23.76</td>
<td>[13.19, 34.33]</td>
<td>5.26</td>
<td>.01</td>
<td>.01</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.01</td>
<td>[-0.13, 0.12]</td>
<td>0.06</td>
<td>-.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>-0.74</td>
<td>[-4.99, 3.52]</td>
<td>2.12</td>
<td>-.05</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>2.02</td>
<td>[-5.77, 9.81]</td>
<td>3.88</td>
<td>.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Step 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.17</td>
<td>.16*</td>
</tr>
<tr>
<td>Constant</td>
<td>22.50</td>
<td>[12.44, 32.56]</td>
<td>5.01</td>
<td>.17</td>
<td>.16*</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.10</td>
<td>[-0.13, 0.11]</td>
<td>0.06</td>
<td>-.02</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.53</td>
<td>[-3.54, 4.61]</td>
<td>2.03</td>
<td>.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>0.35</td>
<td>[-7.04, 7.74]</td>
<td>3.68</td>
<td>.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-Diagnosis Cancer-Related Activism</td>
<td>0.09</td>
<td>[-0.14, 0.33]</td>
<td>0.12</td>
<td>.11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Diagnosis General Activism</td>
<td>0.17</td>
<td>[0.05, 0.28]</td>
<td>0.06</td>
<td>.40</td>
<td>.40**</td>
<td></td>
</tr>
<tr>
<td><strong>Step 3</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.33</td>
<td>.17**</td>
</tr>
<tr>
<td>Constant</td>
<td>21.69</td>
<td>[12.57, 30.81]</td>
<td>4.53</td>
<td>.33</td>
<td>.17**</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.03</td>
<td>[-0.13, 0.08]</td>
<td>0.05</td>
<td>-.07</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>0.09</td>
<td>[-3.61, 3.78]</td>
<td>1.84</td>
<td>.01</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>-2.53</td>
<td>[-9.42, 4.36]</td>
<td>3.43</td>
<td>-.09</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-Diagnosis Cancer-Related Activism</td>
<td>-0.04</td>
<td>[-0.26, 0.19]</td>
<td>0.11</td>
<td>-.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Diagnosis General Activism</td>
<td>0.10</td>
<td>[-0.01, 0.21]</td>
<td>0.06</td>
<td>.25</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Post-Diagnosis Cancer-Related Activism</td>
<td>0.58</td>
<td>[0.24, 0.92]</td>
<td>0.17</td>
<td>.48</td>
<td>.48**</td>
<td></td>
</tr>
</tbody>
</table>

*Note. CI = confidence interval. *p < .05, **p < .01, ***p < .001
Exploratory Hypothesis 1

It was predicted that, in general, parents would retrospectively report maintaining or decreasing their general activism behaviors post-diagnosis and increasing their childhood-cancer-related activism behaviors post-diagnosis.

Paired-samples t-tests were used to evaluate changes from pre- to post-diagnosis on both general and cancer-related activism. For cancer-related activism, raw data was used despite the positive skew of pre-diagnosis data to maintain consistency in the data between the two time points. For general activism, square root-transformed data were used to account for significant positive skew within both post pre- and post-diagnosis data. Results did not change when analyses were conducted using raw data. For cancer-related activism (n = 67), post-diagnosis engagement (M = 10.18) was significantly higher, t(66) = 11.57, p < .001, d = 1.41, 95% CI [1.07, 1.75], than pre-diagnosis engagement (M = 4.01). Notably, 100% of participants engaged in at least three cancer-related activism behaviors following diagnosis, compared to 54% of participants who did so pre-diagnosis. For general activism (n = 55), post-diagnosis engagement (M = 9.93) was not significantly different, t(54) = 1.31, p = .195, d = .18, 95% CI [-.09, .44], from pre-diagnosis engagement (M = 8.98). Results indicate that Exploratory Hypothesis 1 was supported.

Exploratory Hypothesis 1a. It was predicted that parents would display different patterns of change in post-diagnosis activism behaviors (general and childhood cancer related) depending on their pre-diagnosis levels of activism (general and childhood cancer related).

Because the data for pre-diagnosis general activism were positively skewed, the parents who were above the mean (M = 8.68) had greater levels of activism than the top 50% of the sample. Parents who engaged in at least nine general activism behaviors comprised the high pre-
diagnosis general activism group, and parents who engaged in eight or fewer pre-diagnosis general activism behaviors comprised the low pre-diagnosis activism group. Sorting the cases in this way created groups that could more accurately be characterized as having “high” and “low” levels of activism than if parents were split into groups of equal size using the median. See Table 6 for sample sizes of each group, accounting for attrition between each measure.

**Table 6**

*Sample Sizes for Pre-Diagnosis General Activism Groups*

<table>
<thead>
<tr>
<th></th>
<th>Cancer-Related Activism (n)</th>
<th>General Activism (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Pre-Diagnosis General Activism Group</td>
<td>26</td>
<td>24</td>
</tr>
<tr>
<td>Low Pre-Diagnosis General Activism Group</td>
<td>32</td>
<td>31</td>
</tr>
</tbody>
</table>

Paired samples t-tests were used to assess parents’ reported change in activism following their child’s cancer diagnosis. The high pre-diagnosis general activism group demonstrated an increase in cancer-related activism behaviors following diagnosis, \( t(25) = 7.11, p < .001, d = 1.39, 95\% \text{ CI} [.84, 1.93] \). The low pre-diagnosis general activism group also increased their engagement in cancer-related activism, \( t(31) = 7.54, p < .001, d = 1.33, 95\% \text{ CI} [.85, 1.81] \). The high pre-diagnosis general activism group maintained their engagement in general activism following their child’s cancer diagnosis, \( t(23) = .34, p = .738, d = .07, 95\% \text{ CI} [-.33, .46] \). The low pre-diagnosis general activism group also maintained their engagement in general activism, \( t(30) = .155, p = .132, d = .28, 95\% \text{ CI} [-.08, .64] \). Parents reported increasing their engagement in cancer activism and maintaining their engagement in general activism regardless of their pre-diagnosis level of engagement in general activism.
The pre-diagnosis cancer-related activism data were positively skewed. Thus, the same approach to cleaving the data that was used for general activism was also used for cancer-related activism. The mean (\( M = 4.00 \)) was used as a cutoff point for pre-diagnosis cancer-related activism to produce groups that could more accurately be described as “high” and “low” in cancer-related activism than if groups were split equally using the median. Parents who engaged in at least four pre-diagnosis cancer-related activism behaviors comprised the high pre-diagnosis cancer-related activism group, and parents who engaged in three or fewer pre-diagnosis cancer-related activism behaviors comprised the low pre-diagnosis cancer-related activism group. See Table 7 for the sample size of each group, accounting for attrition between each measure.

**Table 7**

*Sample Sizes for Pre-Diagnosis Cancer-Related Activism Groups*

<table>
<thead>
<tr>
<th>Cancer-Related Activism (n)</th>
<th>General Activism (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Pre-Diagnosis Cancer-Related Activism Group</td>
<td>30</td>
</tr>
<tr>
<td>Low Pre-Diagnosis Cancer-Related Activism Group</td>
<td>37</td>
</tr>
</tbody>
</table>

The high pre-diagnosis cancer-related activism group demonstrated an increase in cancer-related activism behaviors following diagnosis, \( t(29) = 5.16, p < .001, d = .94, 95\% \text{ CI}[.51, 1.37] \). The low pre-diagnosis cancer-related activism group also increased their engagement in cancer-related activism following diagnosis, \( t(36) = 14.44, p < .001, d = 2.37, 95\% \text{ CI}[1.74, 3.00] \). The high pre-diagnosis cancer-related activism group maintained their engagement in general activism behaviors following diagnosis, \( t(23) = .49, p = .632, d = -.10, 95\% \text{ CI}[-.50, .30] \). The low pre-diagnosis cancer-related activism group increased their engagement in general activism following diagnosis, \( t(30) = 2.42, p = .022, d = .44, 95\% \text{ CI}[.06, .80] \). Parents reported
increasing their engagement in childhood-cancer-related activism regardless of their pre-diagnosis level of engagement in cancer-related activism. However, only parents who were initially low on pre-diagnosis childhood-cancer-related activism significantly increased their engagement in general activism following their own child’s diagnosis.

