

## **Abstract**

As the rates of cancer diagnoses and the age of parenthood simultaneously rise, the impact of cancer on the family as a unit, particularly on adolescent children, becomes an emerging interest. Guided by stress and coping theory and family resiliency theory, this study used mixed-methods to examine the relationships between adolescent's (a) perceived stress of parental cancer in relation to specific coping strategies, (b) perceived stress of parental cancer and psychosocial functioning, and (c) use of specific coping strategies relative to psychosocial functioning. The study used a sample of 26 primary caregivers completing surveys and six primary caregivers of 11-17-year-olds being interviewed across the United States (mostly White mothers) regarding their child's experience with parental cancer. Quantitative analyses found perceived stress was significantly associated with total psychosocial functioning concern, attention, and internalizing behaviors. There were also significant associations between dimensions of psychosocial functioning concern with disengagement coping, involuntary engagement coping, and involuntary disengagement coping. Lastly, there were also significant correlations between perceived stress and disengagement coping, involuntary engagement coping, and involuntary disengagement coping. The themes that emerged from the qualitative interviews involved compounding of stressful circumstances, behavioral and mental health concerns, importance of social support for coping, and intentional disclosure of information related to cancer. Findings enhance our understanding of adolescent coping behaviors and psychosocial functioning related to familial-level stressors and also potentially for interventional efforts geared towards reducing stressors and improving mental health outcomes of adolescents living with parental cancer.

*Keywords:* parental cancer, stress, coping, psychosocial functioning, adolescents

# PSYCHOSOCIAL WELL-BEING OF YOUTH IMPACTED BY PARENTAL CANCER

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## CHAPTER I. INTRODUCTION

In 2019, it was estimated that there were approximately 1.8 million new cases of cancer diagnosed in the United States alone (Ward et al., 2019). As of 2020, malignant cancer continues to prevail as the second leading cause of death among Americans, so the number of children who have lived with a parent who is deceased from cancer may be exponentially greater (Murphy et al., 2021). Although mothers and fathers of typical childrearing age between 20-49 years old account for only about 20% of all cancer cases in the United States, there are several additional considerations that warrant increased attention to this demographic group (Ward et al., 2019). Namely, the “burden of cancer” and “person-years of life” are identified risks that pose potentially greater concern among the cohort of 20-49-year-olds diagnosed with cancer (Ward et al., 2019). Moreover, the incidence rates of cancer tend to increase with age, while the age of first-time parents in the United States continues to rise as well (Morse, 2022).

Estimates suggest that at least 3 million children in the United States are impacted by a parental cancer diagnosis within their family systems (Inhestern et al. 2021; Weaver 2010; Chernichky-Karcher, 2017). Correspondingly, an estimated 2.85 million children were projected to be living with at least one parent diagnosed with cancer (Weaver et al., 2010). Despite the sizeable number of children impacted by this presumably life-changing situation, limited empirical data illuminate how cancer impacts the family as a unit and how to meet their distinct needs (Krattenmacher, et al., 2012; Osborn, 2007; Huizinga, 2005, Shah et al., 2017; Faulkner & Davey, 2002). Population level data in the United States about children who live with a parent diagnosed with cancer also remains scant. Studies collecting this data in Norway, Finland, Germany, Japan, and Australia all indicate the need for increased understanding of how youth cope with their parent’s cancer diagnosis (Martini et al., 2019; Syse et al., 2012; Niemelä et al.,



2012; Inoue et al., 2015 Barkmann et al., 2007). One Australian study that interviewed health professionals about the psychosocial care provided to children during their parent's cancer treatment further echoes those of previous reports of global population studies on the need to pay far more attention to the offspring living with parental cancer. It was reported that health professionals regraded the children of adult cancer patients as fairly non-existent and described them as "invisible" in their parent's treatment process (Alexander et al., 2020).

Given the possible situational and developmental differences of how youth, adolescents, and a parent manages their cancer diagnosis, there is greater need to analyze the psychosocial impact of cancer on the family. More specifically, how a parent's cancer diagnosis may influence a child's well-being is still not abundantly clear (Morris, et al., 2018). A recent literature review indicates that anywhere from 2.5% to 24% of minors who have a parent with cancer are impacted "with a substantial psychosocial burden" (Inhestern et al., 2021). Relatedly, the impact of adverse childhood experiences (ACEs) on family stability and later developmental outcomes has been discussed at length over the last 30 years (Jones, et al., 2020). For instance, ACEs are associated with abuse/neglect, moving frequently, food insecurity, familial suicide, stress, and maladaptive coping behaviors in youth (Centers for Disease Control and Prevention, 2021). Although parental cancer is not typically labeled as an ACE, it could feasibly contribute to the stress associated with preestablished ACEs and provide similar psychosocial challenges that are associated with taxing family situations.

The existing literature, though limited, finds that a cancer diagnosis can result in negative influences on associated family members (Morris et al., 2018; Huizinga, 2005; Huang et al., 2014; Kristjanson & Ashcroft, 1994). However, few studies have delved into how youth cope with the stress of their parent's cancer diagnosis. There is also limited information on the quality

of life and the potential array of psychosocial symptoms and feelings that can accompany their parent's diagnosis. A review by Inhestern et al. (2021) found the risks of mental health concerns within this population was rather varied. There was little to no consistency in associations between quality of life and other well-being factors, especially in terms of comparisons to control groups, which likely merits further investigation into the psychosocial functioning of children living with parental cancer (Inhestern et al., 2021).

That said, it is not well understood how much an adolescent's mental health status is directly impacted when a family member and particularly a parent has cancer. It is relatively well-known that the current rates of mental health disorders are on the rise among adolescents living in the United States. Some estimates suggest that at least 49.5% of all U.S. adolescents ages 13-18 are diagnosed with a mental health disorder (National Institute of Mental Health, 2023). For those youth facing mental health challenges, is unclear how stress accumulates in specific relation to a parental cancer experience – even though parental cancer could feasibly fall into the ACES risk factor of “household challenges.” It is also unclear which coping skills are most effective to combat the negative implications of this stress and which coping methods for youth and adolescents are most adaptive in managing familial stress and any potential indicators of psychosocial distress. In a study regarding coping of adolescents living with parental cancer in Germany, it was found that the associations between “better functioning” of adolescents and use of emotion-focused coping strategies was more constructive than the use of avoidance-oriented ones (Krattenmacher et al., 2012). These findings were also reiterated in another study of adolescents who either lived in low resource communities and/or were orphaned due to AIDS or other causes in South Africa, which could be informative to understanding how parental health status/absence in general informs different coping responses. Among the adolescents in this

study, those who used avoidant coping strategies had higher rates of general psychological difficulties (Asanbe et al., 2022). However, there is also prevalent concern that the measurement of coping along these dimensions does not fully capture a full picture of the relationship between stress and coping and that a multidimensional model of stress and coping would be better suited to address that issue (Miller, 2008). These findings point to the need to further determine the associations between the stress burden, mental health outcomes and related coping processes of living with parental cancer.

Prior studies on the psychosocial difficulties associated with a parent's cancer diagnosis and the constructs used to assess psychosocial functioning in youth vary in methodology. Previous assessments of psychosocial functioning in children impacted by parental cancer mostly focus on internalizing and externalizing behaviors, depression, anxiety, health-related quality-of-life, and unmet needs (Krattenmacher et al., 2012). A general conclusion drawn is that there are probable negative implications for youth living with a parent diagnosed with cancer (Patterson et al., 2017). Other factors associated with children's psychosocial adjustment to parental cancer include age/gender of the child, timing of major life events of the parent's cancer (i.e., being diagnosed, changes in prognosis, death), family functioning, and even possible positive aspects of the parent's diagnosis as well (Bultmann et al., 2014). There is also a noticeable lack of quantitative evidence specifically regarding mental health symptomology in youth and specific stress and adjustment associated with having a parent with cancer.

Less information is available regarding the specific stress and coping mechanisms of youth grappling with a parent's cancer diagnosis, especially as considered from an adolescent developmental standpoint (Eschenbeck et al., 2018). Collecting data from parents and/or their offspring would assist in mapping differences in stress and coping strategies between parent and

children in response to a parental cancer diagnosis (Alexander et al., 2019; Krattenmacher et al., 2012). Furthermore, the use of perspectives outlined in stress and coping models in conjunction with family resiliency frameworks and theoretical understanding of adolescent development from a psychosocial standpoint could certainly enhance our understanding of the coping processes in youth and adolescents.

The current study seeks to address the gaps regarding the psychosocial well-being of youth who have experienced living with a parent diagnosed with cancer. Psychosocial well-being as well as stress and coping directly related to the parent's cancer diagnosis were assessed. By combining quantitative and qualitative methodological approaches, this study sought to determine perceived stress, coping strategies, and psychosocial indicators of mental health disorders of adolescents who have experienced parental cancer. The study is guided by two main conceptual frameworks: stress and coping and family resiliency (Connor-Smith et al., 2000, Lazarus, 1991;1993; 1994; Henry et al., 2015). Findings from this study will expand the quantitative and qualitative data available regarding psychosocial outcomes of adolescent's experiences of stress and coping with parental cancer. Therefore, the goals of the study are to further understand adolescent's a) perceived stress of parental cancer in relation to specific coping strategies, b) perceived stress of parental cancer and psychosocial functioning, and c) use of specific coping strategies relative to psychosocial functioning.

In the next chapter, relevant research is presented on offspring's experiences of managing a parent's cancer journey. Chiefly, the psychological well-being of children navigating the lived experiences through their parent's cancer regime is examined in relation to understanding stress and coping responses and psychosocial adjustment factors that are associated with the familial impact of a parent's cancer. To obtain an overall illustration of the stress and coping mechanisms

employed by youth, emphasis is placed on adolescents' mental health status. Attention on interventions aimed at improving the psychosocial impact of youth affected by parental cancer can increase understanding of effective strategies to mitigate the negative implications related to such familial-level stressors.

## **CHAPTER II. LITERATURE REVIEW**

### **Impact of Parental Cancer**

Although population data is limited, it is estimated that roughly 14% to 24.7% of diagnoses of adult cancer patients are parents to minor children (Weaver et al., 2010; Ruoqing, 2017). It is also estimated that 11.6% of children in the United States will experience the death of a parent due to cancer (Burns et al., 2020). How children cope with and respond to stress related to having a parent with cancer is gaining increasing attention in the United States and in other countries around the world such as Australia, the United Kingdom, Saudi Arabia, Sweden, Finland, Japan, Iran, the Netherlands, and Norway (Fearnley & Borland, 2017; Ruoqing, 2017; Al-Zaben & Al-Amoudi, 2014; Huizinga, 2005; Kobayashi et al., 2017; Ghofrani et al., 2019). Nevertheless, studies on how children, especially adolescents, cope with and respond to the stress of the persistent and potentially life-threatening nature of a parent's cancer diagnosis remain sparse (Ruoqing, 2017). This gap is unfortunate because disruption of a youth's family life is often related to increased stress and risk of developing psychosocial difficulties. There is also minimal information on the efficacy of interventions for this population, especially with those that are preventative, and child-centered. This chapter provides an overview of studies that focus on youth's stress, coping, psychological well-being, and interventions in relation to having a parent with cancer.

### **Impact of Parental Cancer on their Children's Psychosocial Functioning**

Recent research points to several difficulties that children face when living with a parent diagnosed with cancer (Ellis et al., 2017). In their systematic review of 12 studies regarding the influence of parental cancer on European and American children ages 3-18 years of age, Ellis et al. (2017) identified some of the most prominent factors influencing psychosocial functioning.

The needs of these youth consist of receiving access to developmentally appropriate information regarding the parent's cancer diagnosis, peer support, reduction of isolation, feelings of "normalcy", a safe space for expression of anxieties and concerns, specific interventions to improve coping, and a supportive environment where relationships can be fostered to promote connections with peers and family members. In view of the goals of this study, the following sections highlight the focus on how managing parental cancer influence youth's perceived stress, coping abilities, and mental health status.

### ***Psychological Well-being of Youth with a Parent with Cancer***

The associations between psychopathology and children experiencing parental cancer is of paramount importance to medical professionals, clinicians, educators, and policymakers in designing needs-oriented programs to address children's and family members' well-being. Whereas most studies conducted on national and community samples generally point to behavioral risks of young children, a few suggest both negative (sadness, withdrawal, sleep difficulties) and positive impact (e.g., helpfulness and closeness to family members, improved self-confidence) of parental cancer on children (Inhestern et al., 2021; Stefanou et al., 2020). That said, most studies pertaining to parental cancer tend to focus on psychosocial difficulties experienced by children. What follows provide a broad overview of these studies across different cultural communities.

A rather large discrepancy exists throughout empirical literature in terms of whether adolescents in general and adolescents facing parental cancer are more likely to engage in externalizing or internalizing behaviors. A study of 271 adolescents living with a parent with cancer in the Netherlands continued to shed light on behavioral issues of adolescents. The study reported that compared to the norm group, daughters had higher rates of internalizing behaviors

(Huizinga et al., 2011b). This finding is relatively consistent with quite a few additional studies that propose that internalizing behaviors are higher both for females and typically among females who have a mother with cancer (Gazendam-Donofrio, 2011; Visser et al., 2007). For example, Kim and colleagues (2022) found that among a large group of 3429 Korean adolescents living with a parent with cancer, the rates of suicidal thoughts and ideation, as well as rates of depression increased after the first year following diagnosis and then declined by the second year, especially with daughters and daughters whose mothers have cancer. A longitudinal study by Visser et al. (2007) also described clinically increased rates of internalizing behaviors for both adolescent sons and daughters, especially within the first year after initial diagnoses. The researchers discussed that their study may have included a more inclusive depiction of internalizing behaviors, since it measured symptomology of not only depression and anxiety, but also of somatic complaints and withdrawal behaviors (Visser et al., 2007).

Hauken et al. (2018) evaluated the degree of anxiety and health related quality of life (HRQOL) in 35 children 8-18 years of age in Norway with a mother diagnosed with metastatic cancer and who had gone through long-term treatment. Children's anxiety and HRQOL were compared to Dutch norms as controls. Children affected by parental cancer scored higher on total anxiety and psychological anxiety, but not on the individual measurements of worry and concentration compared to the controls from the Netherlands. Results from the HRQOL also pointed to concerns in the specific dimensions of emotional well-being and school-related issues. Almost half of the children in the study met the scale's clinical cut-off score for emotional distress. Additionally, participants' scores on the school dimension were lower than expected. Results nonetheless suggest that interactions between children and their caregivers/school professionals merit more attention. It is believed that lower scores than anticipated in both scale



dimensions of emotional well-being and school are potentially related to lack of effective communication between parents, the school, and their children. (Hauken et al., 2018). Similar findings were also apparent in a Malayan study of 95 adolescents who have a parent with cancer. Ainuddin et al. (2012) correspondingly reported a decreased quality of life for the adolescents in terms of both emotional functioning and school performance as well.

The stressful nature of parental cancer raises concerns about the prevalence of posttraumatic stress disorder (PTSD) among children. PTSD symptoms are present in 21% of males and 35% of females (11-23 years-old) 1-5 years after a parent has been diagnosed with cancer (Huiz1nga et al., 2015). Partners/spouses may also experience PTSD in conjunction with a cancer diagnosis. PTSD can influence cognitions about traumatic life events and emotional regulation (Chesney & Gordon, 2017; Villalta et al., 2018). In a recent sample of 136 Dutch families (90 parents with a cancer diagnosis and 71 healthy parents) with children between the ages of 8 and 18 experiencing parental cancer, Egberts et al. (2022) examined family level factors and PTSD in children. The purpose of the study was to better understand the symptomology of PTSD among children living with parental cancer. Children reported on their PTSD, trauma cognitions, emotional regulation, family communication, and overall family functioning. About 27% of the children demonstrated clinically relevant PTSD symptoms that were linked to higher levels of child-related trauma cognitions and emotional regulation difficulties. Family-level factors were not reported as major predictors of PTSD (Egberts et al, 2022). Another study conducted in the United States reported that posttraumatic stress symptoms of 7-13-year-olds facing parental cancer could be buffered by engaging in emotional expression to their parents as a coping strategy (Howell et al., 2016). These findings highlight the

importance of considering individual level child factors along with family factors in determining the impact of parental cancer on childhood psychological outcomes.

Relatedly, a few studies concentrated on issues surrounding emotional stability in both children and adolescents that are associated with a parent's mental and physical health status. One such study involving 3,255 children and adolescents connected with Child Protective Services (CPS) and from the second cohort of the National Survey on Child and Adolescent Well-Being (NSCAW II) showed the propensity of children to develop internalizing behavior problems in the face of high levels of family stress (Quinn et al., 2014). Perhaps the most notable finding was that both the mental and physical health of caregivers mediated the relationship between family stress and internalizing behaviors, which could be similar within families facing parental cancer (Quinn et al., 2014). In this regard, a review of literature on youth specifically affected by parental cancer indicated that children from preschool age through adolescence demonstrated internalizing issues, such as increased feelings of guilt, anxiety, depression, and difficulties associated with changes in family roles and routines (Shah et al., 2017).

A random-effects meta-analysis of 15 studies further expanded on relations between children who experienced a mother diagnosed with breast cancer and the propensity of increased depressive symptoms, posttraumatic stress, internalizing/externalizing problems, and mental health distress in children (Purc-Stephenson & Lyseng, 2016). Although the overall effect size for total problem behaviors in this group of studies were small ( $d = -0.13$ ), the risk of experiencing emotional distress such as anxiety and depression can still be considered substantial compared to nonaffected groups. Wong et al. (2006) also retroactively surveyed 30 adults who were 8-17 years of age at the time of their parent's cancer. The adults consisted of 19 women and eight men from the San Francisco Bay area with a mean age of 23.7 years. Participants were

asked to report on their childhood experiences of having a parent with cancer along the dimensions of peritraumatic dissociative experiences, coping strategies, and social support, as well as current PTSD symptoms. Peritraumatic dissociation at the time of the parent's cancer diagnosis was associated with higher rates of posttraumatic stress disorder (PTSD) symptoms as adults. It was suggested that peritraumatic dissociation symptoms developed due to emotional difficulties that arose because of inadequate social support, denial, and disengagement (Wong et al., 2006). The distress among youth reflects broader perspectives of managing emotional distress and mental health concerns through their parent's cancer. For example, Krattenmacher et al. (2012) reported in their review that "a significant minority becomes highly distressed or develops psychosocial problems." The underlying factors that contribute to psychological distress within children who experience parental cancer warrant additional research attention on parental factors that may heighten the distress of children.

Associations between experiencing parental cancer and high levels of distress in children and adolescents are documented in a limited number of studies (Huang et al., 2014; Faccio et al., 2014). Patterson et al. (2017) determined that 60% of offspring of a parent with cancer, mainly from Australia, but also from New Zealand, the United States, England, and other countries reported high or very high levels of distress. The adolescents in this study (mean age of 16.1) were 3 to 6 times more likely to have higher levels of distress than a comparison group. Furthermore, they were also prone to be actively seeking/undergoing mental health treatment (Patterson et al., 2017). Using an identical sample in terms of sociodemographic characteristics, McDonald et al. (2016) assessed levels of distress predictors with offspring who have a parent with cancer. It was found that high levels of distress were associated with unmet needs such as family issues, difficulty expressing emotions, and receiving supplementary support from friends.

Of equal importance to providing emotional and mental health stability to youth coping with parental cancer is the level of availability of information provided to them regarding their parents' cancer regime. Reportedly, difficulties do arise when children are less informed and delivered inaccurate information regarding their parent's cancer diagnosis and/or parents avoid sharing critical components of their diagnosis and treatment (Turner et al., 2007). There may also be cultural factors at play that create boundaries about what a parent will share with their children about their cancer diagnosis and treatment. For instance, the taboo nature of a cancer diagnosis is still prevalent in Tunisia, which places limits on what a parent may disclose about their health (Korbi et al., 2021). A systematic review and meta-synthesis of 16 qualitative studies published in English between 1990 and 2013 on children living with a parent with non-terminal cancer found that younger children in the United States, Canada, UK, Denmark, and Norway were given less detailed and descriptive information regarding the parent's cancer status than older children (Huang et al., 2014). Adolescents were most interested in receiving individualized information regarding their parent's condition from parent's themselves, healthcare providers, school, and from healthcare literature (Huang et al., 2014). Accordingly, this systematic review and meta-synthesis suggested that youth may have varying needs regarding information surrounding their parent's healthcare diagnosis depending on developmental level. A consistent need recognized across developmental levels of children was for open communication between themselves, their parents, and their parent's healthcare providers (Huang et al., 2014).