All four groups of parents significantly increased their engagement in cancer-related activism following diagnosis. Thus, participants who were highly engaged in activism prior to their child’s cancer diagnosis did not report different patterns of change from parents who were minimally engaged in activism prior to diagnosis regarding cancer-related activism. However, parents who had low pre-diagnosis engagement in childhood-cancer-related activism increased their engagement in general activism following diagnosis, exhibiting a different pattern of change than the other three groups. Results indicate that Exploratory Hypothesis 1a was partially supported. Functionally, the purpose of this hypothesis was to investigate whether parents who were engaged in activism prior to their child’s diagnosis would shift the targets of their efforts more exclusively toward children with cancer. Study findings indicate that parents generally broadened their activism efforts to include childhood cancer rather than narrowing their focus following their own child’s diagnosis.

**Exploratory Hypothesis 2**

It was predicted that hope for other children with cancer would account for unique variance in post-diagnosis childhood-cancer-related activism beyond that which could be explained by general hope.

A hierarchical regression was proposed to determine the variance in post-diagnosis childhood-cancer-related activism explained by general hope and hope for children with cancer, respectively. Strength of hope for children with cancer was not associated with post-diagnosis
cancer-related activism. Importance of hope for children with cancer was also not associated with post-diagnosis cancer-related activism. Consistent with the proposed analysis plan, the regression analyses were not conducted due to an insufficient number of predictors that were significantly associated with the outcome variable on a bivariate level. Results indicate that Exploratory Hypothesis 2 was not supported.

**Exploratory Hypothesis 3**

It was predicted that search for meaning in life would be negatively associated with depression among parents of children with cancer.

Correlations between perceived meaning in life and depression were analyzed. Participants who completed the measure of depression ($n = 53$) were included in these analyses. Search for meaning in life was positively associated with depression, the opposite of what was predicted. See Table 2 for results, which indicate that Exploratory Hypothesis 3 was not supported.

**Qualitative Findings**

Thirty-nine participants completed the open-ended questionnaire regarding their activism experiences. See Appendix P for example responses to each question and emergent themes. Parents frequently reported initiating activism efforts shortly after diagnosis ($n = 23$). Overall, parents frequently cited values of either raising awareness for the struggles of pediatric cancer patients or improving medical treatment for children with cancer ($n = 24$) as their reasons for participating. Regarding benefits of activism, one parent stated, “I have felt strength come from activism and found support from other activists and found purpose.” Some parents reported that their spouses and children, including healthy siblings, also engaged in activism ($n = 19$). Several
parents also reported significant burdens relating to activism, including exposure to reminders of traumatic cancer-related experiences \((n = 10)\) and discouraging responses from others \((n = 6)\).

Participants were asked to provide their thoughts on whether medical professionals should encourage families to engage in activism on behalf of children with cancer. Responses that can be categorized as yes \((n = 14)\), no \((n = 11)\), or maybe \((n = 12)\) occurred with similar frequency. Parents who strongly agreed with recommending activism felt that it would increase other parents’ access to a source of community and empowerment. Parents who stated that medical professionals should not encourage families to engage in activism emphasized the personal nature of activism decisions and the already burdensome nature of cancer treatment. Parents who had some reservations suggested that medical professionals should inform parents about activism opportunities without explicitly encouraging them or wait until families have thoroughly adjusted to the diagnosis before initiating a conversation on this topic. Some parents offered suggestions regarding how organizations can minimize burdens when including parents in activism efforts, with one parent stating, “some events are simple, like show up or walk ... but to share personal stories and advocate publicly is too emotional for some parents and that is ok.”

Taken together, the qualitative findings of this study, while not central to the main hypotheses, lend additional understanding to the parental experience of cancer activism.
Discussion

Childhood cancer has a profound impact on the parents of diagnosed children, and the coping strategies employed by these parents are of significant interest. Parental distress is positively associated with the distress of diagnosed children, underscoring the need for effective coping (Bakula et al., 2019). The current study sought to understand if activism is a coping strategy that parents employ following their child’s cancer diagnosis by addressing a) the prevalence of various activism behaviors and b) the associations between the number of activism behaviors a parent engages in and various aspects of coping and well-being.

Summary of Findings

The current study demonstrated that activism, in the form of action taken to support children with cancer as a group, is an activity that many parents engage in following their child’s cancer diagnosis. As was predicted in the study hypotheses, this sample reported a significant increase in their activism on behalf of children with cancer after having a child diagnosed with cancer. Indeed, post-diagnosis engagement in childhood-cancer-related activism was universally reported among the current sample. All 15 types of activism behaviors that were measured in the current study were endorsed by at least 20% of participants, with over 90% of participants engaging in simple actions such as donating funds or sharing information about childhood cancer online. Engagement in activism was higher among parents who otherwise cope effectively with their experiences (e.g., higher levels of active coping and lower levels of avoidant coping; Turner-Sack et al., 2016). Consistent with previous research, active coping was associated with reduced depression and avoidant coping was associated with increased depression on the bivariate level among this sample of parents of children with cancer (Turner-Sack et al., 2016).
Similarly, engagement in activism was higher among parents who reported higher levels of hopefulness and resilience on the bivariate level.

Several study hypotheses were supported by the data, with the results of hierarchical regression analyses underscoring the salience of childhood-cancer-related activism among parents of children with cancer. Active coping was a significant predictor of post-diagnosis childhood-cancer-related activism engagement, explaining over 20% of the variance after accounting for treatment variables. This finding provides insight into the role that activism may play in parental coping with pediatric cancer, as participants in the current study who used higher levels of active coping tended to have higher levels of activism engagement. The strength of the relationship between post-diagnosis cancer-related activism and hopefulness was greater than what could be explained by engagement in pre-diagnosis and general activism behaviors, supporting one of the primary hypotheses of the current study. Parents of children with cancer have previously described experiencing hope for a variety of outcomes, including improved conditions for other diagnosed children (Kamihara et al., 2013). The current study indicates that parents do not only experience this hope passively. Instead, they take a variety of steps to enact changes that serve to manifest the changes they hope for.

Several study hypotheses were not supported. It was predicted that activism and depression would be negatively associated, but there was no statistically significant association between these two variables. Thus, it appears that although activism is related to hope and resilience, high levels of activism engagement do not imply freedom from depression for parents of children with cancer. Similarly, there was no statistically significant relationship between post-diagnosis activism and perceived present meaning in life despite qualitative descriptions of a positive association between these two variables in the literature (Barerra et al., 2009; Meert et
al., 2015). It is unclear why these variables were not significantly associated in this study, as activism was not correlated with either present meaning in life or search for meaning in life. In other words, the lack of significant association between activism and present meaning in life cannot be explained by the claim that parents who are highly engaged in activism are searching for meaning rather than presently experiencing meaning in their lives. It is also notable that searching for meaning in life was positively associated with depression in this sample, as parents have previously reported that seeking meaning in the cancer experience is important to them (Meert et al., 2015). However, given that having high present meaning was associated with fewer depression symptoms while highly searching for meaning was associated with more depression symptoms in the current study, it appears that searching for meaning in one’s experiences may be associated with depression more than actually achieving a sense of meaning even for individuals who have experienced a life-changing event such as childhood cancer.

**Explanation of Findings**

The results of this study provide insight into both the prevalence of activism and how it may function as a coping strategy. Specifically, it appears that activism is positively associated with active coping, negatively associated with avoidant coping, and not significantly associated with socially supported/emotion-focused coping. Conceptually, this finding is consistent with third-wave behavioral theory that emphasizes the importance of acting upon problems that are meaningful to the individual, especially when situational control is limited (Hayes, 2016). In this characterization, activism may be a form of active coping in that collective action seeks to achieve gains in survival rates and treatment outcomes beyond those that have been attained in recent decades (Children’s Oncology Group, 2019; National Cancer Institute, 2018; Ward et al.,
Thus, the purpose of activism behaviors appears to be one of external problem-solving, not one of internal emotional coping.

It is unclear why activism was not significantly correlated with perceived meaning in life or depression, though there are some potential explanations. Regarding meaning, the current sample was primarily composed of parents of survivors while previous qualitative studies have focused on parents of bereaved children (Barerra et al., 2009; Meert et al., 2015). It is possible that parents whose children have survived cancer treatment may experience less of a need to derive meaning from the cancer experience than bereaved parents, but addressing this question was outside the scope of the current study.

Participants’ responses to open-ended questions provide some insight regarding the lack of an observed relationship between activism and depression: Activism was described as both rewarding and stressful. Specifically, parents endorsed experiencing a sense of purpose and community through activism, but exposure to reminders of trauma was repeatedly named as a source of stress. The diversity in parental experiences with activism is captured by the fact that some parents reported experiencing no personal benefits from activism, while some others reported a lack of activism-related stress. Qualitative analyses were outside the scope of the current study; however, the insights that can be gleaned from initial review of the open-ended responses contextualize quantitative findings in this emerging field of research.

**Modeling Activism and Well-Being**

The model of relationships between activism, treatment variables, and emotional well-being proposed in this study was not fully supported. Although hope, resilience, and present meaning in life were positively associated, there was no relationship between present meaning in life and activism. See Figure 4 for a visual representation of the results with the proposed model.
Although the proposed model was not fully supported, it does illustrate an interesting facet of the current findings: parents who were highly engaged in activism had both higher reports of hope and resilience and more health-related stressors via their children’s increased treatment types and perceived side effects. There are many possible explanations for this finding. One is that children who experience multiple side effects and forms of treatment are likely to spend significant amounts of time in the hospital, where families can receive increased exposure to other childhood cancer families. Such exposure may both inspire parents to help other children and provide them with opportunities to meet other parents who are engaged in activism.

Implications of the Current Study

Contributions

The current study illustrates that parents of children with cancer are both at risk for significant depression and capable of adapting to their circumstances. Parents who are hopeful
and oriented toward problem-solving are likely to participate in a variety of activism behaviors on behalf of children with cancer. Previously, activism among parents of children with cancer has been described exclusively in qualitative terms (Barrera et al., 2009; Meert et al., 2015; Molinaro & Fletcher, 2018; Patterson et al., 2004). The current study has generated quantitative data on the types of activism behaviors parents engage in most as well as demonstrated empirical relationships between higher levels of activism, hope, and resilience. Additionally, activism was also found to be positively associated with more parent-reported treatment types and side effects experienced by diagnosed children. Previously, objective measures of child treatment variables have been used when investigating coping in this population (Germann et al., 2015). The results of the current study indicate that parents’ subjective understanding of their child’s cancer experience is also relevant to their coping.

Although analyzing qualitative findings was outside the scope of the current study, parents’ open-ended responses provide some context to the quantitative findings. Parents qualitatively reported benefiting deeply from their experiences (see Table 11 in Appendix P for specific quotes). Some, but not all, parents also reported that activism is a significant source of stress. It is clinically relevant that parents reported that their activism efforts expose them to reminders of trauma, with some parents using “PTSD” to describe their experience of this problem. Additionally, reported burdens on time and energy are a significant concern given the taxing nature of cancer treatment and survivorship care. Among the many stressors that parents of children with cancer face, the struggles of advocating on behalf of their greater community may be overlooked. However, clinicians have a responsibility to appropriately assess and treat psychological distress within parents who have had a child diagnosed with cancer (Patenaude et al., 2015).
From a methodological standpoint, the current study demonstrated the efficacy of a novel, social media-based recruitment approach. Although the current study was underpowered, the sample was accrued in just five weeks at the cusp of the United States COVID-19 outbreak. By engaging in direct outreach to leaders in the childhood cancer community and pledging charitable contributions toward childhood cancer research, the primary investigator was able to generate organic (e.g., unpaid) sharing of study advertisements. At the peak of the recruitment process, 50 participants consented to participate within a 24-hour time period, 42 of whom were included in the final sample. To maximize the effectiveness of the social media-based recruitment approach, advertisement graphics were continuously modified during the course of recruitment to ensure that key information was displayed as prominently and attractively as possible. All modified materials were approved by the Human Subjects Research Committee (see Appendix A). These methodological innovations demand further future investigation.

**Limitations**

This study predominantly included female, White parents of pediatric cancer survivors, which limits the generalizability of these findings to other populations. Parents who are marginalized in several ways may not have as many resources to advocate specifically on behalf of children with cancer as parents who resemble the relatively well-resourced sample of the current study. It is unclear whether the high rate of participation in activism reported in this study is reflective of parents of children with cancer as a whole, as social media advertisements may have reached parents who are especially engaged in the childhood cancer community. Additionally, as this study is the first to quantitatively explore activism in this population, there is no prior literature to which findings can be compared.
A key limitation of this study is its cross-sectional design, which limits understanding of the directionality of findings. It is unclear whether psychologically healthy individuals are more drawn to activism or activism increases hope or resilience, or if both are true. Additionally, study recruitment was prematurely suspended, resulting in a sample size less than one-half of what was proposed. Although several study hypotheses were supported despite low sample size, the current study was underpowered to detect small effect sizes. As mentioned previously, depression was not found to correlate to activism. In the current study, depressive symptoms were the only dimension of distress that was measured. Because parents reported that activism can be associated with reminders of trauma, measuring trauma may have provided additional insight into parental experiences of distress.

An additional limitation to the generalizability of the current study’s findings is that several measures, including all measures of activism, were not validated (or they were modified from validated forms). The finding that hope for children with cancer did not relate to cancer-related activism may have occurred in part because the measures created for this study may not have appropriately captured the construct of interest. The current study relied on retrospective reports of the number of activism behaviors parents have completed (as opposed to, for example, the hours per week parents spend on activism), and alternative methods may yield different results. This study did not address how activism fluctuates over time or how parents balance perceived benefits and stresses of activism efforts, and these may have significant implications for the long-term role of activism as a coping strategy. Child treatment variables, such as the number of side effects parents perceived their children to have experienced, were used as a proxy for exposure to cancer-related stress in this study. The demographic questionnaire used in this study has not been used previously, although treatment variables have previously been
hypothesized to impact coping in this population (Germann et al., 2015; Turner-Sack et al., 2016). Overall, the limitations of the novel methods of measurement in this study need to be considered alongside the contributions of study findings.

**Future Directions**

Given that activism was positively associated with variables such as hopefulness, resilience, and active coping, this study provides support for developing and disseminating activism-based interventions for parents of children with cancer. In community settings such as hospitals and non-profit organizations, there are a variety of opportunities for parents to advocate on behalf of children with cancer (Alex’s Lemonade Stand Foundation, 2020; American Cancer Society, 2020; Mercy Health Foundation, 2020). In the current study, parents qualitatively reported having positive and meaningful experiences with advocating in conjunction with childhood cancer-related organizations. However, none of these programs have ever been investigated empirically to assess its potential as a treatment for parents. Because parents did qualitatively report activism-related distress, and because activism was not associated with lower depression levels, efforts to include parents in advocacy efforts need to be mindful of potential burdens. Given relatively low rates of participation in public speaking and community leadership within this sample, organizations should be especially sensitive to issues that may arise when asking parents to fulfill these roles. Some parents specifically suggested that organizations provide families with low-effort activism opportunities within their open-ended responses. That many parents of survivors have experienced reminders of traumatic events due to activism underscores the importance of trauma-informed care for family members long into the survivorship phase of the child’s treatment.
Conclusion

Childhood-cancer-related activism is significantly related to aspects of positive well-being among parents of children with cancer, specifically hope and resilience. The relationship between childhood-cancer-related activism and hopefulness exceeds what can be explained by general activism, indicating that advocating specifically for children with cancer has unique salience for parents whose children have been diagnosed with the disease. Participants in the current study reported universal engagement in cancer-related activism following their own child’s diagnosis. These findings support developing additional research initiatives to address questions that the current study could not answer. Namely, it is still unknown whether activism leads to increased well-being among parents of children with cancer or if greater well-being enables increased activism efforts. The qualitative data collected in the current study provides specific suggestions for ways to decrease the burden of activism that can be used to inform future research efforts. Overall, this study adds to a growing literature that illustrates both the resilience of families affected by childhood cancer and their need for targeted support.
References