The degree to which children understand the breadth of their parent's cancer diagnosis is another related area of concern in terms of psychosocial adjustment. Varathakeyan et al. (2018) surveyed 371 Australian youth ages 11-26 years old pre- and post-bereavement of a parent's death from cancer. Regardless of social support, participants who were older and female were

more likely to have both higher levels of unmet needs and higher levels of distress. Qualitative interviews of 17–21-year-olds from this study who were aged 5–14 years old when their parent was first diagnosed with cancer were also included. These interviews revealed that children and younger adolescents had more difficulty understanding the broad implications of their parent's prognosis and the need for seeking support. Barriers to youth accessing services were linked to social stigmas and poor mental health literacy. The consequences of grieving a deceased parent from cancer on the youth's day-to-day life activities also provided insights into the critical role of peer and family support (Varathakeyan et al., 2018). Although developmentally appropriate peer support was regularly recognized as meaningful, children in early adolescence did not feel as though their peers could adequately relate to and empathize with their experiences.

Furthermore, the researchers postulated that older adolescents may be more attuned to recognizing and internalizing distress within the family to better verbalize their needs and feelings and gain access to appropriate social supports than younger children (Varathakeyan et al., 2018). There were similar findings from a qualitative study of 15 adolescents from Ireland (Rodríguez, 2020). The adolescents in this study reported feeling as though they were not able to communicate information and/or their feelings effectively about their mother's cancer diagnosis/experience due to not being able to anticipate people's responses and/or fear of overly sympathetic responses from peers and other social supports, that they did not think would be helpful.

Noting the above-mentioned findings, researchers have explored developmental differences in understanding associations between a parent's cancer diagnosis and psychosocial adjustment among children of different ages. For instance, Karlsson et al. (2013) conducted interviews with six European young adults who were recruited because they had a parent

diagnosed with cancer during their adolescence when they were between 13 to 19 years old. The interviews indicated that the adults felt “loneliness despite the presence of others” referring to both physical loneliness and not being surrounded by people who understood their experiences. Another study by Gazendam-Donofrio et al. (2011) reported some similar sentiments in terms of emotional concerns among adolescents ages 11-18 from the Netherlands. By evaluating the emotional and behavioral reactions of adolescents who have/had a parent with cancer, it was found that feelings of loneliness and uncertainty were most closely linked to emotional dysfunction, which lasted beyond a period of adjustment needed to digest the initial reactions of a parent’s diagnosis. A commentary by Annunziata et al. (2015) suggested that shifting family dynamics had a major influence on feelings of isolation and loneliness among teenagers who have a parent with cancer. Similarly, a literature review by Shah et al. (2017) indicated the need for emotional stability through continued support of adolescents, especially with respect to support from peers, which can be considered a long-standing developmental marker of social support amid this age group. This finding is especially poignant because it reiterates the need for additional opportunities for social support from peers and open communication with others in order to address the specific emotional needs among adolescents contending with parental cancer (Karlsson et al., 2013).

There are disagreements about the toll that parental cancer can impart on the adolescent population. As an example, Jantzer et al. (2013), did not find significant levels of externalizing behaviors or juvenile risk behavior among adolescents living with parental cancer. This may be expected as most studies point to an increase in internalizing behaviors among adolescents living with parental cancer (Landi et al., 2021). Although some potentially problematic emotions and behaviors are well recognized among youth who have a parent with cancer, the scope and degree

to which psychosocial functioning is impacted is less clear with some studies presenting an abundance of negative outcomes (Annunziata et al., 2015) whereas others do not (e.g., Levesque & Mayberry, 2012). A study of 77 young adults of teenagers ages 16 and older from Sweden found that feelings of loneliness, poor psychosocial well-being, decreased self-esteem, and increased anxiety and depression were more prevalent for those that had lost a parent to cancer in comparison to the Swedish youth population overall (Lundberg et al., 2018). Likewise, in an analysis of adolescents and young adults ages 12-24 who have/had a parent with cancer in Iran, 99.5% of participants reported having at least one unmet psychosocial need and 94.4% reported 10 or more unmet psychosocial needs (Ghofrani et al., 2019). These findings are similar to a study of adolescents and young adults in Italy where lower levels of HRQOL and internalizing behaviors were associated with heightened feelings of unmet needs. There was also a link between unmet needs and unpredictability of the parent's cancer diagnosis (Landi et al., 2021). These findings point to the importance of increased communication among family members and further availability of opportunities for psychoeducation and support to address the needs of adolescents living with a parent with a cancer diagnosis.

As previously mentioned, not all studies indicate findings of adolescent distress in the context of living with a parent with cancer. A few suggest the benefits youth may accrue when dealing with a parent's cancer experience such as developing resiliency and improvements in family functioning and the home environment (Annunziata et al., 2015). Levesque and Mayberry (2012) conducted a qualitative study with 11 adults ages 18 and over from Australia that showed positive changes in relation to their parent's cancer experience. In reflecting on the plight of their parent's cancer, these adults reported strengthening familial relationships such as improved connections with the parent diagnosed with cancer and recognizing increased value of family

relations. Other benefits included personal development in terms of emotional maturity and increased compassion, as well as having a more positive outlook on life by reassessing life's priorities (Levesque & Mayberry, 2012). In parallel work, Lundberg et al. (2018) surveyed Swedish adolescents and young adults regarding their stressors and psychosocial well-being while coping with bereavement from the loss of a parent from cancer. Adolescents and young adults indicated increased beliefs in a meaningful future. A qualitative study of African American adolescents also presented themes of posttraumatic growth such as discovery of individual strengths, increased appreciation of life, and enriched relationship-making (Kissil et al., 2010). It is speculated that these beliefs and positive viewpoints shown in these studies are connected to participants receiving at least adequate levels of social support, especially from at least one parent (Levesque & Mayberry, 2012; Lundberg et al., 2018; Kissil et al., 2010).

Most would agree that factors within the family unit itself are crucial to perceiving how youth adjust and cope throughout a parent's cancer regime. Family and parental factors are noteworthy to understanding youth's psychosocial functioning with a parent's cancer because both illness-related factors and child-related factors play a monumental role in psychosocial well-being (Krattenmacher et al., 2012). Psychosocial outcomes in youth related to a parent's cancer experience seem to be influenced by both the family environment and perceived level of family functioning. Möller et al. (2014) investigated dimensions of family functioning as a predictor of psychological distress with 258 11-21-year-olds and their parents in Germany. General family functioning was one of the most potent predictors of children's mental health outcomes when living with a parent with cancer across all reporters ( $p = 0.012$  from the "healthy" parent,  $p = 0.003$  from the parent with cancer and  $p = 0.046$  from the child's self-report).



Besides consideration of the family as a unit, specific markers of parent's own well-being may also influence their children's psychosocial functioning. Parent's adjustment, mood, and psychological well-being appear to contribute heavily to psychosocial health among youth. A salient factor to children's negative psychosocial adjustment was parent's general dissatisfaction, unease, and "disruptions from their illness" (Hoke, 2001; Visser et al. 2004). In the same vein, Bultmann et al. (2014) found significant connections between the mental and physical health of the parent and the HRQOL among youth. Götze et al. (2015) further found an association between quality of life in children and high levels of depression and anxiety symptoms following a parent receiving cancer therapy.

Issues associated with the social functioning of offspring managing parental cancer were explored as well. Researchers point to the interchangeable nature of the terms, "social network, psychosocial assets, and perceived social support" throughout the scientific literature to describe the concept of social functioning (Boyce et al., 1983). Variability continues across conceptual definitions of "social functioning" that is broadly conceived as part of the psychosocial well-being of youth facing parental cancer. The bulk of studies examining offspring of parental cancer and social functioning appear to focus mainly on social support. Wong et al. (2009) conveyed that participants who reported greater satisfaction of social support at the time of their parent's cancer diagnosis were less likely to develop PTSD symptoms as adults. A literature review conducted by Morris et al. (2018) also acknowledged several issues that youth face in terms of social support and psychosocial functioning related to living with a parent with cancer. Morris and colleagues (2018) noted,

The deficit in support strategies for offspring was evident in this review.

Offspring perceived no emotional or psychosocial support for themselves in

their parent's care (Finch & Gibson, 2009), and only one study reported on the outcome of a supportive care program (Azarbarzin et al., 2015). (p. 68-69).

Apart from the family being at the core of social support offered to youth, influence from outside parties was deemed equally important. As previously discussed, peer support played a critical role in maintaining social stability throughout a parent's cancer course, especially for adolescents. That being the case, youth from all different age groups identified the need for support from friends, while simultaneously indicating less availability to spend time with their peers after a parent is diagnosed with cancer (Varathakeyan et al., 2018). Moreover, support from friends was identified as the most common of unmet needs in the sample of 217 teen and young adult offspring of a parent with cancer from Iran. It was surmised that social support connections may be much more readily available for the parents with cancer themselves, but not for their offspring specifically (Ghofrani et al., 2019). Correspondingly, adolescents may depend more heavily on social support from peers, as opposed to a wider net of social connections than is usual with adults (Compas et al., 2017). A noticeable absence of social support from healthcare providers and from teachers at school was likewise detected (Fasciano et al., 2007; Turner et al., 2007). It should be mentioned that there is not a discernable pattern of timing for when social support would be most beneficial to youth. Readiness, willingness, and openness to the support services offered are all conceivably instrumental to the level of benefit from any services provided (Varathakeyan et al., 2018). Moreover, there is a critical need for youth and families to be able to gain access to different types of social support that are considered convenient, comfortable, and address coping and communication at both the individual and family group levels (Lundwall, 2002).

### *Stress and Coping*

Difficulties with stress and coping are commonly recognized among children and adolescents through psychosocial adjustment and mental health concerns (Compas et al., 2001). That said, there are gaps in the empirical literature detailing underlying mechanisms of stress and coping of youth, beyond that of a trauma perspective (Aldwin, 2010). For instance, there is a perceptible dearth of research on how the stress and coping patterns develop from developmental, situational, and biopsychosocial perspectives of youth. Respectively, how youth respond to stress and develop coping abilities seems less identifiable. The recognition of stress and coping being a dynamic process that changes over time also appears to complicate the developmental understanding of the process. A prevalent hypothesis speculates that older youth tend to be more prone to stressful circumstances than younger youth (Aldwin, 2010). Drawbacks with this premise, however, include the need to also factor in changes to social context, no matter the developmental stage, which can also influence stress exposure, as well as abilities to form and use coping strategies over time.

Conceptualizations of stress and coping for youth were historically not based on considerations of distinct needs and attentions across varying developmental levels (Compas et al., 2001; Compas et al., 2014). Arguably, this may not be entirely adequate as the most common sources of stress for adolescents tend to be more acute, rather than the more chronic nature of stress for adults (Compas et al., 2017). Building on previous models of stress and coping proposed by different researchers, Compas et al. (2001) suggested that stress formation, particularly for youth, can be divided into voluntary and involuntary responses. Stress responses are then further divided into either an engagement or disengagement response.

The coping skills of adolescents thus may vary from those of adults. Many researchers differentiate coping mechanisms into either problem-focused or emotion-focused coping efforts. Whereas problem-focused coping centers on attempting to change one's stressful situation, emotion-focused coping involves managing the feelings associated with stressful stimuli (Thastum et al., 2008). Seemingly, adolescents in general are more prone to engage in emotion-focused coping than those of adults who engage in problem-focused strategies (Skinner et al., 2007). For example, a study of 762 adolescents from Spain were assessed in their coping strategies in relation to emotional regulation. The researchers found that the more passive and emotion-based coping strategies were correlated with increased anxiety, feeling unhappy with oneself, and weakened relations (Pascual et al., 2016). A study of 40 adolescents from Ireland likewise conveyed that there were significant relationships found between high levels of perceived stress, emotion based (and aggression) coping, with increased emotional distress (Rodríguez et al., 2019). Lastly, adolescent coping compared to those of adults may not be as flexible in terms of the variation of coping skill utilization and adolescents might also have trouble cognitively appraising the threat of a stressor or adapting in the face of increasing stressors (Compas et al., 2012; Garnefski et al., 2004; Skinner & Edge, 2002). Dividing the types of stress responses and coping for youth may be more pertinent in guiding assessment of psychosocial adjustment from a developmental perspective (Compas et al., 2001). These findings point toward the need for additional understanding about the connection between coping strategy application and psychosocial functioning.

Strikingly few studies are available on how stress and ultimately coping skills contribute to better understanding how children and adolescents fare in terms of well-being when a parent is diagnosed with cancer. A literature review by Krauel et al. (2012) reported that approximately

25% of children and adolescents facing parental cancer have stress symptoms that are measured as clinically elevated. Irrespectively, a select few studies distinguish between some of the unique circumstances that explicitly focus on how stress and coping influence the psychosocial well-being of youth who are living with parental cancer. Thastum et al. (2008) interviewed 21 children ages 8-15 along with 13 of their mothers and two of their fathers in Denmark who were diagnosed with various stages and types of cancer. Based on the interviews, the five types of coping skills that were most prevalent among the youth were identified as: helping others, parentification, distraction, keeping it in the head, and wishful thinking. Helping others and parentification were considered problem-focused strategies and distraction, keeping it in the head, and wishful thinking were considered emotion-focused strategies. It was concluded that almost all children used problem and emotion focused strategies, but it seemed that problem focused strategies led to increased feelings of mastery and control. These results were reasonably consistent with a British study finding that emotionally based strategies of distraction and normality were most regularly employed by children older than seven years of age (Kennedy, 2009). Chowdary et al. (2016) reported similar results where 19 daughters of mothers diagnosed with breast cancer engaged in a wide variety of coping strategies, which they referred to as a “multidimensional model of adolescent coping”. These findings seemingly contradict reports of other studies, where problem focused solutions were less likely to be applied by children and emotion focused strategies were linked to increased anxiety and depression. One of the first known studies on Hispanic adolescents in Puerto Rico coping with parental cancer suggest that adolescent children were most frequently employing emotion-focused coping skills and that those emotion-focused coping strategies were less related to psychological concerns than the use of problem-focused approaches (Costas-Muñiz, 2012). Additional research would be useful in

development of a more comprehensive grasp of coping mechanisms among youth who have a parent with cancer (Compas et al. 1996; Huizinga et al., 2011; Thastum et al., 2008).

In their studies, Krattenmacher et al. (2012;2013) sought to ascertain increased understanding of more individual stress and coping needs that impact youth living with a parent with cancer. Emphasis was on distinctive factors at play when a parent is living with cancer, as their children depend on their parents to continue receiving their normalized levels of both day-to-day care and familial support. There are similar yet different dynamics that may develop within the family as opposed to when children themselves, a sibling, or another family member is diagnosed with cancer. Several studies distinguished how illness-related factors, age, and gender influence the psychosocial outcomes of children and youth in terms of coping with parental cancer. As such, Krattenmacher et al. (2012;2013) examined how both emotion-focused and problem-focused strategies lead to adolescent's ability to cope with the stress of their parent's cancer diagnosis. It was found that, the emotion-focused strategies involving approach-oriented patterns, such as acceptance, cognitive restructuring and social support seeking, were associated with better functioning, while those involving avoidance-oriented patterns, such as wishful thinking and distraction, were associated with worse functioning (Krattenmacher et al., 2012;2013). Still, half of the adolescents were apt to use problem-focused strategies and found them to be effective. More needs to be done to better determine the varying coping methods employed by youth impacted by parental cancer.

Perhaps not unexpectedly, efforts have also been made to explore maladaptive coping skills used by youth, specifically about their parent's cancer diagnosis. Among them, diversion and denial were the most recognized strategies used among youth coping with their parent's cancer (Shah et al., 2017). A detectable link is also recognized between the use of denial and

behavioral disengagement during youth and increased PTSD symptoms in adulthood (Wong et al., 2006). Research also suggests that maladaptive coping for adolescents experiencing parental cancer is more prevalent when the offspring is bereaved (Morris et al., 2020). Particularly for adolescents who live with a mother with cancer, there are also increased concerns for higher levels of distress and uses of maladaptive coping strategies for adolescent daughters (Fisher et al., 2022). Although data on the relationships between stress, coping, and parental cancer is limited, there is even less on factors that influence coping in relation to the course of the parent's cancer trajectory. Most studies tend to focus on coping strategies when the parent's cancer status is considered advanced or aligned with the youth's bereavement process after a parent is deceased (Phillips, 2014).

Overall, the underlying functions of stress and coping of youth with parental cancer present critical implications for youth's physical and mental health and psychological well-being. Even though some studies examined children's and adolescent's coping generally, there are few investigations on stress and coping of youth linked to their parent's cancer diagnosis. Moreover, there is limited specifics on how individual stress and coping of children and adolescents is impacted by familial-level influencers, such as living with a parent diagnosed with cancer. More research on how youth cope with specific familial-level stressors would be beneficial in building to what we already know about how offspring of parents with cancer develop maladaptive coping strategies and their connections to mental and physical health.

### ***Interventions***

As in studies on psychosocial functioning for children with parental cancer, the literature on interventions for this group is equally limited. Some empirical evidence is available that interventions for adolescents geared towards improving behavior problems should be tailored

towards recognition of their individual and familial level stressors (Maya et al., 2018). As such, an attempt is made here to provide a summary of findings on interventional studies that focus primarily on child-centered approaches to coping with parental cancer. A review conducted by Inhestern et al. (2016) generated 8,505 articles related to structured psychosocial interventions. Of these, 16 articles were included in the review with only seven presenting information about child-centered interventions with widely varying outcomes depending on program goals. In general, the interventions contained a focus on supporting family relationships, enhancing coping skills, building support networks, and education. Of the seven child-centered studies assessed, five were implemented in the United States, one in Canada, and one in Ireland, with only two providing an evaluation of program outcomes, and only one was from the United States.

It is safe to say that few studies provided insights into child-centered interventions for children of cancer patients. Two qualitative studies by Tucker et al. (2013) and Semple and McCaughan (2013) sought to evaluate outdoor recreational programming for children of cancer patients. Tucker et al. (2013) conducted a focus group with parents and children 9-19 years of age regarding their experiences in a support group for youth that contained an “adventure” focus (On Belay). The support group consisted of outdoor adventure programming with challenge courses that focus more attention on the youth rather than on the parent or even the parent’s cancer diagnosis. The On Belay programming differs from other intervention models in that the focus of the program was not centered on educating the youth about their parent’s illness, but on the “personal power” of the youth and their abilities to cope with difficulties in life and by proxy, their parent’s cancer diagnosis (Tucker et al., 2013). Phillips et al. (2021) also evaluated child participation in a once weekly meeting over the course of a six-week psychosocial support program for children ages 2 to 18 who have a parent with cancer. For the most part, findings



suggest that the program reinforced parent-child communication, which in turn was correlated with the child's improved sleep, decreased anxiety, and increased feelings of security at home.

Other interventional programming seems to be more geared towards children's emotional responses. Two focus groups with 6-11-year-old participants were conducted using the *Children's Lives Include Moments of Bravery* (CLIMB) program in Northern Ireland (Semple & McCaughan, 2013). The CLIMB program is specifically designed to enhance emotional and psychobehavioral functioning, education, and normalization of 6-11-year-old children who have a parent or caregiver with cancer. This program lasts for approximately 90 minutes over the course of six weeks. In 2016, Shallcross et al. conducted a quantitative study that sampled 45 children who participated in the CLIMB program in the United States. There were noticeable decreases in emotional suppression and emotional symptoms in general, as well as increases in emotional awareness after participating in the CLIMB program. Later in 2017, a study testing the efficacy of the CLIMB program was conducted in Japan with youth 6-12 years old. Interestingly, in the Japanese study, youth participation in the program was well-received and led to lower posttraumatic stress scores from pre- to post-intervention ( $p = 0.01$ ) levels (Kobayashi et al., 2017). However, it was determined that one-third of the children still had very high post-traumatic stress scores after the intervention, which could be attributed to familial factors such as being a single parent and the parent's own stress levels. The program failed to appreciably enhance levels of perceived social support between the pre- and post-intervention stages (Kobayashi et al., 2017). Results from this study align well with premises regarding the need to further investigate social support mechanisms, family influences, and how they impact the stress of offspring who experience parental cancer. Taken together, the results of the CLIMB program, although somewhat limited in participants and based in part on a pilot study, can provide much

needed guidance for empirical evaluations of group-based interventions for children who have parent(s) with cancer (Kobayashi et al., 2017; Semple & McCaughan, 2013; Shelcross et al., 2016).