Alex’s Lemonade Stand Foundation (2020). *Ambassador Program*.
https://www.alexslemonade.org/childhood-cancer/for-families/ambassadors-program

https://www.cancer.org/involved/fundraise/relay-for-life.html


https://doi.org/10.1097/NCC.0000000000000662


https://deepblue.lib.umich.edu/bitstream/handle/2027.42/51110/342.pdf?sequence=1&isAllowed=y


https://www.childrensoncologygroup.org/index.php/clinicaltrials-136


Hospital Anxiety and Depression Scale (HADS) and the 9-item Patient Health Questionnaire (PHQ-9) as screening instruments for depression in patients with cancer: Depression screening in oncology. *Cancer, 123*(21), 4236–4243.

https://doi.org/10.1002/cncr.30846


https://doi.org/10.1016/j.beth.2016.11.006


https://doi.org/10.1542/peds.2014-2855


Appendix A: Recruitment Materials

Social Media Post Images

Instagram Post Scripts:

“Hello! My name is Alexandra Neenan, and I am currently conducting the #ChildhoodCancerActivismSurvey as part of my Master’s Thesis at Eastern Michigan University. The goal of this online research study is to understand the role that activism plays in the lives of parents who have ever had a child diagnosed with cancer. If you are a part of this community, please consider completing this survey through the link in @alexandra.neenan Instagram bio. For every completed survey, my research team will donate $2 to childhood cancer research. We are seeking parents with a variety of experiences - from no activism to seasoned advocates. If you are reading this and know someone who may be eligible, please repost this message or post tagging @alexandra.neenan and #ChildhoodCancerActivismSurvey”
“Thank you to everyone who has taken or shared the #ChildhoodCancerActivismSurvey so far! For each response we receive, we are donating $2 to childhood cancer research. We are ultimately seeking 200 parents of childhood cancer fighters to share their experiences with us - any parent who has ever had a child diagnosed with cancer is able to participate. The survey link in @alexandra.neenan bio contains all of the information about our research study, which takes 15-20 minutes to complete.

#childhoodcancer #pediatriccancer #morethan4 #kidsgetcancertoo #gogold #childhoodcancerawareness #itsnotrare #goldribbon #pediatriccancerawareness”

“If you are a parent who has ever had a child diagnosed with cancer, please consider taking 15-20 minutes to complete an online research study! The link to participate is in @alexandra.neenan bio, and further information about the study is listed there.

#gogold #gogoldforchildhoodcancer #morethan4 #childhoodcancer #childhoodcancerawareness #childhoodcanceradvocate #pediatriccancer #pediatriccancerawareness #acutelymphoblasticleukemia #neuroblastomaawareness #neuroblastomawarrior #ewingssarcoma #dipg #dipgawareness #braintumorawareness #fightcancer #kickcancer #cancermom #cancermoms #cancerdad #cancer dads #cancersiblings #nomorecancer #kidsshouldnthavecancer”

“Thank you to all the parents who have volunteered to complete our survey so far! We are ultimately seeking 200 parents who have ever had a child diagnosed with cancer to complete this research study. For each complete response, we are donating $2 to childhood cancer research as an expression of appreciation for your time and insight. The link to participate is in @alexandra.neenan bio.

#gogold #gogoldforchildhoodcancer #morethan4 #childhoodcancer #childhoodcancerawareness #childhoodcanceradvocate #pediatriccancer #pediatriccancerawareness #acutelymphoblasticleukemia #neuroblastomaawareness #neuroblastomawarrior #ewingssarcoma #dipg #dipgawareness #braintumorawareness #fightcancer #kickcancer #cancermom #cancermoms #cancerdad #cancer dads #cancersiblings #nomorecancer #kidsshouldnthavecancer”

Facebook Post Scripts:

“If you are a parent who has ever had a child diagnosed with cancer, please consider taking 15-20 minutes to complete our online survey study. For every completed survey, the research team will donate $2 to childhood cancer research. The purpose of this study is to understand the role that activism plays in the lives of parents who have ever had a child diagnosed with cancer. We are seeking parents with a variety of experiences - from no activism to seasoned advocates. If you are reading this and know someone who may be able to participate, please share this link: https://redcap.emich.edu/redcap/surveys/?s=3HMTN4PMD7”

“Thank you to all the parents who have volunteered to complete our survey so far! We are ultimately seeking 200 parents who have ever had a child diagnosed with cancer to complete this research study. For each complete response, we are donating $2 to childhood cancer research as an expression of appreciation for your time and insight. The survey can be accessed here: https://redcap.emich.edu/redcap/surveys/?s=3HMTN4PMD7”
Appendix B: IRB Approval Letter

Feb 5, 2020 8:55 AM EST

Alexandra Neenan
Eastern Michigan University, Psychology

Re: Exempt - Initial - UHSRC-FY19-20-134 Activism as a Coping Strategy for Parents of Children with Cancer

Dear Alexandra Neenan:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for Activism as a Coping Strategy for Parents of Children with Cancer. You may begin your research.

Decision: Exempt

Selected Category: Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording). Any disclosure of the human subjects’ responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects’ financial standing, employability, educational advancement, or reputation.

Renewals: Exempt studies do not need to be renewed. When the project is completed, please contact human.subjects@emich.edu.

Modifications: Any plan to alter the study design or any study documents must be reviewed to determine if the Exempt decision changes. You must submit a modification request application in Cayuse IRB and await a decision prior to implementation.

Problems: Any deviations from the study protocol, unanticipated problems, adverse events, subject complaints, or other problems that may affect the risk to human subjects must be reported to the UHSRC. Complete an incident report in Cayuse IRB.

Follow-up: Please contact the UHSRC when your project is complete.

Please contact human.subjects@emich.edu with any questions or concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee
Appendix C: Demographics

1. What is your current age?

2. Which best describes your gender? Please select all that apply:
   - Male
   - Female
   - Non-binary/Genderqueer
   - Transgender
   - Not Otherwise Listed (please specify) __________

3. Which best describes your race or ethnicity? Please select all that apply:
   - White or Caucasian
   - Black or African American
   - Hispanic or Latino
   - Asian
   - Middle Eastern
   - American Native
   - Alaskan Native
   - Pacific Islander or Native Hawaiian
   - Biracial or Multiracial
   - Not Otherwise Listed (please specify) ________

4. Which best describes the highest education level you have obtained?
   - Less than high school
   - High school diploma or equivalent
   - Some College
   - Associate Degree or Trade Certification
   - Bachelor’s Degree
   - Master’s Degree
   - Doctoral or other Professional Degree
   - Not Otherwise Listed (please specify) ________

5. Which best describes your current relationship status?
Single
Married
Divorced
Widowed
In a committed non-marital relationship
Not Otherwise Listed (please specify) ________

6. How would you describe your family’s financial situation?
   We have enough to live comfortably
   Our needs are met, with a little left
   We have just enough to meet our basic needs, like food and housing
   We sometimes do not have enough to meet our basic needs, such as food and housing
   Not Otherwise Listed
   Prefer Not to Answer

7. Which best describes your child’s race or ethnicity? Please select all that apply:
   White or Caucasian
   Black or African American
   Hispanic or Latino
   Asian
   Middle Eastern
   American Native
   Alaskan Native
   Pacific Islander or Native Hawaiian
   Biracial or Multiracial
   Not Otherwise Listed (please specify) ________

8. At what age was your child diagnosed with cancer?

9. How long ago was your child diagnosed with cancer?
   0-3 months ago
   3-6 months ago
   6-9 months ago
   9-12 months ago
One year ago
Two years ago
Three years ago
Four years ago
5-10 years ago
More than ten years ago

10. Which best describes is your diagnosed child’s gender? Please select all that apply:
   - Male
   - Female
   - Non-binary/Genderqueer
   - Transgender
   - Not Otherwise Listed (please specify): ________

11. Which of these most accurately describes your child’s experience?
   - My child is not currently in remission/no evidence of disease and/or is receiving cancer treatment
   - My child is currently in remission/no evidence of disease and receives follow-up care only
   - My child is no longer alive

12. How old is your child currently? (question not shown to bereaved parents)

13. What kind(s) of cancer has your child been diagnosed with? Choose all that apply:
   - Acute Lymphocytic/Lymphoblastic Leukemia
   - Neuroblastoma
   - Other Leukemia or Lymphoma (please specify) _______
   - Brain or Central Nervous System Tumor (please specify) ______
   - Tumor outside the central nervous system (please specify) _________
   - Not Otherwise Listed (please specify) ________

14. What kinds of medical treatment has your child received in order to treat or cure their cancer? Choose all that apply:
   - Chemotherapy
   - Surgery
   - Radiation
Immunotherapy
Bone Marrow Transplant
Clinical trial of any kind
Not Otherwise Listed (please specify) _______

15. What kinds of long-term effects of cancer or its treatment have your child experienced?
   Choose all that apply:
   Physical impairment(s)
   Cognitive impairment(s)
   Organ damage
   Secondary cancer/Relapse
   Psychological Distress
   Not Otherwise Listed (please specify) ______

16. How satisfied are you with the treatment option(s) that were available for your child’s cancer?
   Highly dissatisfied
   Dissatisfied
   Neither satisfied nor dissatisfied
   Satisfied
   Highly satisfied
Appendix D: Activism Orientation Scale-Conventional Subscale

(Before Diagnosis instructions) *Please indicate if you participated in any of the following activities on behalf of a cause OTHER than childhood cancer BEFORE your child was diagnosed.*

(After Diagnosis instructions) *Please indicate if you participated in any of the following activities on behalf of a social or political cause OTHER than childhood cancer AFTER your child was diagnosed.*

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Display a poster or bumper sticker with a social or political message? yes/no</td>
</tr>
<tr>
<td>2.</td>
<td>Invite a friend to attend a meeting of a social or political organization or event? yes/no</td>
</tr>
<tr>
<td>3.</td>
<td>Purchase a poster, t-shirt, etc. that endorses a social or political point of view? yes/no</td>
</tr>
<tr>
<td>4.</td>
<td>Serve as an officer in a social or political organization? yes/no</td>
</tr>
<tr>
<td>5.</td>
<td>Attend an informational meeting of a social or political group? yes/no</td>
</tr>
<tr>
<td>6.</td>
<td>Organize a social or political event (e.g., talk, support group, march)? yes/no</td>
</tr>
<tr>
<td>7.</td>
<td>Give a lecture or talk about a social or political issue? yes/no</td>
</tr>
<tr>
<td>8.</td>
<td>Go out of your way to collect information on a social or political issue? yes/no</td>
</tr>
<tr>
<td>9.</td>
<td>Campaign door-to-door for a social political candidate? yes/no</td>
</tr>
<tr>
<td>10.</td>
<td>Present facts to contest another person’s social or political statement? yes/no</td>
</tr>
<tr>
<td>11.</td>
<td>Donate money to a political candidate? yes/no</td>
</tr>
<tr>
<td>12.</td>
<td>Vote in a non-presidential federal, state, or local election? yes/no</td>
</tr>
<tr>
<td>13.</td>
<td>Send a letter or e-mail expressing a social or political opinion to the editor of a periodical or television show? yes/no</td>
</tr>
<tr>
<td>14.</td>
<td>Confront jokes, statements, or innuendoes that opposed a particular group’s cause? yes/no</td>
</tr>
<tr>
<td>15.</td>
<td>Boycott a product for social or political reasons? yes/no</td>
</tr>
<tr>
<td>16.</td>
<td>Distribute information representing a particular social or political group’s cause? yes/no</td>
</tr>
<tr>
<td>17.</td>
<td>Send a letter or e-mail about a social or political issue to a public official? yes/no</td>
</tr>
<tr>
<td>18.</td>
<td>Attend a talk on a particular group’s social or political concerns? yes/no</td>
</tr>
<tr>
<td>19.</td>
<td>Attend a social or political organization’s regular planning meeting? yes/no</td>
</tr>
<tr>
<td>20.</td>
<td>Sign a petition for a social or political cause? yes/no</td>
</tr>
<tr>
<td>21.</td>
<td>Encourage a friend to join a social or political organization? yes/no</td>
</tr>
<tr>
<td>22.</td>
<td>Try to change a friend’s or acquaintance’s mind about a social or political issue? yes/no</td>
</tr>
</tbody>
</table>
23. Donate money to a political organization? yes/no

24. Try to change a relative’s mind about a social or political issue? yes/no

25. Wear a t-shirt or button with a political message? yes/no

26. Keep track of the views of members of Congress regarding an issue important to you? yes/no

27. Participate in discussion groups designed to discuss issues or solutions of a particular social or political group? yes/no

28. Campaign by phone for a political candidate? yes/no
Appendix E: Revised Activism Orientation Scale - Childhood Cancer Activism

(After Diagnosis instructions) For the purpose of this survey, "activism" refers to any action that serves to increase awareness or support for a social or political cause. We are interested in learning about the types of activism that parents of children with cancer may participate in on behalf of other diagnosed children. Please indicate if you participated in any of the following activities AFTER your child was diagnosed with cancer.

(Before Diagnosis instructions) We are also interested in learning about how a child's cancer diagnosis may impact the types of activities that parents participate in. Please indicate if you participated in any of the following activities BEFORE your child was diagnosed with cancer.

1. Displayed a poster or sign with messaging that promotes better treatment for children with cancer?
2. Worn clothing with messaging that promotes better treatment for children with cancer?
3. Attended a fundraiser or other advocacy event for children with cancer?
4. Invited a friend to attend a fundraiser or other advocacy event for children with cancer?
5. Purchased any item that references supporting childhood cancer patients or donates money to a childhood cancer related cause?
6. Created and/or served as a leader of an organization that helps children with cancer?
7. Led a project to benefit children with cancer (GoFundMe, in-person benefit, etc.)?
8. Given a lecture or speech about the importance of helping children with cancer?
9. Sought information about how to support the needs of children with cancer?
10. Donated money to an organization that helps children with cancer?
11. Donated directly to another family affected by pediatric cancer (e.g., donating to GoFundMe, attending a benefit event, etc.)?
12. Contacted a political leader or celebrity about an issue that relates to supporting children with cancer?
13. Shared information promoting better treatment for children with cancer in person?
14. Shared information promoting better treatment for children with cancer online?
15. Attended an event at which presentations or speeches including information on how to care for children with cancer were shared?
Appendix F: The Hope Scale

The Hope Scale

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1 = Definitely False  2 = Mostly False  3 = Mostly True  4 = Definitely True

1. I can think of many ways to get out of a jam. (Pathways)
2. I energetically pursue my goals. (Agency)
3. I feel tired most of the time. (Filler)
4. There are lots of ways around any problem. (Pathways)
5. I am easily downed in an argument. (Filler)
6. I can think of many ways to get the things in life that are most important to me. (Pathways)
7. I worry about my health. (Filler)
8. Even when others get discouraged, I know I can find a way to solve the problem. (Pathways)
9. My past experiences have prepared me well for my future. (Agency)
10. I’ve been pretty successful in life. (Agency)
11. I usually find myself worrying about something. (Filler)
12. I meet the goals that I set for myself. (Agency)
Appendix G: Measure of Hope for Other Children with Cancer

How strong is your belief that there will be cures for all childhood cancers someday? 1 (extremely weak), 2 (very weak), 3 (weak), 4 (average), 5 (strong), 6 (very strong), 7 (extremely strong)

How important is that belief to you and your family? 1 (not at all important), 2 (minimally important), 3 (somewhat important), 4 (moderately important), 5 (important), 6 (very important), 7 (extremely important)
Appendix H: Connor Davidson Resilience Scale–10 Item

For each of the statements below, please rate how it applies to you: not true at all (0), rarely true (1), sometimes true (2), often true (3), true nearly all of the time (4).