In another study of African American families, Davey et al. (2013) conducted family support groups with school-aged children and their parents that were adapted to meet the culturally specific needs of the families, especially in terms of coping mechanisms. While the culturally specific adaptations to the support group was efficient in improving family communication, it did not seem to impact levels of anxiety or depression in youth (Davey et al., 2013). Intervention approaches on parents with a cancer diagnosis typically direct more attention toward the parents, but measure offspring outcomes as well. In one such study of the Enhancing Connections Program, mothers diagnosed with non-metastatic breast cancer received 5 counseling sessions specific to parenting with cancer. The program also sent “assignments” on stress and coping issues home for the mother to complete with their child. Children whose mothers participated in this program demonstrated fewer issues of behavioral-emotional adjustment at two months following the intervention and lower depression at 2- and 12-months follow-up. There were few significant changes in children’s anxiety scores at each of the time periods post-intervention. (Lewis et al., 2006).

The benefits of social support, especially those that are culturally relevant, should not be overlooked. Although no formal intervention was studied, the need to better understand more culturally applicable ways of mitigating stress for young adults coping with parental cancer is also warranted. Mía Marín-Chollom (2017) conducted the first known study of Latinx young adults and their coping response to the perceived stressors of parental cancer. The results of this study indicate that higher levels of familismo, a value that emphasizes family obligation and

support, is associated with lower levels of mental health issues. Similar findings are also seen in research pertaining to parental cancer and the role of filial piety or ‘hyo’ in Asian communities and/or of those that follow Confucian teachings. The consideration of familismo and filial piety is critical from a communication/social support perspective because it may be a key component in understanding how youth feel less alone and isolated as well as manage their stress and coping when living with parental cancer. The use of familismo and filial piety also points towards components that may need to be further examined to increase effectiveness of interventions from a cultural standpoint (Kim et al., 2022; Mía Marín-Chollom, 2017).

Intervention methods that are camp-based specific to youth living with a parent with cancer are still rare. More commonly, camp experiences are geared towards groups of youth with psychosocial needs that are constructed in conjunction with their own healthcare status. For example, there are camps for children living with a variety of chronic illnesses such as congenital heart disease, HIV, cancer, and many other individual diagnoses. Among studies assessing the camp experience as an intervention for youth living with various chronic illnesses, there is a general inclination to determine the positive outcomes on camp attendance. Although benefits are often reported, measurement of concepts tend to be more qualitative in nature and with a wide variety of conceptualizations of well-being. In the evaluation of one such program for youth ages 12-16 that attended a camp for adolescents with HIV, a qualitative longitudinal approach was used to interview the youth at six weeks and six months following the camp experience (Lut et al., 2017). At both follow up times, youth expressed that the camp experience contributed to increased social support, more positive self-identity, and increased autonomy.

There are other camps available for youth coping with similar emotional experiences with threats to their psychosocial well-being, such as bereavement experiences from the death of a

parent or loved one (McClatchey & Wimmer, 2014). Some of these camps occasionally offer sessions that include programming for the caregivers of their children and/or for other members of the family, such as siblings. Taking into consideration that the camp models differ in their approaches, they all ultimately seek to positively influence youth dealing with additional life stressors. It is reasoned that the benefits of these camp experiences should be comparable to youth coping with a parent's cancer diagnosis as well.

The benefits children acquire from the camp experiences are measured broadly focusing on different outcomes. Neville et al. (2019) conducted a review of research on camps that evaluated the psychosocial well-being of youth impacted by their own cancer diagnosis. Although this differs from a youth living with their parent's cancer diagnosis, some of the recognized issues among both groups are similar: namely, a lack of "normalcy" in their lives, problems with relating to their typical social groups, and difficulty with stress and coping. It was concluded that the camp experience was generally effective in improving the psychosocial health of children with cancer (Neville et al., 2019). Of significance is the ability of youth to strengthen relationships with both family and peer support groups from attending camp. There was a call for more data on the coping strategies employed by camp participation to protect against developing mental health conditions.

Only one study could be found that specifically addressed camp programming for youth who have/had a parent figure diagnosed with cancer. While the study did not focus specifically on youth's psychosocial well-being, emphasis was on family communication and ultimately coping skills of the family as a unit. It was found that exhibiting constructive coping skills might be of particular importance for adolescents because they often associate a cancer diagnosis with death (Chernichky-Karcher, 2017). As instructive as these findings are, there was limited

information about the camp programming and goals itself, as it was not a focal point of the study but was used for participant recruitment and mentioned by the participants in some capacity. It was hence speculated that the families involved in camp participation supported the youth's attendance due to possible preexisting difficulties for their child to cope with their parent's cancer diagnosis (Chernichky-Karcher, 2017).

Despite demonstrated benefits of interventions for youth living with a parent with cancer, the timing of when the interventions are most effective is still widely contested and largely unknown (Shah et al., 2017). This is probably connected to some assertions that illness-related factors of parent's cancer may not have a great deal of influence on youth's psychosocial functioning. Phillips et al. (2021) did suggest in their study that parents who sought intervention services for their children within three months of the initial diagnosis tended to yield further advances in terms of positive child outcomes when the parent's goal was to improve communication about the diagnosis and prognosis. Nonetheless, camp programming that is generalized to all stages of a parent's cancer diagnosis would most likely be pertinent to addressing the broader range of stress and coping factors that potentially influence psychosocial well-being. It was also the case that individual level variables regarding the structure of camp itself did not seem to have significant impacts on psychosocial functioning for camp programming geared towards children generally affected by cancer (Neville et al., 2019). Regardless of length of time, activities, camp philosophies, and individual camp variances, there were few differences between camps in terms of improvements in psychosocial health. These issues notwithstanding, the relationships made at the camps seemed to be considerably more important to psychosocial well-being than any of the logistical differences between camps (Neville et al., 2019).

## Limitations

Progress in designing studies that assess how children cope with a parent's cancer diagnosis and the efficacy of interventions to address mental health exacerbation associated with the parental cancer diagnosis is scarce. At the same time, there are several shortcomings with the extant literature. Two reviews identified several methodological and conceptual concerns with studies such as small sample sizes and that most participants were mothers of youth who were diagnosed with breast cancer making generalizability of findings difficult. Few studies focused on both mothers and fathers with a wider range of various cancer diagnoses and there was a conspicuous absence of longitudinal research, especially in terms of developmental trajectories of psychosocial functioning of youth over time.

Another major setback is that few studies collected quantitative data regarding the efficacy of intervention programs addressing a range of psychosocial concerns. Yet, far fewer studies measured the effectiveness of the interventions at different points in time and over sustained time periods (Walczak et al., 2018). There is also a noticeable lack of interventions that are child-centered and/or preventative in nature. Be that as it may, interventions that focus on the child-parent relationships are undoubtedly beneficial and interventions that are specifically geared to assess and consider the unique needs of youth explicitly deserve more attention as well.

There are also discrepancies between studies on the scope of impact that offspring encounter based on living with parental cancer. Empirical data implies that there is only a minority of youth participants who are experiencing psychosocial issues related to their parent's cancer (Osborn, 2007). Others argue that research indicates a "sizable minority" of children and adolescents who experience psychosocial difficulties. The proportion of parents diagnosed with cancer that have children with mental health concerns could be considered more substantial in

terms of psychosocial concerns specifically, especially considering that the conceptualization of psychosocial is often ambiguously delineated (Mosher et al., 2006; Levesque & Mayberry, 2012). As such, the examination of stress and coping mechanisms as integral to psychosocial health are rarely scrutinized within this population.

In considering the information detailed above, there are numerous potential consequences associated with young people living with parental cancer. Reports on youth experiencing parental cancer suggests manifold prospective familial and developmental factors that may influence children's experience with parental cancer. That is, variables of psychological well-being, stress, and coping merit further examination to better understand how they contribute to psychosocial functioning among adolescent and youth who live with a parent with a cancer diagnosis. A further consideration of child-centered interventions that aim to assist youth to manage the potential consequences of parental cancer also need greater consideration. The theoretical bases that underpin these relationships and that guide research on risks associated with offspring experiencing a parental cancer diagnosis are laid out in the subsequent chapter.

### CHAPTER III. THEORETICAL FRAMEWORK

Theoretical and conceptual models on the underlying mechanisms for understanding adolescents' stress and coping responses of living with a caregiver diagnosed with a potentially life-threatening illness are not that well-defined. The combination of multiple frameworks, however, can help shed light on this understudied phenomenon. One framework that may assist in this regard is Lazarus' psychological stress theory that lays out the interrelatedness of stress, coping, and the situational factors that influence one's ability to interpret stressors (Lazarus, 1994; Skinner & Zimmer-Gembeck, 2009). In a similar vein, the core tenets of the family resilience framework are also used to guide our understanding of responses to a parent's cancer diagnosis through a developmental lens. Together, these frameworks attempt to establish a more thorough picture on how children decipher and respond to stressful situations and in particular, their parent's cancer. Accordingly, propositions within these two frameworks are used to guide both quantitative and qualitative studies and are used to frame the research questions and hypotheses in the present work. In the following section, I discuss the major tenants of these two frameworks and their relevance to stress and coping in youth who have/had a parent with cancer.

#### **Stress and Coping**

With its continuous elaborations and expansions, stress and coping theory provides one of the more comprehensive platforms for understanding how individuals cope with stressful life events in the moment (Lazarus, 1991;1993). Originally, Lazarus conceptualized stress as a passive process emanating from subjective psychological and behavioral reactions caused by external threats in a person's environment. Central to this conception of stress is consideration of the wide variety of responses in which people distinguish between how assorted experiences are perceived as taxing. The individual assessment of events and situations in terms of being



perceived as manageable is commonly known as appraisal. How individuals respond to and appraise circumstances as stressful is consequently a key element of psychological stress theory.

There is fairly consistent agreement that the appraisal process is at the core of psychological stress theory. Lazarus defines the appraisal process as the emotional response a person experiences based on their own individual life experiences, the specifications of the encounter at hand, and the perceived significance and outcome of any given situation. The implication of the appraisal process is then quite important as it accounts for both how people react to different situations at different times, and why it is also possible for distinctive people to provide greatly variable reactions to similar experiences (Folkman 2011;2009). Later, Lazarus further delineated the definition of appraisal into primary and secondary components. The focus of primary appraisal is the assessment of any risks to an individual's perceived sense of well-being. Secondary appraisal refers to a person's coping skills and their ability to use those skills in a given situation. Since the descriptions of appraisal and coping may sound overly analogous, Lazarus recognizes the similarities and clearly differentiates between the two terms. Appraisal references the thoughts and evaluation of how one thinks to possibly manage an individual situation. Cognitive coping, which is most closely linked with appraisal, refers to the actual thought or action that arises to process the encounter (Lazarus, 1991).

Historically, coping was commonly defined by Lazarus and Folkman (1984) as, "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.141). This definition of coping suggests that there are different factors that can influence and contribute to both the amount of stress that is experienced, but also the ability of individuals to manage and respond to stressful circumstances. There is also movement towards increased recognition of

how the formation and responses to stress are not limited to a unidirectional path on how an environment impacts the stress response of people, but also that people leave an impact on their environments (Aldwin, 2010). A more recent conceptualization of stress extends the original definition by focusing on the association or interaction between a person and their environment (Krohne, 2001). The basis of this elaboration stems from the recognition that although there are universal stressors, such as chronic illness, a person's reaction to the stressor, in terms of appraisal and coping, is a more important indicator of stress formation (Lazarus & Folkman, 1984). Amendments to the stress and coping theory work towards recognizing and explaining the bidirectional nature of stress and coping abilities. The intricacies of coping processes to stress are further outlined in the following section.

Expanding on the aforementioned definition of coping, Compas et al. (2001) identified coping specifically as a voluntary or involuntary process. A voluntary coping technique describes when a person attempts to respond to stressful stimuli that are impeding their ability to adapt or master their environment. The volitional coping responses are then further delineated into either primary control engagement coping or secondary control engagement coping. Primary control engagement coping is an attempt to modify the stressor by problem solving the situation or the emotional response. Secondary control engagement coping refers to one's efforts to apply cognitive or regulated attention to the issue in order to acclimate to the stressor. Conversely, researchers also identify involuntary stress responses that are not typically considered effective coping strategies (Connor-Smith et al., 2000; Thomsen, 2002). Involuntary stress regularly refers to either conscious or unconscious emotional or behavioral responses to stress such as intrusive thoughts, rumination, and/or emotional numbing (Connor-Smith et al., 2000). Both voluntary and involuntary coping responses are then additionally differentiated as either engagement or

disengagement. Engagement refers to methods geared towards reacting directly to the identified source of stress (Connor-Smith et al., 2000). Disengagement denotes strategies to separate oneself from the source of stress, such as through avoidance or denial (Thomsen et al., 2002).

In their effort to build on the concept of coping, Skinner and Zimmer-Gembeck (2009) also elaborated on the involuntary nature of coping mechanisms, which they refer to as action regulation. These researchers express the importance of action regulation as finding an equilibrium to volatile stress responses. Correspondingly, as voluntary stress reactions seem to be in response to lack of regulation and/or high stress situations, involuntary coping reactions to stress provide insight into the reactions formed in response to low stress exposure and/or ability to efficiently self-regulate. A continued effort is made to distinguish between differentiating the concepts of regulation and coping. Regulation refers to management of individual aspects of temperament such as attention and emotion, while coping more broadly accounts for a variety of emotional, behavioral, physiological, and cognitive reactions (Skinner & Zimmer-Gembeck, 2009). This distinction between the conceptualizations of regulation and coping assist in further comprehending how stress and stress responses can be differentiated between various developmental groups.

The consideration of coping skills throughout the lifespan is also thoroughly outlined by Skinner and Zimmer-Gembeck (2009). Recognition of cognitive strategies to form coping skills first begins to be recognized in 6- to 8-year-olds through middle childhood. During this developmental period, the use of strategies such as cognitive distraction, self-reassurance, cognitive reframing, and seeking social support outside of the family becomes more prevalent. During early adolescence, the ability for metacognition develops and youth can demonstrate venting, aggressive coping, and avoidant coping mechanisms. Adolescent coping predominantly

tends to be based on personal values where adolescents seek social support mainly from outside the family, develop more multifaceted problem-focused coping, and employ the use of humor. Adolescence, unfortunately, also marks the rise of coping strategies considered more maladaptive such as substance use/abuse, increased risk behavior, and social withdrawal (Aldwin, 2010; Skinner & Zimmer-Gembeck, 2009; Thomsen et al. 2015).

### **Family Resiliency**

Building on the notion of individual stress, family resiliency considers how different life events that occur to one person may impact a family system as a unit (Walsh, 2016). The family resilience framework builds upon developmental, ecological, as well as individual and familial stress and coping theories and models to provide a more systematic examination of how families respond to adverse experiences (Henry et al., 2015). The conceptualization of resilience and its application to furthering interpretation of how families function collectively, is critical for exploring the impact of several distressing life events, such as a parent's cancer experience. This framework also emphasizes the importance of determining how some families can flourish and overcome hardships in the face of difficult challenges.

From its origins in the 1980s, the family resiliency framework recognizes that stressful environments are not only the experience of an individual, but also of groups and particularly the family unit as a whole (Hadfield & Ungar, 2018). With the development of the family resilience framework, the challenges associated with the overarching definition of resilience receives considerable attention. Resiliency is typically defined as, "the capacity to withstand and rebound from disruptive life challenges" (Walsh, 2016, p. 313). However, the concept of resiliency also tends to be very broadly defined throughout psychological empirical and historical literature. More recently, there have been attempts to ensure that the definition of resiliency is not limited

to the idea that someone needs to “bounce back” from a challenging experience. The current conceptualization of resiliency depicts a person being able to strengthen themselves due to, and in the face of challenging situations, instead of scraping by despite the challenges (Walsh, 2016).

Other prominent scholars (e.g., Masten & Wright, 2010; Rutter, 2006; Rutter & Sroufe, 2000) have also described resilience as a construct that goes beyond the notions of social competence and mental health outcomes. Essentially, resilience is not only viewed in the context of risk and protective factors associated with a person’s health status, but also through their ability to develop a range of physiological and/or psychological coping skills (Rutter, 2006). In this respect, the basic notion of resilience should be further considered in the context of not only individual factors that impact resiliency, but in conjunction with a wide variety of other influencers. To better account for some of these environmental factors, grounding in an ecological systems perspective enables the consideration of multiple levels of resiliency such as biological, individual, family, community, socio-cultural, and chronological processes (Bronfenbrenner, 1979; Walsh, 2016).

Taking into consideration the multiple spheres of influence delineated in the bioecological perspective, the family is often depicted as the system most closely impacting a person (Bronfenbrenner, 1992). Any potential stressors that occur to one person in a family unit may also have consequences for other members. At the same time, families that experience any number of potentially traumatizing or unfavorable conditions are also able to find healing and constructive progression through confronting their vulnerabilities. It is also established that some families may have more exposures to challenging circumstances due to structural oppression, while others may have more resources to potentially be able to work through their challenges. Within the family resiliency framework, any and all families have the potential to allow its

members to be even more prepared to face future difficulties later in life (Walsh, 2016; Henry et al., 2015).

Henry and colleagues (2015) posit that there is exponential growth of recognizing family resilience as a concept. The notion of family resiliency continues to evolve and grow throughout time and is contextualized throughout three waves of development. The focus of wave 1 expanded on previous family stress frameworks such as the ABCX model and family adjustment and the adaptation response model (FAAR). Similarly, there is an emphasis present in wave 2 on the interactional patterns of families and the family as a system. As such, wave 3 of the framework is in the process of being developed. The growing emphasis of wave 3 is to provide additional specifics regarding the conceptualization of family promotive, protective, and adaptation factors. This is further illuminated through the presentation of the family resilience (FRM) and the family adaptive systems (FAS) models. The FRM centers around the four concepts of the presence of family risk, family protection, family vulnerability, as well as short and long-term adjustment (Henry et al., 2015). Perhaps most importantly, these concepts better elucidate how individual risks sometimes do and do not apply to multiple members of the family unit, how they may not translate across different ethnic and cultural groups, and how one individual or dyad adjusts in the family system may not be how everyone in the system adjusts. Furthermore, FAS added an additional layer of context to the four principles of FRM. The FAS is hypothesized to fall in between family situational meanings, which are closest to the FRM that is positioned between the family situational meanings and the family's ecosystem. The FAS specifically refers to different standards of behavior that are expected by different members of the family system, and how stressors to their lives may change different behaviors and expectations of familial roles (Henry et al., 2015). The addition of the FRS provides leeway for

an expansion of empirical research to more concretely examine family dynamics and stressors that occur to individuals and different members of the group, such as may occur with a parental cancer diagnosis.

### **Integrating Stress, Coping, and Family Resiliency**

The relationship between stress, coping, and resiliency is highly prevalent throughout past literature. Although, previous conceptualizations of coping (as being problem-focused vs. emotion-focused) are currently viewed as being overly simplistic, while those of resilience are also confusingly defined based on whether it is a skill to be achieved or an outcome to adversity. These associations are also less clear when examined through the developmental lens of adolescence and also when the source of the stress is occurring to the family as a unit, and not because of one's individual state. Seemingly, adolescent's abilities to demonstrate coping and resiliency skills are closely related. Since resilience is largely defined as the ability to adapt, cope, and recover from adversity or difficult experiences that are being experienced either by oneself or within a family unit, it is also the case that coping strategies can be viewed as a pathway to forming resilience (Sisto et al., 2019). Adolescents may therefore use these adaptive abilities to better identify and manage stressors while maintaining more positive mental health outcomes (Konaszewski et al., 2021). As evidenced with 96 Taiwanese high schoolers, family resiliency was associated with lower levels of perceived stress among adolescents living with parental cancer (Chen et al., 2017). Adolescent coping is thus an important factor in developing resiliency – the capacity to effectively respond to challenging circumstances with minimal psychological distress. However, various coping styles are explored throughout the risk and resiliency literature with the goal to predict varying levels of adjustment to stressful situations.

In recent years, secondary control coping has emerged as the predominant coping strategy that is perhaps most effective for combating adolescent's stress specifically related to interpersonal situations, and uncontrollable circumstances, such as a parent's cancer (Bettis et al., 2019). Although primary control engagement is sometimes considered more closely related to better mental health outcomes, it is not always differentiated from secondary control coping as they are both active engagement strategies. Data available on the link between the use of primary engagement coping and mental health outcomes, especially in relation to family stress origins are not as robust as those between use of secondary control coping and mental health outcomes among adolescents (Blöte et al., 2022). By contrast, disengagement coping, an avoidant coping strategy, can be considered as maladaptive in adolescents who have a parent with cancer if it is used as a primary strategy to cope with their distress. This type of coping has been linked to lower psychological well-being and increased levels of depression and anxiety among adolescents with a parent with cancer. Moreover, research suggests that disengagement strategies are associated with poorer physical health outcomes such as higher stress hormone levels, disrupted sleep patterns, and poor immune functioning (Curzon, 2021).

Taken together, the tenants of the stress and coping and resiliency frameworks with a focus on adolescent development assisted in guiding the framing of the research questions, hypotheses, and selection of the measures in this study. More specifically, expansions of the original stress and coping theory distinguished between voluntary and involuntary responses to stress, engaged and disengaged responses, and primary control and secondary control coping strategies, in relation to mental health status led to the selection of two measures that focus on discrete dimensions of stress and coping in youth between 11- and 17 years of age and psychosocial functioning. Both the quantitative and qualitative dimensions of the study employ



an overarching emphasis on the strategies that adolescents exert to cope with a parent's cancer diagnosis. There is limited qualitative and even less quantitative research available on stress and coping responses of adolescents and their psychosocial functioning in relation to living with a parent diagnosed with cancer. Previous studies have demonstrated relationships such as how appraisal of parental cancer is "uncertain and lonely", which are related to increased issues in psychosocial functioning, but does not consider perceived notions of stress or associated coping methods (Gazendam-Donofrio et al., 2011). There is also extant literature describing adolescents using problem and emotion based coping strategies with managing parental cancer, but it is less clear which specific coping strategies are linked to higher psychosocial functioning and less perceived stress (Gabiak et al., 2007). Using the stress and coping and resiliency frameworks from a developmental perspective as a backdrop, this study explores the following questions related to mental health, stress, and coping in youth living with a parent with cancer.

## **Research Questions and Hypotheses**

### ***Quantitative Dimension***

To further understand the stress and coping mechanisms of adolescents that have experienced living with parental cancer based on developmental considerations of stress and coping and family resiliency frameworks, the quantitative portion of the study strives to find answers to the following questions:

**Research Question 1:** Is there an association between psychosocial functioning and perceived stress among youth living with parental cancer?

**Hypothesis 1:** There will be a positive association between psychosocial functioning concern and perceived stress among youth living with parental cancer.

**Research Question 2:** Is there an association between psychosocial functioning and use of coping strategy among youth living with parental cancer?

**Hypothesis 2:** There will be a positive association between psychosocial functioning concern and use of disengagement and involuntary coping strategies.

**Research Question 3:** Is there an association between perceived stress and use of coping strategy among youth living with parental cancer?

**Hypothesis 3:** There will be a positive association between perceived stress and use of disengagement and involuntary coping strategies.

### ***Qualitative Dimension***

Based on the aforementioned stress and coping and family resiliency frameworks, a descriptive phenomenological method will be employed to develop themes and sub-themes to shed further light on mental health, stress, and coping among youth living with parental cancer.

**Research Question 4:** How do parents perceive stress influences of 11-17 year old children with a parent diagnosed with cancer?

**Research Question 5:** How do parents perceive coping strategies of 11-17 year old children with a parent diagnosed with cancer?

## CHAPTER IV. METHODS

### Participants

This study employed a cross-sectional, mixed-method design to obtain both quantitative and qualitative data. For the quantitative segment, participants included 37 primary guardians of 11–17-year-olds who have/had a cancer diagnosis. These families were dispersed across the United States. Eleven respondents were dropped from the study due to incomplete participant responses. The mean age of the 26 survey respondents was 49 (SD=8.03) (93% were mothers). More detailed sociodemographic information on the survey sample is presented in Table 1. Demographic information related to the parent’s cancer status and their child’s mental health status are included in Table 2.

An additional six respondents of 11-17-year-olds who either have/had a cancer diagnosis or a partner with a cancer diagnosis were recruited for the qualitative aspect of the study. Participants for the qualitative portion were enlisted through referrals and snowball sampling. All interview participants are from the United States and identify as White (100% mothers). The primary caregiver that had the cancer diagnosis were predominantly the mother (83% mothers). Two of the primary caregivers resided in the Northeastern U.S, one in the Midwest, and three in the Pacific Northwest.

**Table 1**

*Sociodemographic Details of Survey Participants*

Variable	<i>n</i> (%)	<i>Mean</i>	<i>Standard Deviation</i>
Primary Caregiver Role			
Biological Mother	24 (93)		
Adopted Father	1 (3)		
Grandmother	1 (3)		

**Table 1 Continued**

Variable	<i>n</i> (%)	<i>Mean</i>	<i>Standard Deviation</i>
Age of Primary Caregiver Completing Survey			
30-40	1 (3)	49	8.03
41-50	14 (54)		
51-60	8 (31)		
60+	3 (12)		
Age of Primary Caregiver at Time of Cancer Diagnosis		44	10.87
20-30	1 (3)		
30-40	11 (42)		
41-50	9 (35)		
51-60	3 (12)		
60+	2 (8)		
Marital Status			
Single	2 (8)		
Divorced	6 (23)		
Married	11 (42)		
Widowed	7 (27)		
Ethnicity			
Black/African American	1 (3)		
Asian	2 (8)		
Hispanic	3 (12)		
White	19 (73)		
Other	1 (3)		

**Table 2***Details of Primary Guardians Cancer Statuses and Children's Mental Health Statuses*

Variable	<i>n</i> (%)	Mean	Standard Deviation
Primary Caregiver with Cancer Diagnosis			
Mother	13 (50)		
Father	10 (38)		
Both	3 (12)		
Stage of Parent's Cancer			
Stage 1	5 (19)		
Stage 2	3 (12)		
Stage 3	4 (15)		
Stage 4	4 (15)		
Other	4 (15)		
Deceased	6 (23)		
Status of Parent's Cancer			
Active Treatment	5 (19)		
Remission	15 (57)		
Deceased	6 (23)		
Child's Gender			
Female	16 (62)		
Male	10 (38)		
Child's Age		13.5	2.42
11-14	16 (62)		
15-17	10 (38)		

**Table 2 Continued**

Variable	<i>n</i> (%)	<i>Mean</i>	<i>Standard Deviation</i>
Child's Grade in School		7.65	2.26
5-8	15 (57)		
9-12	11 (42)		
Support Services			
Does receive social support services	3 (12)		
Does not receive social support services	23(88)		
Mental Health Status			
Diagnosed with mental Health disorder/receives Therapy	11 (42)		
Not diagnosed with mental Health disorder/receives Therapy	15 (57)		

Families were recruited for the surveys through Camp Kesem, a U.S.-based national organization dedicated to providing no-cost camp experiences for youth 6-18 years old that have/had a parent or primary caregiver diagnosed with cancer. The goal of Camp Kesem is to provide “traditional” outdoor recreation programming (such as swimming, arts and crafts, and cooperative play in nature) to encourage youth to engage in developmentally appropriate activities with others that are sharing similar experiences to their own. Approximately 9,000 youth attended one of Camp Kesem’s sessions in 2018 and about 10,000 youth attended in 2019. Due to the Covid-19 pandemic, the Camp Kesem program was moved online. Thus in 2020, 8,691 campers participated in “virtual camp sessions”. In 2021, 5,338 campers attended virtually, while approximately 1,600 participated in-person through “weekend camp” and in field trips/day

programs in the fall. Currently, Camp Kesem hosts approximately 100 camp sessions in-person throughout the summer that are led by college students from their respective undergraduate institutions (Kesem, 2023). For the qualitative component of the study, participants were recruited through convenience and snowball sampling. All primary caregivers were sent a description of the study, the family's role in it, and their rights to withdraw from the study. Electronic consent was provided to survey participants. Oral consent was provided to interview participants, and all chose to have a copy of the consent form emailed to them following the interview. The study received Institutional Review Board approval from Syracuse University (IRB #21-102).

### **Procedure—Quantitative Dimension**

The original intention was to collect data in person at various camp session orientations during Summer 2020. As a result of the Covid-19 pandemic, Camp Kesem moved their summer camp programming virtually during the Summers of 2020 and 2021. Accordingly, it was decided to send participants Qualtrics surveys via a link from the national organization. The Camp Kesem national team is very consciously oriented towards protecting their participating families from not being overwhelmed or burdened with messages from the organization in the hopes of not inundating their constituents with excessive electronic communication. As such, Camp Kesem strategically emailed the survey to 1,500 families during 2021-2022 at times when they were not already receiving regular email communication from the organization.

### **Procedure—Qualitative Dimension**

Interviews were conducted with six primary guardians who either themselves or their partners have/had a cancer diagnosis at the time where at least one of their children was between the ages of 11-17-years-old while they were undergoing diagnosis and active treatment. The

interviews occurred using the Zoom communications software, which also recorded the interviews (with the permission of the participants). The interviews occurred in Spring 2023 and lasted on average for approximately 52 minutes. Five of the six mothers who participated have been previously diagnosed with cancer and are all currently in remission. One mother who participated provided information about her partner (the children's stepfather) that had cancer and is deceased.

### **Measures**

Primary caregivers were asked to provide consent and then fill out an electronic version of a sociodemographic questionnaire, the Pediatrics Symptom 17 Checklist (PSC-17), and the Responses to Stress Questionnaire-Parental Cancer-Parent Report scale (RSQ) (Connor-Smith et al., 2000) through Qualtrics. The full versions of the scales being used in the study can be found in the appendices. The primary caregiver was defined as a principal guardian of the youth who resides in the same household of the child for a majority of the time. Per the national camp organization's suggestion, surveys were distributed to Camp Kesem participants of their choosing through their email database.

### ***Sociodemographic Information***

The primary caregiver was asked to provide information on the child's age, child's gender, number of children in the household, caregiver's level of educational attainment, child's educational level, primary language, caregiver's relationship to child, family socioeconomic status, ethnicity, religious/spiritual affiliation, social support, community participation, child's diagnoses of mental health disorders, participation in therapeutic services, and number of times the child previously attended Camp Kesem and other camp programming. Caregivers were also asked to provide information on the parent's cancer experience in terms of role of caregiver



diagnosed with cancer, status of cancer diagnosis, type of cancer diagnosis, and age of parent when initially diagnosed with cancer.

### ***Psychosocial Functioning (PSC-17)***

The Pediatrics Symptom 17 Checklist (PSC-17) is a screening tool that is widely used to assess psychosocial functioning in terms of emotional and behavioral problems to provide an overall recognition of potential concern for mental health in children and adolescents. Primary caregivers rated 17 items that evaluate symptoms consistent with anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), conduct disorder, and other behavioral issues. The reliability of the scale with parents as raters has been good (0.87) (Murphy et al., 2016). There are also three subscales of the PSC-17, which are internalizing, externalizing, and attention. Reliability scores for the 3 subscales in a recent study using a national sample were 0.78, 0.82, and 0.80, correspondingly (Murphy et al., 2016). The items on the PSYC-17 are rated on a 3-point Likert scale (0 = not true, 1 = somewhat true, 2 = certainly true). An overall score of 15 or greater warrants concern for general psychosocial distress. The recent study previously mentioned also included percentages of “positive” scores for 4–16-year-olds scoring above particular thresholds. The total positive scores for this study were reported at 11.6%. Internalizing scores equal to or greater than 5 indicate increased associations with mood and anxiety disorders with positive scores being reported at 10.4%. Externalizing scores equal to or greater than 7 are more typically related to behavioral and conduct disorders (positive scores of 10.2%), while an attentional score greater than or equal to 5 are linked to diagnoses of ADHD/ADD (positive scores at 9.1%) (Murphy et al., 2016). The PSC-17 was completed by the youth’s primary caregiver to assess the presence of mental health exacerbation in terms of potential psychosocial distress.

### ***Responses to Stress Questionnaire (RSQ)***

Primary caregivers were also asked to fill out the Responses to Stress Questionnaire-Parental Cancer-Parent Report scale. The RSQ (Connor-Smith et al., 2000) asks for reports on their child's perceived stress and stress responses. The RSQ was originally designed to measure perceived stress and coping mechanisms pertaining to a specific situation, such as parental cancer. An original version of the parent report on stress and coping of offspring regarding parental cancer was developed at Vanderbilt University's Stress and Coping Research Lab. However, the preexisting version of the survey did not quite fit the criteria for the current sample being studied in terms of developmental appropriateness to specifically assess adolescents and also to account for increased variations of experiences throughout a parent's cancer progression. Therefore, through back-and-forth email communication with researchers from Vanderbilt University's Stress and Coping Research Lab, the questionnaire was amended to best fit the demographics and specific stressors of this sample. The modified questionnaire contains 66-closed ended items that are rated on a 4-point scale. The first 11 items form a separate unidimensional scale on perceived stress. Items are rated from "1" = not at all to "4" = very. The remaining 55 items are rated from ("1" = none to "4" = a lot). The original authors of the scale (Connor-Smith et al., 2000) suggested using relative scores for data analysis. However, there are only two other known studies that measured adolescent's stress/coping responses to parental cancer along the same dimensions and both of which used raw scores for their analyses. Scores in this current study were therefore calculated with raw scores as well to remain consistent with other similar studies of breadth and size. Greater cumulative scores indicate increased utilization of a particular coping mechanism and/or a stronger proclivity towards an individual stress response.

The RSQ measures one dimension of perceived stress and five dimensions of coping directly related to the parent's cancer: primary control coping, secondary control coping, disengagement coping, involuntary engagement, and involuntary disengagement. Primary control engagement coping describes efforts to exert control in attempts to change one's emotional response and/or the source of the stress. This nine-item dimension includes three items each pertaining to problem solving, emotional regulation, and emotional expression. Secondary control engagement coping represents one's ability to adapt to stressful circumstances to gain a sense of control over the stress source. Secondary control engagement coping consists of eight items: three each of positive thinking, cognitive restructuring, and two of acceptance. Disengagement coping consists of resigning control over the source of the stressor in attempts to reduce the stress and/or emotional reaction. This dimension includes nine items: three each of avoidance, denial, wishful thinking and distraction.

Involuntary engagement and involuntary disengagement are the two involuntary stress coping responses measured. Both involuntary coping measures involve an automatic stress response where an individual is either engaged or disengaged with the stressor. Involuntary engagement stress responses consist of 15 total items: three items each of rumination, intrusive thoughts, emotional arousal, physiological arousal, emotional arousal, and two of involuntary action. Involuntary disengagement stress responses are comprised of 12 total items: three items each of emotional numbing, cognitive interference, inaction, and escape. Overall, the items focus on youth's stress and coping mechanisms and are directly formulated to correspond to perceived difficulties surrounding their parent's cancer diagnosis. Examples of items included in each of the subscales are exemplified in Table 3.

The internal consistency for the overall scale was good (.78). The response items for both the perceived stress and five coping dimensions of the RSQ have demonstrated good reliability and validity in terms of internal consistency, test–retest reliability, and convergent and discriminant validity. (Connor-Smith et al., 2000). Additional empirical data on the RSQ are available regarding other specific stressors such as children’s own cancer experience or coping with parental depression. However, this current study provides a more thorough examination of the use of the RSQ among the less commonly reported parent’s ratings of their adolescent’s responses to their parent’s cancer experience (Compas et al., 2014).

**Table 3**

*Dimensions and Subscales of the RSQ*

Dimension	Subscale	Example Item	Number of Items
Perceived Stress	Stress response to parental cancer	Feelings of guilt associated with the parent's cancer	11
Primary Control Engagement Coping	Problem-solving	He/she asks other people or things for help or for ideas.	3
	Emotional regulation	He/she keeps their feelings under control when they have to, then lets them out when they won't make things worse.	3
	Emotional expression	He/she gets sympathy, understanding, or support from someone.	3
Secondary Control Engagement Coping	Positive thinking	He/she tells themselves that they can get through this, or that they will be okay.	3
	Cognitive restructuring	He/she tells themselves that things could be worse	3
	Acceptance	He/she takes things as they are; they can go with the flow.	2
	Distraction	He/she thinks about happy things to take their mind off of parental cancer	3
Disengagement Coping	Avoidance	He/she tries not to feel anything.	3
	Denial	When around other people he/she acts like their parent’s cancer never happened.	3
	Wishful thinking	He/she wishes that they were stronger and less sensitive so that things would be different.	3
Involuntary Engagement Coping	Rumination	After something stressful happens related to their parent’s cancer diagnosis, they can’t stop thinking about they did or said.	3
	Intrusive thoughts	Thoughts about parental cancer just pop into his/her head	3
	Physiological arousal	He/she gets really jumpy when dealing with the stress of parental cancer.	3
	Emotional arousal	His/her thoughts start racing when they are faced with the stressful parts of parental cancer.	3
	Involuntary action	When stressful things happen related to parental cancer, he/she sometimes acts without thinking.	2

<b>Table 3 Continued</b>			
Involuntary Disengagement Coping	Emotional numbing	When he/she is dealing with the stress of parental cancer, they really don't know what they feel.	3
	Cognitive interference	His/her mind goes blank when something stressful happens related to parental cancer, they can't think at all.	3
	Inaction	He/she is dealing with the stressful parts of parental cancer, they end up just lying around and sleeping a lot.	3
	Escape	He/she just has to get away from everything when they are dealing with the stress of parental cancer.	3

### **Data Analysis-Quantitative Dimension**

IBM SPSS version 27 software was utilized to analyze the data. The survey question responses from the primary guardians were collected from Qualtrics and directly downloaded into SPSS. After the data were assessed for normality, linearity, and homoscedasticity, three sets of analyses were performed. The first phase involved obtaining descriptive information (mean, standard deviation, range, p-values) on the sociodemographic variables. Next, mean group effect sizes (Hedges' g version of Cohen's d), to correct for positive bias in the pooled standard deviation, were also calculated to determine comparisons between key variables of the RSQ with similar studies comprised of small sample sizes of participants. Finally, Pearson and Spearman correlations were computed to assess the associations between perceived stress and coping styles, perceived stress and psychosocial functioning, and coping styles with psychosocial functioning.

### **Qualitative Dimension- Interviews**

Primary caregivers of six adolescents who have lived with a primary caregiver diagnosed with cancer participated in semi-structured interviews. Five interviews were conducted with mothers that were in remission from cancer at the time of the interview and one mother whose partner (the children's stepfather) had passed away from cancer. The interviews were conducted from 48-57 minutes long over Zoom. The participants were asked the same eight questions with the attempt to decrease bias (questions provided in appendix c). They were also asked some

follow-up questions to further clarify a response and/or request elaboration of an answer. The interviews were recorded and then transcribed verbatim.

### **Qualitative Dimension-Transcription and Synopsis**

Verbatim transcriptions were made of the interviews obtained from the 6 families after which a thematic content analysis was conducted. This analytical strategy, "...is an appropriate and powerful method to use when seeking to understand a set of experiences, thoughts, or behaviors across a data set" (Kiger & Varpio, 2020, p. 847). The aim of using this approach was to identify common themes and patterns related to coping mechanisms used by youth in response to the stressors associated with having a parent with cancer. The first step in the analysis was familiarization with the data by conducting several repeated readings of the transcripts to gain an overall understanding of the content. Afterward, an initial list of codes was developed using brief phrases that summarized the meaning of specific segments of the transcriptions. The codes were then grouped into broader categories based on their shared themes, and these categories were refined through a process of comparison and revision of the participant responses. Overarching themes were then identified that encapsulated the essence of the data and the ways in which individuals coped with the stressors associated with having a parent with cancer on individual, familial, and environmental levels. The analysis process was iterative in nature, with themes being refined and revised as more data were collected and analyzed. The final themes were then finalized and supported by illustrative quotes from the interviews.

## CHAPTER V. RESULTS

This study sought to examine associations among psychosocial functioning, perceived stress, and coping strategies in 11–17-year-olds who have experienced living with a parent diagnosed with cancer. This chapter first describes findings pertaining to the quantitative dimensions of the study, which is followed by descriptions of the main thematic concepts obtained from the qualitative data. The qualitative findings shed further light on the psychosocial functioning, stress, and coping mechanisms associated with youth living with a parent diagnosed with cancer.

### **Quantitative; Preliminary Analyses**

Data on the 26 participants were used for all quantitative analyses. There was not any missing data from the PSC-17 scale and less than 2% of data were missing at random from the RSQ scale (MAR). Thus, mean imputation was used to deal with missing data. The Shapiro-Wilk test was run to determine whether distribution of responses on the PSC-17 and the RSQ subscales were normally distributed. Total scores of the overall scales and scores on all subscales of both measures, except for externalizing and internalizing of the PSC-17, were considered normally distributed. As such, a nonparametric test (e.g., Spearman Rho) was used in analyzing the externalizing and internalizing subscales and parametric tests were used to analyze all of the other measures.