1. Able to adapt to change
2. Can deal with whatever comes
3. Tries to see humorous side of problems
4. Coping with stress can strengthen me
5. Tend to bounce back after illness or hardship
6. Can achieve goals despite obstacles
7. Can stay focused under pressure
8. Not easily discouraged by failure
9. Thinks of self as strong person
10. Can handle unpleasant feelings
Appendix I: Meaning In Life Questionnaire

Please take a moment to think about what makes your life feel important to you. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

Absolutely
Untrue (1), Mostly Untrue (2), Somewhat Untrue (3), Can’t Say True or False (4), Somewhat True (5), Mostly True (6), Absolutely True (7)

1. I understand my life’s meaning.
2. I am looking for something that makes my life feel meaningful.
3. I am always looking to find my life’s purpose.
4. My life has a clear sense of purpose.
5. I have a good sense of what makes my life meaningful.
6. I have discovered a satisfying life purpose.
7. I am always searching for something that makes my life feel significant.
8. I am seeking a purpose or mission for my life.
9. My life has no clear purpose.
10. I am searching for meaning in my life.

MLQ syntax to create Presence and Search subscales:
Presence  1, 4, 5, 6, & 9-reverse-coded
Search  2, 3, 7, 8, & 10
Appendix J: The COPE

Please consider each of the following statements and rate how each applies to you: (1) “I usually don't do this at all,” (2) "I usually do this a little bit," (3) "I usually do this a medium amount,” and (4) "I usually do this a lot.”

Active coping

I take additional action to try to get rid of the problem.
I concentrate my efforts on doing something about it.
I do what has to be done, one step at a time.
I take direct action to get around the problem.

Planning

I try to come up with a strategy about what to do.
I make a plan of action.
I think hard about what steps to take.
I think about how I might best handle the problem.

Suppression of competing activities

I put aside other activities in order to concentrate on this.
I focus on dealing with this problem, and if necessary let other things slide a little.
I keep myself from getting distracted by other thoughts or activities.
I try hard to prevent other things from interfering with my efforts at dealing with this.

Focus on & venting of emotions

I get upset and let my emotions out.
I let my feelings out.
I feel a lot of emotional distress and I find myself expressing those feelings a lot.
I get upset, and am really aware of it.

Seeking social support for instrumental reasons

I ask people who have had similar experiences what they did.
I try to get advice from someone about what to do.
I talk to someone to find out more about the situation.
I talk to someone who could do something concrete about the problem.
Seeking social support for emotional reasons
I talk to someone about how I feel.
I try to get emotional support from friends or relatives.
I discuss my feelings with someone.
I get sympathy and understanding from someone.

Restraint coping
I force myself to wait for the right time to do something.
I hold off doing anything about it until the situation permits.
I make sure not to make matters worse by acting too soon.
I restrain myself from doing anything too quickly.

Positive reinterpretation & growth
I look for something good in what is happening.
I try to see it in a different light, to make it seem more positive.
I learn something from the experience.
I try to grow as a person as a result of the experience.

Acceptance
I learn to live with it.
I accept that this has happened and that it can't be changed.
I get used to the idea that it happened.
I accept the reality of the fact that it happened.

Turning to religion
I seek God's help.
I put my trust in God.
I try to find comfort in my religion.
I pray more than usual.

Denial
I refuse to believe that it has happened.
I pretend that it hasn't really happened.
I act as though it hasn't even happened.
I say to myself "this isn't real."
Behavioral disengagement
I give up the attempt to get what I want.
I just give up trying to reach my goal.
I admit to myself that I can't deal with it, and quit trying.
I reduce the amount of effort I'm putting into solving the problem.

Mental disengagement
I turn to work or other substitute activities to take my mind off things.
I go to movies or watch TV, to think about it less.
I daydream about things other than this.
I sleep more than usual.
Appendix K: Patient Health Questionnaire-9

For each of the following, please rate how much it has bothered you over the past two weeks: 0 (not at all), 1 (several days), 2 (more than half the days), 3 (nearly every day)

1. Little interest or pleasure in doing things
2. Feeling down, depressed, or hopeless
3. Trouble falling or staying asleep, or sleeping too much
4. Feeling tired or having little energy
5. Poor appetite or overeating
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down
7. Trouble concentrating on things, such as reading the newspaper or watching television
8. Moving or speaking so slowly that other people could have noticed. Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual
9. Thoughts that you would be better off dead, or of hurting yourself

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not at all difficult
Somewhat difficult
Very difficult
Extremely difficult
Appendix L: Open-Ended Comments on Childhood-Cancer-Related Activism

1. How long after diagnosis did you get involved in childhood-cancer-related activism?

2. Why did you get involved in activism on behalf of children with cancer?

3. What personal benefits have you experienced through activism, if any?

4. Have other family members, including your children, participated in activism? If so, have they experienced any benefits?

5. What kinds of stress are associated with your activism efforts?

6. Do you think medical staff should encourage families to get involved in local activism efforts that benefit children with cancer? Why or why not?

7. Is there anything else you would like us to know about the role that activism plays in your family’s efforts to cope with pediatric cancer?
Appendix M: Means and Standard Deviations Across Treatment Phases

Table 8

Means, Standard Deviations, and Analysis of Variance for Key Study Variables Across Treatment Phases

<table>
<thead>
<tr>
<th>Measure</th>
<th>In Treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>F (df)</td>
<td>η²</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PDCRA</td>
<td>11.38</td>
<td>3.74</td>
<td>10.06</td>
<td>3.03</td>
<td>9.67</td>
<td>3.67</td>
<td>0.69 (2, 64)</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOS-C (After)</td>
<td>8.14</td>
<td>9.14</td>
<td>10.40</td>
<td>9.16</td>
<td>7.00</td>
<td>4.36</td>
<td>0.36 (2, 52)</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PrDCRA</td>
<td>6.88</td>
<td>3.98</td>
<td>3.53</td>
<td>4.16</td>
<td>4.50</td>
<td>1.38</td>
<td>2.49 (2, 64)</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AOS-C (Before)</td>
<td>12.43</td>
<td>9.59</td>
<td>8.67</td>
<td>7.41</td>
<td>6.00</td>
<td>3.61</td>
<td>1.00 (2, 55)</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AHS</td>
<td>28.00</td>
<td>3.12</td>
<td>24.68</td>
<td>3.39</td>
<td>20.67</td>
<td>4.32</td>
<td>7.79** (2, 64)</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD-RISC-10</td>
<td>30.62</td>
<td>4.41</td>
<td>26.96</td>
<td>6.58</td>
<td>22.60</td>
<td>9.86</td>
<td>2.29 (2, 62)</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MLQ-P</td>
<td>23.63</td>
<td>2.67</td>
<td>20.41</td>
<td>5.26</td>
<td>17.20</td>
<td>7.63</td>
<td>2.43 (2, 59)</td>
<td>.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MLQ-S</td>
<td>15.00</td>
<td>5.78</td>
<td>18.59</td>
<td>5.00</td>
<td>13.60</td>
<td>7.20</td>
<td>3.26* (2, 59)</td>
<td>.10</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active Coping</td>
<td>40.88</td>
<td>5.30</td>
<td>34.69</td>
<td>5.70</td>
<td>30.25</td>
<td>6.60</td>
<td>5.65** (2, 57)</td>
<td>.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SSEFC</td>
<td>33.88</td>
<td>7.38</td>
<td>31.96</td>
<td>7.73</td>
<td>30.25</td>
<td>8.18</td>
<td>0.34 (2, 57)</td>
<td>.01</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Avoidant Coping</td>
<td>19.38</td>
<td>5.01</td>
<td>20.46</td>
<td>5.32</td>
<td>24.5</td>
<td>6.25</td>
<td>1.27 (2, 57)</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PHQ-9</td>
<td>8.83</td>
<td>4.96</td>
<td>8.82</td>
<td>6.41</td>
<td>12.33</td>
<td>11.37</td>
<td>0.41 (2, 50)</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Side Effects</td>
<td>2.00</td>
<td>1.60</td>
<td>1.47</td>
<td>1.31</td>
<td>1.83</td>
<td>1.33</td>
<td>0.66 (2, 64)</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Types</td>
<td>2.00</td>
<td>1.31</td>
<td>2.30</td>
<td>1.10</td>
<td>3.33</td>
<td>1.21</td>
<td>2.68 (2, 64)</td>
<td>.08</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TSD (Months)</td>
<td>13.50</td>
<td>15.87</td>
<td>68.02</td>
<td>38.45</td>
<td>42.00</td>
<td>39.25</td>
<td>13.09*** (2, 63)</td>
<td>.29</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Strength of Hope</td>
<td>4.83</td>
<td>1.47</td>
<td>4.30</td>
<td>1.36</td>
<td>5.67</td>
<td>1.16</td>
<td>1.72 (2, 50)</td>
<td>.06</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance of Hope</td>
<td>6.67</td>
<td>0.82</td>
<td>5.57</td>
<td>1.76</td>
<td>6.67</td>
<td>0.58</td>
<td>1.65 (2, 50)</td>
<td>.06</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>41.25</td>
<td>5.65</td>
<td>43.00</td>
<td>8.96</td>
<td>43.00</td>
<td>10.47</td>
<td>0.14 (2, 64)</td>
<td>.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. PDRCA = Post-Diagnosis Cancer-Related Activism. AOS-C = Activism Orientation Scale. PrDCRA = Pre-Diagnosis Cancer-Related Activism. AHS = Adult Hope Scale. CD-RISC-10 = Connor-Davidson Resilience Scale, 10-item. MLQ-P = Meaning In Life Questionnaire, Presence Subscale. MLQ-S = Meaning In Life Questionnaire, Search Subscale. SSEFC = Socially Supported/Emotion-focused Coping. TSD = Time Since Diagnosis. *p < .05, two tailed. **p < .01, two-tailed. ***p < .001, two-tailed.
Appendix N: Correlations for Primary Hypotheses–Posttreatment Parents Only

Table 9

Primary Correlation Analyses for Primary Hypothesis 1, Primary Hypothesis 2, and Exploratory Hypothesis 3 – Posttreatment Parents Only

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDCRA (n = 53)</td>
<td>10.06</td>
<td>3.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. AHS (n = 53)</td>
<td>24.68</td>
<td>3.39</td>
<td>.46***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. CD-RISC (n = 52)</td>
<td>26.96</td>
<td>6.58</td>
<td>.39**</td>
<td>.79***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. MLQ-P (n = 49)</td>
<td>20.40</td>
<td>5.26</td>
<td>.24</td>
<td>.55***</td>
<td>.36**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. MLQ-S (n = 49)</td>
<td>18.59</td>
<td>5.00</td>
<td>.17</td>
<td>-.01</td>
<td>.15</td>
<td>.35*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Active Coping (n = 48)</td>
<td>34.69</td>
<td>5.70</td>
<td>.54***</td>
<td>.52***</td>
<td>.36*</td>
<td>.24</td>
<td>.20</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. SSEFC (n = 48)</td>
<td>31.96</td>
<td>7.73</td>
<td>.22</td>
<td>.18</td>
<td>.24</td>
<td>-.11</td>
<td>.33*</td>
<td>.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Avoidant Coping (n = 48)</td>
<td>34.69</td>
<td>5.70</td>
<td>-.25</td>
<td>-.39**</td>
<td>-.44**</td>
<td>-.49***</td>
<td>.16</td>
<td>-.20</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PHQ-9 (n = 44)</td>
<td>8.81</td>
<td>6.41</td>
<td>-.15</td>
<td>-.44***</td>
<td>-.48**</td>
<td>-.57***</td>
<td>.36*</td>
<td>-.02</td>
<td>.56***</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Treatment Types (n = 53)</td>
<td>2.30</td>
<td>1.10</td>
<td>.27*</td>
<td>.15</td>
<td>.07</td>
<td>.01</td>
<td>.25</td>
<td>.17</td>
<td>-.15</td>
<td>.33</td>
<td>.24</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Side Effects (n = 53)</td>
<td>1.47</td>
<td>1.31</td>
<td>.25</td>
<td>.08</td>
<td>-.01</td>
<td>-.23</td>
<td>.28</td>
<td>.28</td>
<td>-.03</td>
<td>.20</td>
<td>.26</td>
<td>.37**</td>
<td></td>
</tr>
<tr>
<td>12. TSD (Months) (n = 52)</td>
<td>68.01</td>
<td>38.45</td>
<td>.20</td>
<td>.15</td>
<td>-.02</td>
<td>.13</td>
<td>-.13</td>
<td>.21</td>
<td>-.31*</td>
<td>.07</td>
<td>.16</td>
<td>.41**</td>
<td>.31*</td>
</tr>
</tbody>
</table>

*Note.* Analyses are presented for posttreatment parents only to allow comparison between results of posttreatment parents and the full sample. PDCRA = Post-Diagnosis Cancer-Related Activism. AHS = Adult Hope Scale. CD-RISC = Connor Davidson Resilience Scale – 10 Item. MLQ-P = Meaning In Life Questionnaire, Presence Subscale. MLQ-S = Meaning In Life Questionnaire, Search Subscale. SSEFC = Socially Supported/Emotion-focused Coping. PHQ-9 = Patient Health Questionnaire – 9 Item. TSD = Time Since Diagnosis. *p < .05, two-tailed. **p < .01, two-tailed. ***p < .001, two-tailed.
### Appendix O: Correlations for Regression Analyses—Posttreatment Parents Only