### ***Descriptive Analysis***

An attempt is made in this section to provide an overview of patterns of caregiver responses regarding offspring stress, coping patterns, and psychosocial functioning. Table 4 presents the means and standard deviations for the key variables of the PSC-17 and RSQ scales.

**Table 4***Descriptive Statistics for Scales and Subscales (n=26)*

	Mean	SD	Possible Range	Actual Range	$\alpha$
<i>Pediatric Symptom Checklist (PSC-17)</i>					
Externalizing	3.24	2.71	0-14	0-12	.78
Internalizing	2.77	2.25	0-10	0-7	.78
Attention	3.38	2.04	0-10	0-7	.56
Total PSC-17	9.4	5.91	0-34	0-23	.86
<i>Responses to Stress Questionnaire- Parental Cancer-Parent Report (RSQ)</i>					
Perceived Stress	19.73	7.12	11-44	11-40	.91
Primary Control Engagement Coping	20.59	4.54	9-36	9-31	.76
Secondary Control Engagement Coping	25.25	5.09	11-44	17-37	.76
Disengagement Coping	17.96	5.13	9-36	10-27	.79
Involuntary Engagement	26.65	8.24	14-56	14-44	.92
Involuntary Disengagement	21.33	6.35	12-48	12-35	.87

By far, the most selected answer on the PSC-17 with a 1 or 2 by parents was the statement, “worries a lot”. A selection of 2 for “often” was selected by 27% of participants and 50% selected 1 for “sometimes.” Only 2 participants (8%) rated the children’s total externalizing behavior as “positive” or above the cut-off for concern, although the “worries a lot” statement was categorized under the externalizing subscale. By contrast, caregivers rated the item “takes things that do not belong to him or her” as the least concerning item with only 2 caregivers (8%) who viewed this as a serious concern. As indicated in Table 5 below, the attentional subscale was the least selected grouping of psychosocial symptomology, with only 3% of parents providing ratings high enough for attentional difficulty concern. The internalizing subscale contained the



highest scored items with 27% of participants rating their children as positive for internalizing behavior concerns. Overall, total impairment scores in psychosocial functioning, which warrants concern for the presence of behavioral, emotional, and/or other mental health issues, was evident among adolescent children from 38% of respondents.

**Table 5**

*PSC-17 Subscale Ratings*

Subscale	Positive n (%)
Attentional Difficulties $\geq 7$	1 (3)
Internalizing $\geq 5$	7 (27)
Externalizing $\geq 6$	2 (8)
Total $\geq 15$	10 (38)

The subscales of the RSQ were broken down into perceived stress, primary control engagement coping, secondary control engagement coping, disengagement coping, involuntary engagement, and involuntary disengagement. The perceived stress subscale measured potential concerns that adolescents would predominantly come across with the parental cancer experience. The lowest rated item on the perceived stress subscale was the statement “feelings of guilt associated with the parent’s cancer”. None of the parent participants selected 4 “a lot” and the majority of participants selected 1 “not at all” (69%). The statement that elicited the highest mean response (2.23) was “feeling uncertain about their future, parent with cancer, family in general, or any combination of the above”. A related, but separate statement to the perceived stress dimension asks, “how much control does your child generally think they have over these problems.”. Only one participant selected 1 “not at all” for this response.

The primary control engagement coping subscale elicited responses related to problem solving, emotional regulation, and emotional expression. There were three responses concerning problem-solving and two out of three of them were rated the lowest by participants. The

problem-solving response, “he/she tries to think of different ways to change or fix the situation” did not receive a rating by participants above 2. Consequently, 88% of participants chose a response of 1 for this item. The response, “he/she does something to try to fix the stressful part of parental cancer was likewise not scored above a 3.

The secondary coping engagement subscale consists of responses related to positive thinking, cognitive reconstructing, acceptance, and distraction. Two of the responses related to cognitive reconstructing received the lowest mean scores. Neither “he/she tells himself/herself that it doesn’t matter, that isn’t a big deal” and “he/she thinks about the things they are learning from parental cancer, or something good will come from it” were given a score over 3. One item of the secondary control engagement subscale, “he/she keeps their mind off stressful parts of parental cancer”, that is considered a distraction response, again had an atypically high mean score of 2.92.

Disengagement coping can be further delineated into primary control and secondary control disengagement coping, although they are typically measured together, as was done in the present study. Primary control disengagement coping comprised of responses asking about avoidance and denial, while secondary control disengagement coping refers to wishful thinking. Two primary control disengagement coping dimensions of avoidance responses and one denial response received particularly high mean scores of 2.46. These findings are consistent with previous literature on disengagement coping as this strategy is more likely to be used when the stressor is deemed as “uncontrollable”, such as with a parent’s cancer progress (Compas et al., 2005).

The involuntary engagement subscale contains responses pertaining to rumination, intrusive thoughts, physiological arousal, emotional arousal, and involuntary action. Over half of

participants (62%) chose a 3 or higher for the emotional arousal response of, “when he/she is faced with the stressful parts of parental cancer, they feel really angry, worried/anxious, sad, and/or scared”. Similarly, the response, “after something stressful happens related to their parent’s cancer diagnosis, they can’t stop thinking about what they did or said” was scored as a 3 or higher by 38% of participants. The involuntary engagement subscale successively contains items asking about emotional numbing, cognitive interference, inaction, and escape. The emotional numbing response of, “when he/she is dealing with the stress of parental cancer, they really don’t know what they feel” was given a score of 3 or higher by 65% of participants. Alternatively, the cognitive interference item of, “when something stressful happens related to parental cancer, they can get so upset that they can’t remember what happened or what they did”, which was given a score of 1 by 77% of participants.

### **Quantitative; Mean Comparison Effect Sizes**

On account of the small sample size, its inherent limitations in conducting more advanced analyses, and the limited statistics available of stress and coping responses from the RSQ scale, an attempt is made to examine mean group effect sizes between two similar studies. Youth self-reported their perceived stress and coping scores in these similar studies. Therefore, the effect sizes also provide a better sense if the parent reports in the current study are comparable to those from adolescent self-reports. The effect sizes ( $d$ ) are reported in Table 6. Effect sizes are loosely characterized and interrupted as  $.2 = \text{small}$ ,  $.5 = \text{medium}$ , and  $.8 = \text{large}$  (Lakens, 2013). The most “negligible” difference between groups was between this study and the Mía Marín-Chollom (2017) study in primary control engagement coping ( $d=0.15$ ). There were also moderate effect sizes in disengagement coping between this study and Chowdhary et al. (2016) ( $d=0.58$ ) and Mía Marín-Chollom (2017) ( $d=0.52$ ). The other moderate effect size was with the Marín-Chollom

(2017) study in involuntary disengagement coping. All other effect sizes are rather large, which indicate some perceptible confoundment between groups.

**Table 6**

*Mean Group Scores and Effect Sizes From This Study (n=26) Compared with Other Studies*

RSQ Dimensions	This Study, Mean (SD)	Chowdhary et al., (2016), Mean (SD)	Mía Marín-Chollom (2017), Mean (SD)	This Study and Chowdhary et al., (2016)- Effect Size, d	This Study and Mía Marín-Chollom (2017)- Effect Size, d
Sample Size	26 parents	19 adolescent daughters	38 Latinx AYA	-	-
Perceived Stress	19.73 (7.12)	-	28.53 (7.75)	-	1.17
Primary control engagement coping	20.13 (4.58)	30.05 (6.84)	20.92 (5.47)	1.76	0.15
Secondary control engagement coping	25.25 (5.09)	20.00 (3.89)	19.55 (4.38)	-1.136	-1.22
Disengagement coping	17.96 (5.126)	20.95 (5.25)	20.84 (5.73)	0.58	0.52
Involuntary engagement coping	26.65 (8.238)	36.21 (8.94)	33.32 (10.81)	1.12	0.68
Involuntary disengagement coping	21.33 (6.358)	27.37 (8.04)	24.92 (8.46)	0.85	0.47

## **Quantitative; Associations Between Perceived Stress, Coping, and Psychosocial**

### **Functioning**

Three primary goals of this study were to determine links between perceived stress, coping efforts, and psychosocial functioning. As indicated already, to determine the associations between these variables, both Pearson and Spearman correlations were used based on the normal distribution of responses on the various scale components. The coefficients for associations

between different measures are presented in Table 7. As can be seen in this Table, there were relatively strong associations between key variables.

**Table 7**

*Correlations Between PSC-17 and RSQ Dimension Variables*

Variables	1	2	3	4	5	6	7	8	9	10
<b>PSC-17</b>										
1. Internalizing	-									
2. Externalizing	.57** <sup>b</sup>	-								
3. Attentional Difficulties	.48* <sup>b</sup>	.69** <sup>b</sup>	-							
4. Total Psychosocial Functioning	.83** <sup>b</sup>	.87** <sup>b</sup>	.79** <sup>a</sup>	-						
<b>RSQ</b>										
5. Perceived Stress	.51** <sup>b</sup>	.62** <sup>b</sup>	.54** <sup>a</sup>	.74** <sup>a</sup>	-					
6. Primary Control Engagement Coping	-.13 <sup>b</sup>	.07 <sup>b</sup>	.23 <sup>a</sup>	-.035 <sup>a</sup>	.02 <sup>a</sup>	-				
7. Secondary Control Engagement Coping	.00 <sup>b</sup>	.01 <sup>b</sup>	-.01 <sup>a</sup>	-.10 <sup>a</sup>	-.03 <sup>a</sup>	.36 <sup>a</sup>	-			
8. Disengagement Coping	.50** <sup>b</sup>	.37 <sup>b</sup>	.22 <sup>a</sup>	.47* <sup>a</sup>	.53** <sup>a</sup>	-.02 <sup>a</sup>	.26 <sup>a</sup>	-		
9. Involuntary Engagement Coping	.31 <sup>b</sup>	.46* <sup>b</sup>	.48* <sup>a</sup>	.57** <sup>a</sup>	.71** <sup>a</sup>	.15 <sup>a</sup>	.14 <sup>a</sup>	.57** <sup>a</sup>	-	
10. Involuntary Disengagement Coping	.47* <sup>b</sup>	.59** <sup>b</sup>	.47* <sup>a</sup>	.60** <sup>a</sup>	.67** <sup>a</sup>	.035 <sup>a</sup>	.17 <sup>a</sup>	.76** <sup>a</sup>	.88** <sup>a</sup>	-

<sup>a</sup> Pearson correlation, <sup>b</sup> Spearman's rho, \*\*p < .01, \*p < .05

***Associations Between Perceived Stress and Psychosocial Functioning***

There were significant positive associations between perceived stress and total psychosocial functioning ( $r = .74$ ,  $p < .01$ ), and attention ( $r = .54$ ,  $p < .01$ ), respectively. There were also significant positive associations between perceived stress and externalizing ( $r_s = .62$ ,  $p < .01$ ), as well as perceived stress and internalizing ( $r_s = .51$ ,  $p < .01$ ).

### ***Associations Between Psychosocial Functioning and Coping Strategy***

There were significant relations between the dimensions of the PSC-17 and 3 types of coping: disengagement coping, involuntary engagement coping, and involuntary disengagement coping. There was a significant correlation between attention and involuntary engagement coping ( $r = .48, p < .05$ ) and attention and involuntary disengagement coping ( $r = .47, p < .01$ ). Other significant correlations were detectable between total psychosocial functioning and involuntary engagement coping ( $r = .57, p < .01$ ), total psychosocial functioning and involuntary disengagement coping ( $r = .60, p < .01$ ), and total psychosocial functioning and disengagement coping ( $r = .47, p < .05$ ). There were also significant associations between externalizing and involuntary engagement coping ( $r_s = .46, p < .05$ ) and externalizing and involuntary disengagement coping ( $r_s = .59, p < .05$ ). The subscale of internalizing had significant associations with disengagement coping ( $r_s = .50, p < .01$ ) and internalizing and involuntary disengagement coping ( $r_s = .47, p < .05$ ) as well.

### ***Associations Between Perceived Stress and Coping Strategy***

Positive significant associations were found between perceived stress and disengagement coping ( $r = .53, p < .01$ ), involuntary engagement coping ( $r = .71, p < .01$ ), and involuntary disengagement coping ( $r = .67, p < .01$ ) correspondingly.

### **Qualitative Analysis**

Given the overall focus on stress, coping, and psychosocial adjustment in adolescents living with a parent diagnosed with cancer, themes and subthemes that emerged from the qualitative data centered on these issues as well. Although the parents interviewed did not typically categorize their adolescent's coping skills into any specific categories (active vs.

passive, primary vs. secondary control, good vs. bad, etc.), they were able to pinpoint which specificities related to cancer were more or less stressful than others. They also identified a variety of distinct coping strategies that were effective, and even some that the adolescents commonly relied upon that were not constructive to managing stressors specific to parental cancer. Some common themes and subthemes that were derived from the interviews across the six caregivers are presented in Table 8 below. As can be gathered from this Table, thematic content analysis and direct quotes from the participants are provided in support of the themes and research questions.

**Table 8**

*Qualitative Interview Themes and Subthemes*

Research Question 4- How does stress influence 11–17-year-old youth living with a parent diagnosed with cancer?		
Themes	Subthemes	Example Quote
Theme 1- Compounding of Stressful Circumstances	Parental cancer compounding already present stressors	“So, you know, everyone has other circumstances going on, you know, all of these much personal uh personal journeys and it's not even just the cancer that you're.... you're dealing with, you know, what your other life circumstances are... because the teenage years, the early teenage years and all that's going on in their lives and the changes and uh so anyhow, it's never easy.”
Theme 2- Behavioral and Mental Health Concerns	Behavioral issues at school	“Um, so I think she, she wasn't hiding that she was doing badly but she, whenever we talked about it, she kind of seemed really helpless and disempowered and not able to figure out how she could do better... motivated. But, yeah, that was the only year that the teacher actually called us for a spring conference. Normally in our district, everybody gets a fall conference but you don't get called for a spring conference if your child is doing fine and only if there's a problem....”

**Table 8 Continued**

Research Question 5- How do 11–17-year-old youth cope with the perceived stress of living with a parent diagnosed with cancer?			
Themes	Subthemes		Example Quote
Theme 3- Importance of social support for coping	Additional time spent as a family	Importance of shared experiences	“Find support groups... because that's how I found other moms with kids that are like, oh my gosh. Like, what do I do? What did you do? Like, um, and then you can almost create a network of friends with kids that are going through it and then those kids can become friends and like and have someone to share stuff with if they need it.”
Theme 4- Intentional disclosure of information related to Cancer	Perceptiveness of adolescents		“I remember telling her...I remember sitting on her bed telling her ... and she kind of knew because we were, I don't know, it just...it was her intuition or she knew all the testing I was having done, and she's like, you have cancer, don't you? And I was like, I do. And I just remember her covering her head up with her blankets and yeah, it was it was hard telling her ....be open because if you try to hide things and you know ... it's just it makes them more concerned. Um it makes them worry more.”

### ***Theme 1- Compounding of Stressful Circumstances***

The primary caregivers interviewed amply identified a breadth of perceived stressors experienced by their adolescent child(ren). Among the interviewees, there wasn't necessarily a clear consensus about what parts of their cancer journey was more stressful for their child/children over other aspects. For some families, the initial “shock” of the diagnosis felt expressly overwhelming. Other primary caregivers explicitly mentioned the parent either losing their hair or “looking/feeling” particularly sick as taxing to the children. Yet another primary caregiver communicated that finding out information regarding the parent's cancer status on social media before they were informed directly, was very stressful to their teenage child. No



single pattern emerged by the child's age, gender, etc. that were related to the high stress points of their parent's cancer experience. One participant succinctly explained their stress related to parental cancer as,

Um because what, what I think is really challenging about a cancer diagnosis is that you and the people around you, I don't know, it's, it's hard to sort of figure out whether you're supposed to be in fear or whether you're supposed to be in hope.

Considering the sentiment from this quote, perhaps the stress experiences for the adolescent children were largely intertwined with parental cancer issues and with other events happening in their lives, which elicited heightened negative feelings for them, such as fear or managing the unknown.

In continued relation to the subtheme, the parents perceived that their adolescent children were already contending with several other stressors in their lives simultaneously. Although there was no singular part of the experience that was identified as more or less stressful than others, there was evident accord that the adolescent's stress associated with their cancer seemed to heighten the intensity surrounding preexisting stressors in their lives. All primary caregivers named previously existing circumstances that were already taxing to their adolescent child and seemed to require coping efforts, such as their family recently moving to a new town/school, being bullied by peers, and/or complications related to the COVID-19 pandemic. The stress experience related to the parental cancer was not necessarily problematic in and of itself but appeared to amplify ongoing issues. As an example,

I mean she would get in that fight, flight, flee mode. Most of the time she would flee, which then got her in trouble. So then she would kind of like fight like...

not physically fight. She was being bullied. Really bad, really bad. So it was just a really bad time for her ... and then that just spiraled mental health issues altogether ...that we're still fighting.

This quote highlights how the stress of the parental cancer experience by itself did not necessarily provide the adolescents with something out of their capabilities to cope with. However, the accumulation of compiling stressors and the addition of needing to cope with various facets from living with a parent with cancer then exceeded their coping abilities because they were already being challenged by other issues. As one participant concisely stated, “there's like the straw that breaks the camel's back”.

### ***Theme 2- Behavioral and Mental Health Concerns***

With respect to the 2<sup>nd</sup> theme of behavioral and mental health concerns, parents noted that their adolescent children's stress sometimes manifested as issues with a wide array of externalizing, internalizing, and attentional problems. Some of these issues were present before the parent's diagnosis, but then others seemed to manifest or intensify during the parent's course of treatment.

He was just, yeah, he was defiant and I don't know if it was because I was sick or if it was just, that's just what he was gonna do, no matter what...we had behaviors before that and then escalated during and then it got even worse, you know, after I was done with treatment.

Parents frequently found that the behavioral issues reported from school officials were especially problematic. At times, the parents remarked that there were indications of behavioral changes or concerns for psychosocial functioning at home, but they felt as though those issues seen at home could be addressed effectively, either through therapeutic interventions or at a personal/familial

level. It appeared more alarming to the parents that the adolescents were having escalating difficulty with school, especially when they had not expressed stress or difficulty managing school experiences prior to the parent's cancer diagnosis. One parent described,

I mean, I think it was just, she began to have some challenges in school, um, about four or five months after my diagnosis and I could just see her distancing herself. Um, and I felt like at times that she was too bombarded with-  
How is your mom?

The subtheme about the behavioral issues at school did bring forth some commonalities among the participants. Namely, interviewees speculated that whereas spending time/sharing information with peers would have normally been considered a coping skill to their typical stressors, their peers were not able to provide the same type of support that they commonly would have prior to their parent's cancer experience. As one participant stated,

Um, they didn't have any peers that had experienced a parent's cancer ...  
So, unlike COVID, where everybody was kind of going through it together, and so was something they couldn't necessarily, like, they didn't have a social support network that they could relate to about it both because social networks had been so disrupted. But then also because it's just a unique experience, especially for kids as young as they are.

This quote suggests that whereas adolescent children maybe relied more heavily on their peers for coping with other stressors besides parental cancer, they seemingly couldn't be depended upon for reducing the stressors of parental cancer. The parents accordingly conceived that the behavioral issues manifesting in school could have been related to the adolescent's feelings of an acute awareness of being "isolated" and "alone" during school because they were facing

difficulties that they did not feel like peers or other adults at the school could relate with appropriately.

### ***Theme 3- Importance of Social Support for Coping***

The use of “social support” as a principle coping mechanism in reducing stress purposely related to parental cancer for adolescents was highly prevalent throughout the interviews. Intermittently, primary caregivers discussed various coping tactics involving the engagement in “outlets” for the adolescents such as recreational and diversional activities with sports, pets, and music. These outlets seemed to coincide with both the adolescent’s individual interests and with the effort to maintain day-to-day routines as “normally” as possible. With respect to the associated subtheme, it was noticed that teenagers occasionally experienced difficulties connecting with others about their parent’s cancer experience. Primary caregivers subsequently observed that they fared better when they had social support in a more “relatable” atmosphere. Engaging in social support that included relatedness of the cancer experience looked different to different families. Some of the families expressed that their adolescents and themselves relied heavily on spirituality/faith, their spiritual/faith communities, and/or other methods of tangible support- such as help with rides and meals.