#### Table 10

**Preliminary Correlations for Planned Hierarchical Regression Analyses – Posttreatment Parents Only**

<table>
<thead>
<tr>
<th>Variable</th>
<th>$M$</th>
<th>$SD$</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. PDCRA ($n = 53$)</td>
<td>10.06</td>
<td>3.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. AHS ($n = 53$)</td>
<td>24.68</td>
<td>3.39</td>
<td>.46***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Active Coping ($n = 48$)</td>
<td>34.69</td>
<td>5.70</td>
<td>.54***</td>
<td>.52***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. SSEFC ($n = 48$)</td>
<td>31.96</td>
<td>7.73</td>
<td>.22</td>
<td>.18</td>
<td>.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Avoidant Coping ($n = 48$)</td>
<td>20.46</td>
<td>5.32</td>
<td>-.25</td>
<td>-.39**</td>
<td>-.20</td>
<td>.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Treatment Types ($n = 53$)</td>
<td>2.30</td>
<td>1.10</td>
<td>.27*</td>
<td>.15</td>
<td>.17</td>
<td>-.16</td>
<td>.33*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Side Effects ($n = 53$)</td>
<td>1.47</td>
<td>1.31</td>
<td>.25</td>
<td>.08</td>
<td>.28</td>
<td>-.03</td>
<td>.20</td>
<td>.37**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. PrDCRA ($n = 53$)</td>
<td>3.53</td>
<td>4.16</td>
<td>.21</td>
<td>.10</td>
<td>.21</td>
<td>.01</td>
<td>.44**</td>
<td>.10</td>
<td>-.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. PrDGA ($n = 48$)</td>
<td>8.67</td>
<td>7.41</td>
<td>.18</td>
<td>.31*</td>
<td>.16</td>
<td>.14</td>
<td>.01</td>
<td>.19</td>
<td>.04</td>
<td>.03</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. PDGA ($n = 45$)</td>
<td>10.40</td>
<td>9.16</td>
<td>.41**</td>
<td>.51**</td>
<td>.42**</td>
<td>.10</td>
<td>-.05</td>
<td>.29</td>
<td>.19</td>
<td>-.01</td>
<td>.77***</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Strength of Hope ($n = 44$)</td>
<td>4.30</td>
<td>1.36</td>
<td>.30*</td>
<td>.16</td>
<td>.01</td>
<td>-.38*</td>
<td>-.08</td>
<td>-.02</td>
<td>-.36**</td>
<td>-.04</td>
<td>.09</td>
<td>.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Importance of Hope ($n = 44$)</td>
<td>5.57</td>
<td>1.76</td>
<td>.11</td>
<td>.15</td>
<td>-.13</td>
<td>-.06</td>
<td>.02</td>
<td>-.08</td>
<td>-.23</td>
<td>.06</td>
<td>-.22</td>
<td>-.04</td>
<td>.30*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Age ($n = 53$)</td>
<td>43.00</td>
<td>8.96</td>
<td>.11</td>
<td>-.01</td>
<td>.02</td>
<td>-.12</td>
<td>-.14</td>
<td>.04</td>
<td>.03</td>
<td>-.13</td>
<td>-.08</td>
<td>.11</td>
<td>.03</td>
<td>-.12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Female Gender ($n = 53$)</td>
<td>NA</td>
<td>NA</td>
<td>-.16</td>
<td>.07</td>
<td>-.17</td>
<td>.29*</td>
<td>.04</td>
<td>-.23</td>
<td>.03</td>
<td>-.13</td>
<td>-.14</td>
<td>-.26</td>
<td>-.28</td>
<td>.14</td>
<td>-.40**</td>
<td></td>
</tr>
<tr>
<td>15. Non-Hispanic White Race /Ethnicity ($n = 53$)</td>
<td>NA</td>
<td>NA</td>
<td>.14</td>
<td>.03</td>
<td>.04</td>
<td>.10</td>
<td>.01</td>
<td>.17</td>
<td>.16</td>
<td>-.08</td>
<td>-.01</td>
<td>NA*</td>
<td>NA*</td>
<td>NA*</td>
<td>.14</td>
<td>-.03</td>
</tr>
</tbody>
</table>
Note. Analyses are presented for posttreatment parents only to allow comparison between results of posttreatment parents and the full sample. PDCRA = Post-Diagnosis Cancer-Related Activism. AHS = Adult Hope Scale. SSEFC = Socially Supported/Emotion-focused Coping. PrDCRA = Pre-Diagnosis Cancer-Related Activism. PrDGA = Pre-Diagnosis General Activism. PDGA = Post-Diagnosis General Activism. *p < .05, two tailed. aCould not be computed because only non-Hispanic White participants responded to the question(s). **p < .01, two-tailed. ***p < .001, two-tailed.
### Appendix P: Selected Quotes from Qualitative Data

**Table 11**

*Emergent Themes from Qualitative Data*

<table>
<thead>
<tr>
<th>Question (n) / Theme (n)</th>
<th>Example Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How long after diagnosis did you get involved in childhood-cancer-related activism? (39)</strong></td>
<td>“Immediately!” – parent of survivor</td>
</tr>
<tr>
<td>Very soon after diagnosis (23)</td>
<td>“Right away.” – parent of survivor</td>
</tr>
<tr>
<td><strong>Why did you get involved in activism on behalf of children with cancer? (39)</strong></td>
<td>“Because I never want anyone to have to go through what my [child] has endured.” – parent of survivor</td>
</tr>
<tr>
<td>Desire to improve medical treatment for other children with cancer (15)</td>
<td>“To help my child and [others] have a better outlook, more treatment options.” – bereaved parent</td>
</tr>
<tr>
<td>Desire to raise awareness for the struggles of pediatric cancer patients and their families (9)</td>
<td>“To inform people not [familiar] with this situation.” – parent of survivor</td>
</tr>
<tr>
<td>Coping with individual experience (5)</td>
<td>“To help people understand the world in which I was trying to survive in and to be a voice for the children who were suffering from cancer.” – parent of survivor</td>
</tr>
<tr>
<td><strong>What personal benefits have you experienced through childhood-cancer-related activism, if any? (35)</strong></td>
<td>“I felt so helpless that I couldn't physically attack what was attacking my child. Activism was a way I could fight back for my child.” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“To help my son and get a better understanding of my beliefs.” – parent of survivor</td>
</tr>
<tr>
<td>Question (n) / Theme (n)</td>
<td>Example Quotes</td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Experiencing connection with the greater childhood cancer community (9)</td>
<td>“A community of people that understand what we were going through.” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“I have felt strength come from activism and found support from other activists and found purpose.” – parent of survivor</td>
</tr>
<tr>
<td>Experiencing connection with the greater childhood cancer community (9)</td>
<td>“A community of people that understand what we were going through.” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“I have felt strength come from activism and found support from other activists and found purpose.” – parent of survivor</td>
</tr>
<tr>
<td>Sense of contributing to a greater cause (20)</td>
<td>“Feeling like my son didn't suffer for nothing, but instead was a crucial part in paving a way to better treatment options for future children.” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“A renewed purpose to live while we find a cure for childhood cancer.” – parent of child in treatment</td>
</tr>
<tr>
<td>Lack of perceived personal benefits (6)</td>
<td>“None that I can think of” - parent of survivor</td>
</tr>
<tr>
<td>Have other family members, including your children, participated in activism? If so, have they experienced any benefits? (38)</td>
<td>“[My family members] feel empowered and love to encourage others.” – parent of survivor</td>
</tr>
<tr>
<td>Benefits are similar across family members (19)</td>
<td>“No.” – parent of survivor</td>
</tr>
<tr>
<td>Low family engagement in activism (8)</td>
<td>“[Talking] to families going through earlier stages of the journey can be a little traumatic - stark reminder of very dark difficult days I might wish I could forget.” – parent of survivor</td>
</tr>
<tr>
<td>What kinds of stress are associated with your childhood-cancer-related activism efforts? (36)</td>
<td>“I don't find it stressful just sometimes disappointed as many people seem to [turn] a blind eye and would rather pretend it doesn't happen.” – parent of survivor</td>
</tr>
<tr>
<td>Exposure to reminders of traumatic events and other cancer-related experiences (10)</td>
<td></td>
</tr>
<tr>
<td>Question (n) / Theme (n)</td>
<td>Example Quotes</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Demands on time, energy, and relationships (8)</td>
<td>“[Right] now is just making time and having money to contribute.” – parent of child in treatment</td>
</tr>
<tr>
<td></td>
<td>“Just time away from other responsibilities.” – parent of survivor</td>
</tr>
<tr>
<td>Minimal activism-related stress (12)</td>
<td>“Not nearly as much as the actual cancer treatments.” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“None that I can think of.....it has given me a new mission in life.” – parent of survivor</td>
</tr>
<tr>
<td>Do you think medical staff should encourage families to get involved in local activism efforts that benefit children with cancer? Why or why not? (38)</td>
<td></td>
</tr>
<tr>
<td>Agree (14)</td>
<td>“Yes, they have an outlet for [their] worries.” – parent of survivor</td>
</tr>
<tr>
<td>Disagree (11)</td>
<td>“No. The medical staff is there to fight the cancer and to support the family through a horrible time. Battling cancer is exhausting and overwhelming...suggesting that families should have to do something else on top of that is inappropriate and would have made me feel angry.” – parent of survivor</td>
</tr>
<tr>
<td>Agree, with reservations (12)</td>
<td>“Depends on the person... the age of the parent, their life experiences, etc. and what they think the parent can gain from the experience. Some events are simple, like show up or walk ... but to share personal stories and advocate publicly is too emotional for some parents and that is ok.” – parent of child in treatment</td>
</tr>
<tr>
<td>Is there anything else you would like us to know about the role that activism plays in your family's efforts to cope with pediatric cancer? (23)</td>
<td></td>
</tr>
<tr>
<td>Activism impacts long-term coping with the cancer experience (8)</td>
<td>“We will continue to be active in pediatric cancer activism for the rest of our lives” – parent of survivor</td>
</tr>
<tr>
<td></td>
<td>“Our [child] has seen and met so many other kids with cancer through these cancer groups. [My child] wants to major in bioengineering to make more effective chemos with less side effects - and [my child] wants to do it for kids.” – parent of survivor</td>
</tr>
<tr>
<td>Minimal additional feedback (8)</td>
<td>“No.” – parent of survivor</td>
</tr>
</tbody>
</table>