Participants who described experiences where their teenage children were able to connect with other youth sharing similar experiences was paramount to their ability to cope. One adolescent returned from attending a weeklong session of summer camp for youth facing parental cancer in which his parent described,

...I'll never forget I was driving somewhere and he was like mom, I learned how to laugh again. Like, and I just remember being like, oh...and he said so it's like I learned how to have fun. I um...so they're going back like every year now.

That was probably one of the best decisions because it's not focused on cancer.

But, you know, you're with people that have gone through it. And so everyone's in the same boat, like trying to find joy and get rid of their stress and anxiety and just be kids.

These experiences, along with support groups, were frequently cited as a very effective coping method for their children. Another parent, whose adolescent child also attended a week of summer camp session for children who have/had lived with parental cancer said her child reported,

And I asked her, I don't know, she'd been home maybe a week and I asked her so like on a scale of 1-10-where 1 is like awful horrible and 10 is like the best thing ever. Like what was camp? Because she hadn't ever done a sleepaway camp up to that point. She said it was a 10, no hesitation. And ... it was really good experience.

Parents typically brought up the use of various therapeutic interventions as coping methods with mixed feelings. Some parents believed that therapy was very helpful for their adolescent child, some believed they hadn't found a therapist that connected well with their child individually, they tried attending therapy virtually (either for convenience or due to COVID) to no avail, or their child refused to attend. Some of the parents revealed that their children were already seeing a mental health professional prior to their cancer diagnosis, and although they hoped that therapy was "overall helpful" to them, they did not know if it was specifically impactful for coping with parental cancer, managing other stressors, or even at all.

The subtheme of additional time spent as a family stemmed from the interviewees expressing that additional time together as a family unit was also implemented as a coping skill

by their adolescent children. The conception of what constituted spending time as a family varied between participants. Some primary caregivers mentioned that they “bonded” with their adolescent children by “giving them roles” in the cancer experience such as requesting prayers before bedtime, assisting with medication management, or having them shave their head before receiving chemotherapy treatment. Others stated that because their family was having this “shared experience”, they were conscientious to participate with their adolescent children, even if that meant just maintaining routines or attending family vacations that their children were looking forward to- even if the parent wasn’t feeling well, which they believed was well received by the children. One participant felt like her adolescent child would cope better if she felt like she was included in the cancer journey with her parent:

My kids were not old enough to go with me to treatment because you had to be 16...I think that was the minimum to accompany somebody to treatment. But I brought home the little drip bags that I got the chemo through with all the wires and everything and I showed it to them. I was like, this is what's happening for me when I go to treatment. So they could picture it. You know, I sit in this chair and they put the medicine in these bags and it drips through these lines into my port. And um they were kind of like ew, but I wanted them to be able to have a concrete picture because again, if the mind...the mind is going to go places, is going to imagine things. So I tried to give them actual tangible information to fill their imagination instead of um them making stuff up.

Overall, the adolescent children in these families ostensibly could depend on their family members to provide relatable social support throughout various stages throughout the course of

their parent's cancer. As another participant elegantly described, "...even though it's like 1,000% bad you know, there's, there were some good things that came out of it."

#### ***Theme 4- Intentional Disclosure of Information Related to Cancer***

There was also a consensus among the interview participants that their adolescent children would be able to cope more "effectively" with the parent's diagnosis and treatment based on intentional and careful delivery of information about the cancer prognosis and course. It was commonly affirmed by participants that they didn't want to "impose" their negative feelings, such as fear or their anxieties about the cancer experience "onto" their children. In essence, the parents were careful and deliberate when providing them information related to the cancer. All participants unanimously agreed that at no point they thought about "hiding" the diagnosis or treatment from their adolescent children. One participant said "I mean there wouldn't have been any hiding it. There wouldn't....it would have been hard to hide ... and I don't think, I just don't think it would have been good for them." Most participants shared similar sentiments, although they emphasized that they were "selective" with the information that they shared based on what they thought was appropriate depending on age and developmental level.

And so I was also careful with the information I shared not to overshare and give them more than they were asking for, but to see what questions they had after I shared kind of the basic outline.....So disclosing things that are appropriate and that the kids can understand on the spectrum from, you know, total transparency to total secrecy. Neither end of that spectrum I think is healthy but choosing based on knowing your kids like what they can hear. Like I didn't tell them what the oncologist had told me, which was...I asked if I, you know what if I don't wanna do treatment. What if I just want to live the remaining days that I have

with a good quality of life and then not just not do all the things, how long would I have? And she said less than a year and I said, oh....sign me up for the treatment. That's a little sooner than I'm, um, prepared to leave this earth.

The participants further elaborated that besides not wanting to hide their diagnosis from their children, they believed adolescents were simply too “perceptive”. They strongly believed that their teenagers were very attuned to what was going on with them individually and as a family unit, they would know when something was “off”. One participant recounted how she was simultaneously being treated for cellulitis before telling her children about being tested for cancer, when her son had already hinted at knowing something more serious was happening,

Um, but my older one is a very, very perceptive little boy and he could tell by the mood that something was wrong. And that night he asked my husband, like, can you die from cellulitis? Because he could tell something was very wrong.

Besides not wanting to “gatekeep” information from their adolescent children, all participants were firmly decided that due to the “perceptiveness” of their teenage children, they would have only hindered their coping abilities by “withholding” of their cancer status.



## CHAPTER VI. DISCUSSION

With increasing rates of cancer in adults across the world, greater attention has been paid to the mental health status, stress, and coping strategies of children living with a parent diagnosed with cancer. Perhaps one of the interview participants of the current study stated it best when she said,

I think, you know, when you're a kid, your parents have such a powerful role in your life, they seem invincible, they seem immortal, they seem all knowing. And I think part of the shock for her was just like, what, you know, my mom is not invincible, immortal, whatever those unconscious conceptions are that she had. And then of course, just the, the shock of like, that's a really serious diagnosis.

A growing body of research has pointed to the diverse coping strategies and varied mental health outcomes in children living with parental cancer (Ellis et al., 2017, Faccio et al., 2018, Huang et al., 2014, Morris et al., 2018). Building on prior work in this area, this study sought to provide additional insights into the experiences of 11–17-year-olds when faced with living with a parent/primary guardian who has been diagnosed with cancer. Grounded in propositions in stress and coping and family resiliency theories from a developmental standpoint, this mixed-methods study aimed to examine relationships between adolescent's (a) perceived stress of parental cancer in relation to specific coping strategies, (b) perceived stress of parental cancer and psychosocial functioning, and (c) use of specific coping strategies relative to psychosocial functioning. It is hoped that the quantitative and qualitative data gathered herein will assist us to better understand how adolescents manage the intricacies of parental cancer and guide the development of prevention and intervention programs.

## Perceived Stress and Coping

As per the hypothesis, there were significant positive correlations between higher levels of perceived stress and disengagement coping, involuntary engagement, and involuntary disengagement coping. Although most studies did not compare specific coping strategies to rates of stress, the increased rates of the aforementioned coping strategies for adolescents is consistent with previous literature (Shah et al., 2017). There appears to be a prevailing assumption throughout empirical literature that higher rates of stress are associated with coping that is typically considered as more maladaptive, which was supported by the results of this study. However, this study did not expect, nor did it demonstrate significant correlations between more “adaptive” coping strategies and lower levels of perceived stress. Since the specific type of stress measured in this study is generally perceived as uncontrollable, separate from “expected” stressors of adolescence, and appraised as particularly alarming due to its life-threatening nature, it is likely that more adaptive coping strategies would not be as typically employed. It is also conceivable that the parents who are rating their adolescent’s stress did not perceive their stress as high until they were engaging in perceivably less adaptive coping strategies.

These associations are further in accord with those found in other samples of adolescents coping with parental cancer as evidenced by the mean comparison effect sizes. The effect sizes of mean comparisons between disengagement coping between this study and the Chowdhary et al. (2016)’s study ( $d=0.577$ ) and the Mía Marín-Chollom (2017) study ( $d=0.524$ ) are moderate. One of the possible reasons for the moderate effect sizes of disengagement coping across studies could be attributed to developmental use of disengagement coping, and disagreements as to whether the subscale of distraction should be measured as secondary control engagement coping (as was measured in these studies) or as a disengagement coping strategy. It has been debated

whether the use of distraction is a conscious choice to adapt to the stressor or as a strategy to separate oneself from the stressor. Previous research argues that measures of distraction such as sleeping, increased screen time (social media, video) and/or social withdrawal, would routinely involve increased isolation, which would presumably reflect disengagement strategies (Waugh et al., 2020). Although previous studies have confirmed construct validity with distraction loading onto secondary control engagement coping, perhaps the subscale should be reexamined to allow continuous differentiation on advancing knowledge between various distraction strategies as a coping skill (Compas, 2005).

It is relatively well-known that adolescence is a developmental stage that consists of substantial physiological, cognitive, emotional, and social growth (Lansford & Banati, 2018; Roberts & Lopez-Duran, 2019), so much so, that it is often pointed out that the word adolescence most likely derives from the Latin word “adolescere”, which translates as “to grow to maturity” (Lansford & Banati, 2018; Slee & Shute, 2015). As such, it can be argued that the influx of growth during this stage is related to the mounting stress of navigating developmental changes and challenges. A type of stress that is not predominantly “expected” during adolescence is managing complexities that arise within a family system, such as when a parent is diagnosed with a serious and potentially life-threatening disease, such as cancer. Arguably, some stress during adolescence, mainly in terms of managing academics, social and familial relationships, and other factors should be expected, but it may be seen as exceptionally stressful to have a disruption to family dynamics that affects the status quo (Maya et al., 2018). Research suggests that adolescents who have a parent with cancer are at elevated risk for perceiving stress because they comprehend more particulars surrounding the impact of a parental cancer diagnosis that would disrupt individual and familial functioning levels, more so than younger children would be

able to process (Azarbarzin et al., 2016). This is exemplified by an interview participant who agreed with this notion when she remarked that, “You know maybe if they were like 2 or 3 it would have been easier. But not...not at their age.” Even so, comparatively little is known about how adolescents who are stressed perceive their experience with parental cancer. In comparison to a similar study, the mean sizes of perceived stress was larger and the effect size of perceived stress between this study and the Mía Marín-Chollom (2017) is interrupted as large ( $d=1.17$ ). It appears that samples of adolescents with parental cancer may not have similar perceptions of stress related to experiencing parental cancer, perhaps because of rater differences and/or cultural-level stressors/perceptions of stress. The variable nature of the stressors described during the qualitative interviews of the present study was also consistent with past research that revealed many of the same stressors with those of adolescent children’s “worries” and “distresses” in relation to parental cancer (Zahlis, 2001).

It is also the case that coping responses of adolescents are customarily structured around operational constructions of adults coping with stress (Compas et al., 2010). There is even further discrepancy in understanding, principally for adolescents, on whether typical coping responses can be categorized as “good” or “bad” or even “adaptive” or “maladaptive”. For example, past research categorizes distraction and/or disengagement coping as maladaptive (Perzow, 2019). Other researchers disagree with this stance and have found that adolescents partake in these coping strategies regardless of source or number of stressors (Stapley et al., 2023; Stapley et al., 2020a). Considering that the prefrontal cortex of the brain is not fully developed in adolescents where the more “adaptive” strategies of problem-solving and emotional regulation would be processed, distraction and even disengagement coping may be more adaptive than previously believed (National Academies of Sciences, Engineering, and Medicine

[U.S.], 2019; Abrams, 2022). Lately, researchers have addressed this by distinguishing between “good”, “neutral”, and “bad” distraction. “Good” distraction is any type of distraction that elicits positive emotional responses (Perzow, 2019). The ratings of coping should thus continue to be examined under a developmental lens so assumptions of what is adaptive coping for an adult or even child is not assumed to be consistent for those of adolescents. These constructs should also be scrutinized for a more definitive connection between which individual stressors elicit which coping responses specifically.

The interview participants were forthright about how many additional stressors their teenagers faced, besides the parental cancer experience. Following the theoretical notions of Compas (2005) that stress is not general, but based on specific circumstances, the present study measured the singular perceived stress dimension of parental cancer. The responses of the interview participants illuminate the notion that even if stress is not generalized, multiple specific measures of perceived stress should feasibly be accounted for, specifically with adolescents. Considering the ACEs model, that if these stressors are conceptualized as risk factors, the accumulation of these stressors may be compiling onto an adolescent sufficiently enough to move them away from a path towards resiliency, and rather onto one where they are needing to employ less adaptive coping strategies (Centers for Disease Control and Prevention, 2021).

### **Perceived Stress and Mental Health**

Relations between stress and mental health are reasonably well documented in the psychological sciences. The bulk of this research, though, is normally centered around the connections between perceived stress and psychosocial measures most commonly among adults (Romeo, 2017). To that end, comprehensive links between perceived stress and psychosocial functioning in adolescents, who are markedly more “perceptive” and sensitive to environmental

risks, such as with familial level factors accompanying parental cancer than other developmental groups, are not well established (Landi et al., 2022; Inhestern, 2021). In this study, there were significant correlations between perceived stress of parental cancer not only with total psychosocial functioning, but with all three subscales of the PSC-17 in terms of externalizing, internalizing, and attentional scores as well. As suggested by parents in the interviews, some youth already struggled with psychosocial functioning prior to their diagnosis, while other issues of psychosocial adjustment arose throughout the progression of a parent's cancer journey. There should be additional exploration to determine specificities about how perceived stress of living with a parental cancer exacerbates an adolescent's mental health status. Connor-Smith et al. (2001) clearly specified that the coping responses to perceived stress that one would most frequently employ were likely related to the individual qualities of the stressor- such as its "intensity and controllability". Considering that the stress of living with parental cancer is unexpected, impacts "normal" daily life, and is often assessed as completely out of the adolescent's control, it is possible that the coping responses that are generally recognized as "less adaptive" would be employed. The results of this study are congruent with these previous findings more broadly regarding stress and mental health of adolescents (Sigfusdottir et al., 2016). However, the social stress model of health posits viewing stress as, "a reorientation away from viewing stress as an isolated risk factor and toward its consideration as a link in a causal chain beginning with social conditions and ending with differences in risk for psychological distress" (Sigfusdottir et al., 2016; Aneshensel, 1992). Perhaps additional research should explore the interplay between exposure to multiple, but specific circumstances that are rated as generally more stressful than others, and their relationship to psychosocial outcomes.

## **Mental Health and Coping**

Based on existing research, it was expected that increased impairment in psychosocial functioning would be associated with coping strategies that are generally considered less adaptive (Compas et al., 2001; Dijkstra & Homan, 2021). This trend was also found in the present study as high psychosocial functioning issues were significantly correlated with use of disengagement, involuntary engagement, and involuntary disengagement coping methods. Coping is becoming more routinely recognized as a multidimensional process. Meaning, people do not traditionally employ just one type of coping strategy and they are often used in conjunction with each other (Perzow, 2019). There is also evidence that more traditionally categorized maladapted coping approaches (disengagement, involuntary engagement, and involuntary disengagement) are used as a last resort when one or more of the other more adoptive coping skills were not initially successful in reducing stress. Disengagement strategies are also distinctly recognized as being more highly used during short-term uncontrollable circumstances but are maybe more maladaptive and related to poorer psychosocial outcomes if used in the long-term (Perzow et al., 2021). There is also past research that supports the notion that adolescents feel limited on who they can discuss, vent, and communicate to about their parent's cancer experience (Alexander et al., 2023; Morris et al., 2018), as was shared during the qualitative interviews. Given that theoretical conceptions of adolescents are largely characterized as being heavily dependent on their peers for support and coping, this also may change and/or limit their perceived coping capabilities (Giesbers, 2010). The need for extended social support to enhance coping abilities is echoed in past literature, such as indicated in a small-scale qualitative study of adolescents facing parental cancer in Australia (Maynard et al., 2013). This finding was also denoted in a Swedish study that conducted a focus group where adolescents

reveled that not only were they selective about which peers they shared information about their parent's cancer diagnosis with and had difficulty with informing peers, but they also did not feel like peers and friends could visit their house as frequently due to their parent being sick and/or more prone to infections (Jansson & Anderzén-Carlsson, 2017). Indeed, Tremolada et al., (2016) concluded in their research study that perceived social support was the "key" to psychological well-being of adolescents. However, other studies reported that increased social support was not influential on coping behavior (Su & Ryan-Wenger, 2007; Lewis et al., 1993). Although the RSQ measure of the survey did not specifically measure social support as a coping construct, it can be argued that increased use of primary and secondary control coping strategies would be best facilitated, modeled, and implemented with the support of peers, friends, and family. It's feasible that those adolescents navigating parental cancer must reconceptualize what social support entails in their specific circumstances.

In this study, there was a positive correlation between increased externalizing behaviors and use of both methods of involuntary coping, which is somewhat consistent with patterns found in prior research, even though externalizing behaviors are historically less recognized as problematic among adolescents (Compas et al., 2017). Since involuntary coping is measured by strategies such as physiological arousal, emotional arousal, involuntary action, and escape, it is feasible that some of the adolescent's perceived externalizing behaviors could be simultaneously serving as coping responses to them. Scores on the attentional subscale showed significant and positive correlations with both types of involuntary coping. Overall, this may suggest that adult's perceptions of issues with attention could be concurrently working as an effective method of stress reduction for adolescents. Additionally, significant correlations were established between internalizing behaviors and both types of disengagement coping. This too makes sense bearing in



mind that disengagement coping is classified by use of avoidance, denial, emotional numbing, and cognitive interference tactics, where those internalizing behaviors can provide a means to coping. Some of the interview participants contributed much of their and their adolescent's ability to engage in "adaptive" coping to their participation and support from faith groups. There is not any known research that assessed the use of faith groups as social support when coping with parental cancer, but one previous study did find a strong positive correlation between religious faith and posttraumatic growth and another between the cultural concept of *Espiritu* with reduced appraised stress (Marín-Chollom & Revenson, 2022; Ward, 2014).

### **Limitations**

Despite the fact that this study determined links between coping strategies and behavioral difficulties among children living with parental cancer, it has several limitations. On the methodological front, the sample size is rather small, relatively homogeneous, and largely recruited through convenience sampling. All of the parent participants of the quantitative data portion of the study were already engaged with programming through Camp Kesem. Especially given what the parents in the qualitative interviews mentioned about the importance of social support for their adolescent children, previous participation with Camp Kesem may have played a role in influencing the measurement of stress and coping abilities of those families who have already sought out such programming.

Originally scheduled for Summer 2020, data collection was delayed due to the overarching ramifications of the COVID-19 pandemic. It became impossible and unethical to collect the survey data in person, even in Summers 2021 and 2022, considering that the study involved surveying a mostly immunocompromised sample. Consequently, the survey collection portion was moved online and subject to the timing of communication from the partner

organization. Although cooperation and interactions with the partner organization were robust, the Camp Kesem representatives may have been correct in the assessment of this sample being routinely inundated with email communication and was not interested in completing an online survey, regardless of incentive offered. On top of that, there is the possibility that the survey was viewed as too long. A few participants (that were not included in the study) started the survey and then abandoned it part of the way through. All of this resulted in a very small sample size that limited the types of statistical analyses that were able to be performed. Moreover, the sample was also subjected to influences by an overwhelming majority of WEIRD (western, educated, industrialized, rich and democratic) participants. The lack of diversity in the sociodemographic characteristics of the sample (most identified as White, biological mothers) in both the quantitative and qualitative portions of the study, prevents generalizability of the findings to other cultural/ethnic groups.

The quantitative design of the study was cross-sectional and collected throughout the Covid-19 pandemic. Moreover, the results were largely correlational and thus precluded causal inferences about relations between variables being established. Given that COVID-19 was a stressful event for many individuals in the United States and around the world, it is conceivable that stress accumulation of COVID-19 factors could have impacted the findings, either positively or negatively. One parent interviewed made the comment that when she told her children about being diagnosed with cancer, she thought maybe they weren't as "shocked" as they would have been before the pandemic because it is possible that they built up some resiliency coping with all the unknowns and stressors of COVID-19.

The survey questions in the current study did ask participants to rate their adolescent's perceived stress/coping in relation specifically to the parent's cancer experience. As the

participants in the interviews astutely distinguished, at times, their adolescents appeared to have stress from a variety of sources (including for some COVID-19). Ergo, it is subsequently difficult to pinpoint exactly when stress and associated coping skills were parental cancer related and which were associated with other stressful events and experiences. The surveys and interviews were also based on parental reports of their children's experiences. Some disagreement is found throughout empirical literature on whether parental reports provide "accurate" depictions of their children's perceptions. Recent research indicates that there is usually some discordance between parents and their adolescent children's reporting behaviors, primarily within dimensions of family functioning (De Los Reyes et al., 2019).

### **Implications and Recommendations for Future Research**

As cancer persists as a serious threat to health in the United States and throughout the world and as the average age of people becoming parents increases, there is an ever-growing need to discern more about how a parent's cancer impacts their offspring. There is an additional rising concern about the lack of availability of cancer screenings that were accessible throughout the COVID-19 pandemic. Some research and health professionals are indicating upsurges in the diagnosis of late-stage cancer diagnoses due to the lack of preventative care opportunities from this period (Guyen et al., 2021; Joung et al., 2022; Mentrasti et al., 2022; Zhou et al., 2022). This concern denotes the need for additional support and interventions to address the psychosocial ramifications associated with familial cancer, namely with the increasing threats to coping associated with late-stage diagnoses (Niemelä et al., 2016). The current study provided additional details about manifold critical relationships, such as the associations with higher levels of perceived stress, less adaptive coping skills, and added concern for issues of psychosocial

functioning and higher rates of perceived stress, and use of potentially less constructive coping strategies.

This study contributes to the limited body of knowledge about adolescent stress, coping, and mental health in conjunction with a parent's cancer. It is the only known study to have used parents' ratings of adolescent's direct measurements of perceived stress and coping explicitly related to parental cancer. As previously stated, the findings from this study are based on a very small sample size. Future studies would benefit from continuing research within this area with larger sample sizes, especially where variables can be more broadly measured and controlled for (gender, type of cancer, parent-child dyad- fathers and sons, mothers and daughters, etc.). Of note, the parents/primary guardians as sole reporters of their adolescent child's behaviors could be improved upon. Obtaining replies from multiple respondents including the adolescent's themselves and teachers at school would have been preferable (De Los Reyes et al. 2019). Including a more diverse sample would have also been preferable as it would have increased the generalizability of the findings between stress and coping and adolescent mental health. Conducting mean comparisons across studies and computing corresponding effect size did show commonalities, namely in primary control engagement coping across studies. However, continued analysis of samples with more diversity in several sociodemographic domains would be highly beneficial for enhancing knowledge of cultural and familial level variables that might contribute to the adolescent's experiences of navigating parental cancer.

Results from this study would have been more enlightening if it included a control group of adolescents not living with parental cancer. There is tremendous variation with respect to perceived stress, coping methods, and psychosocial functioning of adolescents. It would thus seem prudent to have clearer conceptions on the perceived stress levels of adolescents without

managing parental cancer and how that plays a role in their coping abilities and psychosocial functioning. Parents in the interviews identified that parental cancer was one of the numerous sources of stressors that adolescents were contending with. It is relatively well-established that stressors perceived as “out of one’s control” are associated with less useful coping strategies. Following the Compas model (2000) that stress is based on specific criterion, it would be exceedingly advantageous to know more about whether the threshold for the amount and/or negative implications of individual and familial-level stressors exceed or challenge one’s ability to cope most effectively.

The qualitative portion of the study was instrumental in demonstrating the importance of coping in terms of adolescents having access to peers and support where they feel like they can express their thoughts and feelings, without burdening others with them. While some program evaluation reports exist specifically for children living through parental cancer, there is a prevailing need for expansion in this area (Phillips et al., 2021). During interviews, some parents expressed that their adolescent children actively benefited from peer and other social opportunities where they could spend time with others sharing similar experiences to living with a parent with cancer, but not necessarily with the intended goals of the program/intervention to be therapeutic in nature. This notion is also congruent with past literature on mental health interventions for children coping with parental cancer where they were concerned about increased therapeutic interventions becoming burdensome and/or stigmatizing (Romer et al., 2007). At the same time, it would be exceptionally beneficial to have continued elaboration on how interventions should be tailored to reduce stress and increase adaptive coping skills for managing parental cancer. Very recent interventional research has started to explore this notion with demonstrating emphasis on communication between parents with cancer and their

adolescent children (Hauken & Farbroth, 2022). Overall, the results of this study indicate that interventional programming for adolescents who are managing parental cancer would be seemingly beneficial if the interventions consisted of opportunities to socially connect with others that are experiencing similar stressors, may be therapeutic in nature, but are not designed specifically to achieve therapeutic goals related to parental cancer, and also assist adolescents in communication of their stress experiences of parental cancer to peers, school officials, and other people that they interact with on a regular basis. The use of interventional programming specifically to enhance coping skills is a fairly regular practice among people who have undergone life-threatening conditions themselves but would also appear to be beneficial to those adolescents who are both managing living with a family member undergoing serious illness and testing out a number of different coping strategies that they could carry with me through adulthood (Morris et al., 2020).

The results of this study also validate prioritization of research that delineate factors impacting individual and familial level resiliency. The connection between coping skills and resiliency in adolescents is mutually reinforcing. From a developmental standpoint, it is standard that adolescents can somewhat comprehend the risks and consequences of a parent receiving a cancer diagnosis. As a result, their adaptation and abilities to engage coping methods associated with positive mental health when a family's situation is the source of the stressor would support critical demand of facilitating enhanced awareness surrounding adolescent resiliency development from both individual and familial levels. Effective coping skills contribute to the development of resilience in adolescents, which in essence, leads to better adjustment to a plethora of life challenges. As such, adolescents rated as "resilient" have an increased likelihood

to engage in a more diverse range of coping skills that enhances their ability to effectively cope with stressors, even those that are unexpected, and sustain their psychosocial well-being.

One of the more surprising subthemes that emerged from the interviews was related to issues that arose in the areas of academics and school, mainly with mother-daughter dyads. Almost all participants in the interview specified emerging school related issues, though perhaps more intensely with daughters than sons who had a mother diagnosed with cancer. One interview participant voiced, “Oh my daughter decided she was done with school. Just gave up.” The existing research is limited concerning the impact of parental cancer on children’s performance and behaviors in school. One study did not find associations between living with parental cancer and school-related issues in children and another even reported improved performance in school (Jeppesen et al., 2016; Inhestern et al., 2021), but other studies have reported that children felt like they had limited support and communication available at school (Hauken et al., 2018; Ainuddin et al., 2012). Hauken et al. (2018) surmised that there is a relationship between children with higher anxiety living through parental cancer and increased school-related issues. It would be beneficial to conduct further investigations on school-home communication and peer relationships of adolescents throughout parental cancer. A related area of inquiry could involve expanding upon the noteworthy but limited previous interventional work regarding preparedness for school officials regarding communicating with and helping their students with distresses surrounding parental cancer (Fasciano et al., 2007).

Although studies of stress and coping are certainly common throughout empirical literature, this study contained a few unique components that could warrant further investigation in future research. Mainly, measures of individual stress are still relatively novel, especially in relation to a multidimensional model of coping. Since the relationship between perceived stress

and coping, especially for adolescents is not as clearcut as previously imagined, the exploration of other variables as mediators between stress and coping, such as those related to individual resiliency (positive emotions, optimism, hopefulness), family resiliency (familial resources, cultural components, family support, parental modeling of coping strategies), general stress, and the use of social support would merit additional elaboration. Further research on these variables would also be influential in designing interventional programs that would specifically be suited to addressing perceived stressors that seem atypical and unexpected, such as a parent's cancer diagnosis. Research on stress and coping continues to merit critical investigation into improving the lives of youth, families, and adolescents in order to enhance their mental health status and improve overall psychosocial functioning.



## APPENDIX A

### Institutional Review Board Approval



#### INSTITUTIONAL REVIEW BOARD MEMORANDUM

**TO:** Jaipaul Roopnarine  
**DATE:** July 16, 2021  
**SUBJECT:** Expedited Protocol Review - Approval of Human Participants  
**IRB #:** 21-102  
**TITLE:** *Psychosocial Well-Being of Youth who are Impacted by Parental Cancer*

The above referenced protocol was reviewed by the Syracuse University Institutional Review Board for the Protection of Human Subjects (IRB) and has been given **expedited approval**. The protocol has been determined to be of no more than minimal risk and has been evaluated for the following:

1. the rights and welfare of the individual(s) under investigation;
2. appropriate methods to secure informed consent; and
3. risks and potential benefits of the investigation.

This protocol is approved as of **July 16, 2021**. An Expedited Status Report will be requested annually, until you request your study be closed.

It is important to note that federal regulations require that each participant indicate their willingness to participate through the informed consent process and be provided with a copy of the consent form. Regulations require that you keep a copy of this document for a minimum of three years after your study is closed.

Your consent form has been date stamped with the approval date. If at any time during the course of your research, a revised consent document is submitted to the IRB via an amendment, it will be stamped with the date the amendment is approved.

Formal amendment requests are required for any changes to the initially approved protocol. It is important to note that changes cannot be initiated **prior** to IRB review and approval; except when such changes are essential to eliminate apparent immediate harm to the participants. In this instance, changes must be reported to the IRB within five days. All protocol changes must be submitted on an amendment request form available on the IRB web site at: [Amendment-Request-Form.doc](#).

Any unanticipated problems involving risks to subjects or others must be reported to the IRB within 10 working days of occurrence on the Report of Unanticipated Problems form located on the IRB website at: [Report-of-Unanticipated-Problems.doc](#).

Thank you for your cooperation in our shared efforts to assure that the rights and welfare of people participating in research are protected.

Katherine McDonald  
IRB Chair

DEPT: FALK Human Development & Family Science, 174 White Hall

STUDENT: DeAnna Bay

Office of Research Integrity and Protections  
214 Lyman Hall, 100 College Place  
Syracuse, NY 13244

T: 315.443.3013  
orip@syr.edu

TO: Jaipaul Roonnarine  
DATE: February 22, 2023  
SUBJECT: **Amendment Approval - Use of Human Participants**  
IRB#: 21-102  
AMENDMENT#: 1 - A) Consent Form Changes (New);  
B) Change in and/or Addition of Research Instruments/Tools  
TITLE: *Psychosocial Well-Being of Youth Who are Impacted by Parental Cancer*

Katherine McDonald  
IRB Chair

**STUDENT:** DeAnna Bay

**T: 315.443.3013**  
orip@syr.edu

## APPENDIX B

### Recruitment Materials

#### Email to primary guardians

Subject: Survey of Camp Kesem Families and Raffle Prize Entry

Hello,

My name is DeAnna “Fin” Bay and I am not only a Mental Health Professional and Hotline Operator with Camp Kesem, but I am also a Doctoral Student in Human Development and Family Science at Syracuse University.

Being part of the wonderful Camp Kesem family has led me to want to direct my research endeavors into learning more information that can potentially help families affected by a parent diagnosed with cancer.

I am therefore inviting you to participate in a survey that asks questions about your 11-17-year-old child's mental health, stress, and coping mechanisms in relation to their parent's diagnosis. **You are eligible to participate if you are a parent and/or legal guardian (aged 18+) of a child aged 11-17 who has/had a parent diagnosed with cancer, have an electronic device and email account to take the survey, and can read/write in English. If you have more than one child in that age group, you can answer the questions with whichever child you feel you can best answer the questions for.** It will take about 20-30 minutes to complete the questionnaires.

At the end of the study, you will also have the opportunity to:

- 1) Share your child's email in order to obtain results to compare between parents and their children's responses and
- 2) Be entered into a raffle to win a \$50 Amazon gift card.

Your participation in this survey is completely voluntary and all your responses will be kept confidential. No personally identifiable information will be associated with your responses to any reports of these data. The Syracuse University Institutional Review Board has approved this survey. Should you have any comments or questions, please feel free to contact me at [dbay01@syr.edu](mailto:dbay01@syr.edu).

The link to the survey can be found here:

[https://syracuseuniversity.qualtrics.com/jfe/form/SV\\_06RWU9UrTApJiUl](https://syracuseuniversity.qualtrics.com/jfe/form/SV_06RWU9UrTApJiUl)

Thank you very much for your time and support with this research. Advancing knowledge of families who experience living with a parent with cancer is very important to us.

CLAM,

DeAnna

## Survey consent form

Syracuse University  
IRB Approved  
JUL 16 2021



### Informed Consent of Parent Electronic Consent

Psychosocial Well-being of Youth who are Impacted by Parental Cancer

Jaipaul Roopnarine  
[jroopnar@syr.edu](mailto:jroopnar@syr.edu)  
315-443-4586

DeAnna Bay  
[Dbay01@syr.edu](mailto:Dbay01@syr.edu)  
315-572-0910

My name is DeAnna Bay and I am a Doctoral Candidate in Human Development and Family Science at Syracuse University and Jaipaul Roopnarine is the faculty mentor. I am asking you to participate in this study on the experiences and adjustment patterns of a child living with a parent diagnosed with cancer. Any parent and/or legal guardian of a child aged 11-17 who has/had a parent diagnosed with cancer is eligible to participate.

The purpose of this form is to provide you with additional information concerning this research study and allow you the opportunity to decide if you would like to participate. You can take as much time as you wish to decide and can ask any questions you may have now, or during or after the research is complete. Your participation is voluntary.

The purpose of this study is to learn more about the stress and coping mechanisms of youth ages 11-17 who live with a parent diagnosed with cancer.

You will be asked to complete online questionnaires on your child's mental health symptoms, stress, and coping patterns and to provide sociodemographic information about yourself and your family (i.e., education level, age, gender, etc.). You will be asked to fill out the Pediatric Symptom Checklist 17 (PSC-17; i.e., Does your child feel down on him or herself) and the Responses to Stress Questionnaire (RSQ; i.e. He/she decides that they are okay the way they are, even though they are not perfect). If you have more than one child in the 11-17 age group, you can answer the questions with whichever child you feel you can best answer the questions for. These questionnaires should take approximately 20-30 minutes to complete.

The risk to you, as a participant, is no greater than what you would encounter in everyday life. There is always a minimal risk to confidentiality when participating in research, but the researchers are making every attempt to keep the answers confidential. You are not required to answer any question that you do not want to answer. You can skip any question at any time. You may withdraw from the study at any time without penalty. If you or your child do not want to take part, you or your child have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you/your child have the right to withdraw from the study at any time, without penalty.

Syracuse University  
IRB Approved  
JUL 16 2021



Data will be collected in a private location through the participant's private home electronic devices. The data being recorded will be secured on DeAnna's password-protected laptop. However, whenever one works with email or the Internet, there is always the risk of compromising privacy, confidentiality, and/or technology being used. It is important for you to understand that no guarantees can be made regarding the interception of data sent via the Internet via third parties.

There are no direct individual benefits to participating in this study. However, data from this study may help us better understand, stress and coping among youth who have/had a parent with cancer.

The responses from you and your child will be kept as confidential as possible. We will assign a number to you and your child (e.g., 001 parent 001 child) and only the researchers will have the key to indicate which number belongs to which participant. In any articles we write or any presentations that we make, we will not reveal details about you or your child. After the removal of identifiable private information, the information may be used for future research studies without additional consent from the participant or the legally authorized representative.

All study materials will be secured electronically on a password-protected laptop. All data will be kept as confidential as possible, with the exception of certain information we must report for legal or ethical reasons (e.g., child abuse which must be reported to the state authorities).

If participating in the study produces any feelings of discomfort or unease, you may contact me, DeAnna Bay at [dbay01@syr.edu](mailto:dbay01@syr.edu) and I will provide you with the contact information of a licensed mental health practitioner that you can connect with virtually.

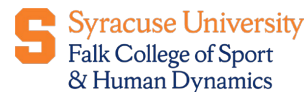
By participating in this study, you will be able to enter your name in a raffle to win a \$50 amazon gift card. Every person in your family that participates has a chance of winning one of the 4 \$50 gift cards and the odds of winning the gift card are 1 in 50.

As a research participant, you/your child have the following rights...

- You/your child's participation is voluntary
- You/your child may skip and/or refuse to answer any question for any reason
- You/your child is free to withdraw from this research study at any time without penalty.

For questions, concerns, or more information regarding this research you may contact DeAnna Bay at [dbay01@syr.edu](mailto:dbay01@syr.edu) or at 315-572-0910 or Jaipaul Roopnarine at [jroopnar@syr.edu](mailto:jroopnar@syr.edu) or at 315-443-4586. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator, or if you cannot reach the investigator, contact the Syracuse University Institutional Review Board at 315-443-3013.

Syracuse University  
IRB Approved  
JUL 16 2021



All of my questions have been answered, I am 18 years of age or older, and I wish to participate and/or have my child between 11 and 17 years of age participate in this research study. I have printed a copy of this form for my personal records.

If you agree to having your child participate in the study, please provide detail of that agreement in the boxes below (e.g., "I consent to the procedures described in the Informed Consent document you provided, and my child (John) provided verbal assent to participating and they can be contacted using the following email address ([john@bearelementary.edu](mailto:john@bearelementary.edu))").

I agree to having my child participate in the study and their name and email is included below (if you do not agree, leave the following boxes blank):

<b>Name:</b> _____	<b>Email:</b> _____
--------------------	---------------------

By continuing I agree to participate in this research study.

☐ I agree

->

## Interview consent form

Syracuse University  
IRB Approved  
FEB 22 2023



### Oral Consent of Adult Participants Electronic Consent

Psychosocial Well-being of Youth who are Impacted by Parental Cancer

Jaipaul Roopnarine  
[jroopnar@syr.edu](mailto:jroopnar@syr.edu)  
315-443-4586

DeAnna Bay  
[Dbay01@syr.edu](mailto:Dbay01@syr.edu)  
315-572-0910

My name is DeAnna Bay and I am a Doctoral Candidate in Human Development and Family Science at Syracuse University and Jaipaul Roopnarine is the faculty mentor. I am asking you to participate in this study on the experiences and adjustment patterns of a child living with a parent diagnosed with cancer. Any parent and/or legal guardian of a child aged 11-17 who has/had a parent diagnosed with cancer is eligible to participate.

The purpose of this form is to provide you with additional information concerning this research study and allow you the opportunity to decide if you would like to participate. You can take as much time as you wish to decide and can ask any questions you may have now, or during or after the research is complete. Your participation is voluntary.

The purpose of this study is to learn more about the stress and coping mechanisms of youth ages 11-17 who live with a parent diagnosed with cancer.

You will be asked to participate in an interview either in person, on the phone, or over zoom. The interview should take approximately 45 minutes-1 hour to complete. Approximately 6 participants will be contributing interviews to the study.

The risk to you, as a participant, is no greater than what you would encounter in everyday life. There is always a minimal risk to confidentiality when participating in research, but the researchers are making every attempt to keep the answers confidential. You are not required to answer any question that you do not want to answer. You can skip any question at any time. You may withdraw from the study at any time without penalty. If you do not want to take part, you have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you have the right to withdraw from the study at any time, without penalty.

Whenever one works with email or the Internet, there is always the risk of compromising privacy, confidentiality, and/or technology being used. It is important for you to understand that no guarantees can be made regarding the interception of data sent via the Internet via third parties.

Syracuse University  
IRB Approved  
FEB 22 2023



There are no direct individual benefits, though the benefits to others include that you may be contributing to the body of knowledge regarding stress and coping of youth that have/had a parent with cancer in order to be able to better assist other youth and families that are in similar situations as their own.

Your responses will be kept as confidential as possible. The interview will be audio recorded with your permission. The recordings will be transcribed and then they will be deleted after transcription is complete. The recordings will solely be used for data collection and analysis. Dr. Roopnarine and DeAnna Bay are the only people that will have access to the recordings. The data will be de-identified before being stored and saved electronically on a password-protected computer. In any articles we write or any presentations that we make, we will not reveal details about you or your family. After the removal of identifiable private information, the information may be used for future research studies without additional consent from the participant or the legally authorized representative.

All study materials will be secured electronically on a password-protected laptop. Your data will be kept as confidential as possible, with the exception of certain information we must report for legal or ethical reasons (e.g., child abuse which must be reported to the state authorities).

If participating in the study produces any feelings of discomfort or unease, you may contact me, DeAnna Bay at [dbay01@syr.edu](mailto:dbay01@syr.edu) and I will provide you with the contact information of a licensed mental health practitioner that you can connect with virtually.

As a research participant, you have the following rights...

- Your participation is voluntary
- You may skip and/or refuse to answer any question for any reason

For questions, concerns, or more information regarding this research you may contact DeAnna Bay at [dbay01@syr.edu](mailto:dbay01@syr.edu) or at 315-572-0910 or Jaipaul Roopnarine at [jroopnar@syr.edu](mailto:jroopnar@syr.edu) or at 315-443-4586. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator, or if you cannot reach the investigator, contact the Syracuse University Institutional Review Board at 315-443-3013.

Do you have any questions?

Are you 18 years of age or older?

Do you agree to be audio recorded?

How can I provide you with a copy of this consent script?



## APPENDIX C

## Data Collection Surveys

## Sociodemographics

2/22/2021

Qualtrics Survey Software

## Default Question Block

What do you consider your primary language?

☐ English☐ Other:

How old is your child?

☐ 6☐ 7☐ 8☐ 9☐ 10☐ 11☐ 12☐ 13☐ 14☐ 15☐ 16☐ 17☐ 18

What grade in school did your child complete last?

☐ Kindergarten☐ 1st grade☐ 2nd grade☐ 3rd grade☐ 4th grade☐ 5th grade☐ 6th grade☐ 7th grade☐ 8th grade☐ 9th grade☐ 10th grade☐ 11th grade☐ 12th grade

How does your child identify in terms of gender?

☐ Male☐ Female☐ Transgender☐ Other:

How many times has your child previously attended Camp Kesem?

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- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5+

**Has your child attended another camp?**

- ☐ Yes and if so, which ones?
- ☐ No

**Does your child attend events or receive other services specifically (i.e support groups) in relation to their caregiver's cancer diagnosis in school or in the community?**

- ☐ Yes and if so, which ones?
- ☐ No

**Does your child currently have any mental health diagnoses and/or receive therapeutic services?**

- ☐ Yes and if so, which ones?
- ☐ No
- ☐ Click to write Choice 3

**How many of children live in your home?**

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5+
- ☐ Other:

**How many people total live in your household?**

- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7+
- ☐ Other:

**What is your estimated yearly household income?**

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- ☐ \$20.00 and under
- ☐ \$20,000-\$100,000
- ☐ More than \$100,000

**What do you consider your primary ethnicity?**

- ☐ White
- ☐ Black or African American
- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Pacific Islander
- ☐ Hispanic, Latino, or Spanish origin
- ☐ Other:

**What is your religious/spiritual preference, if any?**

- ☐ Jewish
- ☐ Muslim
- ☐ Buddhist
- ☐ Hindu
- ☐ Protestant
- ☐ Catholic
- ☐ Atheist
- ☐ Agnostic
- ☐ Other:

- ☐ None

**Demographics- Parent not diagnosed with cancer****Are you the child's primary caregiver that is diagnosed with cancer?**

- ☐ Yes
- ☐ No
- ☐ Both of the child's primary caregivers are diagnosed with cancer

**How old are you?****What is your role as your child's caregiver?**

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Grandma
- ☐ Grandpa
- ☐ Aunt/Uncle
- ☐ Foster Mother
- ☐ Foster Father

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- ☐ Adopted Mother
- ☐ Adopted Father
- ☐ Other:

**What is the caregiver's role in the family who is diagnosed with cancer?**

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Grandma
- ☐ Grandpa
- ☐ Aunt/Uncle
- ☐ Foster Mother
- ☐ Foster Father
- ☐ Adopted Mother
- ☐ Adopted Father
- ☐ Other:

- ☐ Multiple

**What is your marital status?**

- ☐ Single
- ☐ Divorced
- ☐ Married
- ☐ Widowed
- ☐ Domestic partnership
- ☐ Other:

**How old was the caregiver in your household when they were first diagnosed with cancer?****What type of cancer is the caregiver diagnosed with?****What stage is the caregiver's cancer diagnosis currently?**

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Deceased
- ☐ Unknown

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**What is the current status of the caregiver's cancer diagnosis?**

- ☐ Active treatment
- ☐ Remission
- ☐ Newly diagnosed
- ☐ Terminal
- ☐ Deceased
- ☐ Unknown

**What is the highest education level achieved of the caregiver diagnosed with cancer?**

- ☐ High school/GED
- ☐ Some college
- ☐ College graduate
- ☐ Advanced (i.e. master's or doctorate) college graduate

**Demographics-Parent with cancer diagnosis****How old are you?****What is your role as your child's caregiver?**

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Grandma
- ☐ Grandpa
- ☐ Aunt/Uncle
- ☐ Foster Mother
- ☐ Foster Father
- ☐ Adopted Mother
- ☐ Adopted Father
- ☐ Other:

**What is your marital status?**

- ☐ Single
- ☐ Divorced
- ☐ Married
- ☐ Widowed
- ☐ Domestic partnership
- ☐ Other:

**How old were you when first diagnosed with cancer?**

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What type of cancer are you diagnosed with?

What stage is the cancer diagnosis currently?

- ☐ Stage 1
- ☐ Stage 2
- ☐ Stage 3
- ☐ Stage 4
- ☐ Deceased
- ☐ Unknown

What is the current status of the cancer diagnosis?

- ☐ Active treatment
- ☐ Remission
- ☐ Newly diagnosed
- ☐ Terminal
- ☐ Deceased
- ☐ Unknown

What is your highest education level achieved?

- ☐ High school/GED
- ☐ Some college
- ☐ College graduate
- ☐ Advanced (i.e. master's or doctorate) college graduate

## PSC-17

### Pediatric Symptom Checklist 17 (PSC-17)

Emotional and physical health go together in children. Because parents are often the first to notice a problem with their child's behavior, emotions, or learning, you may help your child get the best care possible by answering these questions. Please indicate which statement best describes your child.

Please mark under the heading that best describes your child:      Never      Sometimes      Often

◆	Fidgety, unable to sit still	0	1	2
■	Feels sad, unhappy	0	1	2
◆	Daydreams too much	0	1	2
●	Refuses to share	0	1	2
●	Does not understand other people's feelings	0	1	2
■	Feels hopeless	0	1	2
◆	Has trouble concentrating	0	1	2
●	Fights with other children	0	1	2
■	Is down on him or her self	0	1	2
●	Blames others for his or her troubles	0	1	2
■	Seems to have less fun	0	1	2
●	Does not listen to rules	0	1	2
◆	Acts as if driven by a motor	0	1	2
●	Teases others	0	1	2
■	Worries a lot	0	1	2
●	Takes things that do not belong to him or her	0	1	2
◆	Distracted easily	0	1	2

RSQ

### RESPONSES TO STRESS – [Initials of Stressor Version] (SR-C)

This is a list of things about living with a parent who has/had a cancer diagnosis that children and teenagers sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for your child in the past 6 months.

	Not at All	A Little	Somewhat	Very
a. Concerns about conflict within the family	1	2	3	4
b. Concerns about the other parent/caregiver becoming sick	1	2	3	4
c. Having other people take care of him/her like a babysitter or another family member because parent(s) are gone so much	1	2	3	4
d. Having to take care of other people in his/her family (e.g., brothers and sisters)	1	2	3	4
e. Doing things that his/her parent would usually take care of	1	2	3	4
f. Feelings of guilt associated with the parent's cancer	1	2	3	4
g. Feeling uncertain about his/her own, parent with cancer, and/or family's future	1	2	3	4
h. Concerns about death/dying	1	2	3	4
i. Not relating well to peers (e.g., not knowing what to say to his/her friends and other people about the parent with cancer)	1	2	3	4
j. Concerns about "normal daily routines" being interrupted (e.g., social activities and school).	1	2	3	4
k. Concerns about his/her own health and/or getting cancer himself/herself	1	2	3	4

Circle the number that shows how much control your child generally thinks they have over these problems.

1                      2                      3                      4  
None                  A little                  Some                  A lot

Below is a list of things that children and teenagers sometimes do, think, or feel when they are dealing with a parent who has/had a cancer diagnosis. Everyone deals with problems in their own way – some people do a lot of the things on this list or have a bunch of feelings, other people just do or think a few of these things.

**Think of all the stressful parts of a parent's cancer diagnosis that you indicated above.** For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** your child does or feels these things when he/she has the problems with parental cancer like the ones you indicated above. Please let us know about everything he/she does, thinks, and feels, even if you don't think it helps make things better.

WHEN DEALING WITH THE STRESS OF A PARENT WHO HAS/HAD CANCER	How much do you do this?			
	Not at all	A little	Some	A lot
1. He/she <b>tries</b> not to feel anything.	1	2	3	4
2. When dealing with the stress of with a parent who has/had a cancer, he/she feels sick to their stomach or gets headaches.	1	2	3	4
3. He/she tries to think of different ways to change or fix the situation.	1	2	3	4



WHEN DEALING WITH THE STRESS OF A PARENT WHO HAS/HAD CANCER:		How much do you do this?			
		Not at all	A little	Some	A lot
Write one plan he/she thought of: _____					
4.	When faced with the stress of parental cancer, he/she doesn't feel anything at all, it's like they have no feelings.	1	2	3	4
5.	He/she wishes that they were stronger and less sensitive so that things would be different.	1	2	3	4
6.	He/she <b>keeps remembering</b> what is happening/happened to their parent with cancer or <b>can't stop thinking about</b> what might happen.	1	2	3	4
7.	He/she lets someone or something know how they feel. <i>(remember to circle a number.)</i> → <b>Check all you talked to:</b> <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these	1	2	3	4
8.	He/she decides that they are okay the way they are, even though they are not perfect.	1	2	3	4
9.	When around other people he/she acts like their parent's cancer never happened.	1	2	3	4
10.	He/she just <b>has</b> to get away from everything when they are dealing with the stress of parental cancer.	1	2	3	4
11.	He/she deals with the stress of parental cancer by wishing it would just go away, that everything would work itself out.	1	2	3	4
12.	He/she gets really jumpy when dealing with the stress of parental cancer.	1	2	3	4
13.	He/she realizes that they just have to live with things the way they are.	1	2	3	4
14.	When he/she is dealing with the stress of parental cancer, they just <b>can't</b> be near anything that reminds them of the parent's cancer diagnosis.	1	2	3	4
15.	He/she <b>tries</b> not to think about it, to forget all about it.	1	2	3	4
16.	When he/she is dealing with the stress of parental cancer, they really don't know what they feel.	1	2	3	4
17.	He/she asks other people or things for help or for ideas about how to make things better. <i>(remember to circle a number.)</i> → <b>Check all you talked to:</b> <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these	1	2	3	4
18.	When he/she is trying to sleep, they <b>can't stop</b> thinking about the stressful aspects of parental cancer or they bad dreams about the parent's cancer.	1	2	3	4
19.	He/she tells themselves that they can get through this, or that they will be okay.	1	2	3	4
20.	He/she lets their feelings out. <i>(remember to circle a number.)</i> → <b>He/she does this by:</b> (Check all that you did.) <input type="checkbox"/> Writing in my journal/diary <input type="checkbox"/> Drawing/painting <input type="checkbox"/> Complaining to let off steam <input type="checkbox"/> Being sarcastic/making fun <input type="checkbox"/> Listening to music <input type="checkbox"/> Punching a pillow <input type="checkbox"/> Exercising <input type="checkbox"/> Yelling <input type="checkbox"/> Crying <input type="checkbox"/> None of these	1	2	3	4

How much do you do this?  
Not at all   A little   Some   A lot

**WHEN DEALING WITH THE STRESS OF A PARENT WHO HAS/HAD CANCER:**

**You're half done. Before you keep working, look back at the first page so you remember the aspects of having parental cancer that have been stressful for your child lately. Remember to answer the questions below thinking about these things.**

21. He/she gets help from other people or things when they are trying to figure out how to deal with their feelings. *(remember to circle a number.)* → 1   2   3   4

**Check all that you went to:**

- ☐ Parent   ☐ Friend   ☐ Brother/Sister   ☐ Pet   ☐ Clergy Member  
☐ Teacher   ☐ God   ☐ Stuffed Animal   ☐ Other Family Member   ☐ None of these

22. He/she **just can't** get themselves to face the stress of parental cancer. 1   2   3   4

23. He/she wishes that someone would just come and take away the stressful aspects of Parental cancer. 1   2   3   4

24. He/she does something to try to fix the stressful parts of parental cancer. 1   2   3   4

**Write one thing they did:** \_\_\_\_\_

25. Thoughts about parental cancer just pop into his/her head. 1   2   3   4

26. When he/she is dealing with parental cancer or the stress of parental cancer, they feel it in their body. *(remember to circle a number.)* → 1   2   3   4

**Check all that happen:**

- ☐ Their heart races   ☐ Their breathing speeds up   ☐ None of these  
☐ They feel hot or sweaty   ☐ Their muscles get tight

27. He/she **tries** to stay away from people and things that make them feel upset or remind them of parental cancer. 1   2   3   4

28. He/she don't feel like themselves when they are s dealing with the stress of parental cancer. It's like he/she are far away from everything. 1   2   3   4

29. He/she just take things as they are; they can go with the flow. 1   2   3   4

30. He/she thinks about happy things to take their mind off parental cancer. 1   2   3   4

31. When something stressful happens related to parental cancer, he/she **can't stop** thinking about how they are feeling. 1   2   3   4

32. He/she gets sympathy, understanding, or support from someone. *(remember to circle a number.)* 1   2   3   4

**Check all you went to:**

- ☐ Parent   ☐ Friend   ☐ Brother/Sister   ☐ Pet   ☐ Clergy Member  
☐ Teacher   ☐ God   ☐ Stuffed Animal   ☐ Other Family Member   ☐ None of these

33. When something stressful happens related to the parental cancer diagnosis, they **can't** always control what they do. *(remember to circle a number.)* → 1   2   3   4

**Check all that happen:**

- ☐ They can't stop eating   ☐ They can't stop talking  
☐ They do dangerous things   ☐ They have to keep fixing/checking things  
☐ None of these

34. He/she tells himself/herself that things could be worse. 1   2   3   4

35. His/her mind just goes blank when something stressful happens related to parental cancer, they can't think at all. 1   2   3   4

WHEN DEALING WITH THE STRESS OF A PARENT WHO HAS/HAD CANCER:	How much do you do this?			
	Not at all	A little	Some	A lot
36. He/she tells himself/herself that it doesn't matter, that it isn't a big deal.	1	2	3	4
37. When he/she is faced with the stressful parts of parental cancer, right away they feel really: (remember to circle a number.) → <b>Check all that you feel:</b> <input type="checkbox"/> Angry <input type="checkbox"/> Sad <input type="checkbox"/> None of these <input type="checkbox"/> Worried/anxious <input type="checkbox"/> Scared	1	2	3	4
38. It's really hard for him/her to concentrate or pay attention when something stressful happens related to parental cancer.	1	2	3	4
39 He/she thinks about the things they are learning from parental cancer, or something good will come from it.	1	2	3	4
40. After something stressful happens related to their parent's cancer diagnosis, they <b>can't stop</b> thinking about what they did or said.	1	2	3	4
41. When stressful parts of the parental cancer diagnosis occur, he/she says to themselves "This isn't real."	1	2	3	4
42. When he/she is dealing with the stressful parts of parental cancer, they end up just lying around or sleeping a lot.	1	2	3	4
43. He/she keeps their mind off stressful parts of parental cancer by: (remember to circle a number.) → <b>Check all that you do:</b> <input type="checkbox"/> Exercising <input type="checkbox"/> Seeing friends <input type="checkbox"/> Watching TV <input type="checkbox"/> Playing video games <input type="checkbox"/> Doing a hobby <input type="checkbox"/> Listening to music <input type="checkbox"/> None of these	1	2	3	4
44. When something stressful happens related to parental cancer, he/she gets upset by things that don't usually bother him/her.	1	2	3	4
45. He/she does something to calm himself/herself down when they are dealing with the stress of parental cancer. (remember to circle a number.) → <b>Check all that you do:</b> <input type="checkbox"/> Take deep breaths <input type="checkbox"/> Pray <input type="checkbox"/> Walk <input type="checkbox"/> Listen to music <input type="checkbox"/> Take a break <input type="checkbox"/> Meditate <input type="checkbox"/> None of these	1	2	3	4
46. He/she just freezes when they are dealing with stressful parts of parental cancer, they <b>can't</b> do anything.	1	2	3	4
47. When stressful things happen related to parental cancer, he/she sometimes acts without thinking.	1	2	3	4
48. He/she keeps their feelings under control when they have to, then lets them out when they won't make things worse.	1	2	3	4
49. When something stressful happens related to the parent's cancer diagnosis, he/she can't seem to get around to doing things they are supposed to do.	1	2	3	4
50. He/she tells themselves that everything will be all right.	1	2	3	4
51. When something stressful happens related to parental cancer, he/she <b>can't stop</b> thinking about <b>why</b> this is happening.	1	2	3	4
52. He/she thinks of ways to laugh about it so that it won't seem so bad.	1	2	3	4
53. His/her thoughts start racing when they are faced with the stressful parts of parental cancer.	1	2	3	4
54. He/she imagines something really fun or exciting happening in their life.	1	2	3	4

WHEN DEALING WITH THE STRESS OF A PARENT WHO HAS/HAD CANCER:	How much do you do this?			
	Not at all	A little	Some	A lot
55. When something stressful happens related to parental cancer, they can get so upset that they can't remember what happened or what they did.	1	2	3	4
56. He/she tries to believe that it never happened.	1	2	3	4
57. When he/she is dealing with the stress of parental cancer, sometimes they <b>can't</b> control what they do or say.	1	2	3	4

**Guiding Interview Questions**

1. Tell me some background information about you, your family, and who lives in your household.
2. Tell me about the what the diagnosis procedure and course of treatment for the cancer diagnosis has been like.
3. How long after receiving the diagnosis and how did you tell your children about their parent's cancer diagnosis?
  - a. Is there any specific reasoning on the timing of when you told your children and why?
4. What parts of the cancer experience has seemed most stressful/taxing to your child(ren) and why do you think that is?
  - a. Were there any parts of the experience with cancer that you thought stressed them out more or less than what you initially believed?
5. How do you think your children "deal with" or cope with those cancer related stressors?
  - a. Are there any ways that they cope that you think are highly effective or any that don't really seem helpful?
6. Have any of the stressors or any of the children's coping strategies changed or transformed throughout the course of the cancer or as they have grown and developed?
7. If you could go back in time and help reduce the stressors associated with the cancer diagnosis or help your children cope, would you do anything differently?
8. What advice would you give to other parents who have/had cancer of adolescent aged children?

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<https://doi.org/10.1001/jamanetworkopen.2021.48581>

## CURRICULUM VITAE

### DeAnna Bay-Markins

#### EDUCATION

Syracuse University- Syracuse, NY GPA: 3.9  
 Doctor of Philosophy Human Development and Family Science-June 2023  
 Dissertation Title: Psychosocial Well-Being of Youth Impacted by Parental Cancer  
 Mentor: Dr. Jaipaul Roopnarine  
 Certificate of Advanced Study- Global Health May 2019  
 Springfield College- Springfield, MA Career GPA: 3.8  
 Master of Education Therapeutic Recreation Management/Child Life May 2012  
 Wagner College- Staten Island, NY  
 Bachelor of Science Dual Major: Psychology and Spanish Minor: Biology May 2010

#### CERTIFICATIONS

CCLS- Certified Child Life Specialist  
 CTRS- Certified Therapeutic Recreation Specialist  
 CIMI- Infant Massage USA Parent Education Certification  
 CYT- 200-hour Yoga Alliance Teacher Certification, Breathe for Change- Wellness Champion  
 HeartMath Certified Practitioner- Pending

#### COLLEGIATE EXPERIENCE

##### Southwestern College

Fall 2020-Present

Assistant Professor of Psychology

Winfield, KS

- Educate approximately 100+ students a semester completing psychology and psychology-based fieldwork courses. Courses taught include:

**PSYC 112: General Psychology**

**PSYC 455: The Human Family**

**PSYC 218: Child Psychology**

**PSYC 255: Multicultural Psychology**

**PSYC 320: Abnormal Psychology**

**PSYC 459: Practicum in Psychology (online-Blackboard)**

**PSYC 219: Social Psychology**

**PSYC 460: Internship in Psychology (online-Blackboard)**

**PSYC 301: Human Sexuality**

**PSYC 321: Introduction to Clinical & Counseling Psychology**

**PSYC 455: Adolescence and Emerging Adulthood**

- Advise approximately 30-50 students on academic-related objectives
- Develop opportunities for students to engage and apply their skills in community settings
- Serve as Vice-chair and Recorder for the school-wide assessment committee
- Support the Social Sciences Honors Program through serving as a recruitment chair and teaching/co-teaching sections of the honors courses

##### Syracuse University

Fall 2019

Adjunct Instructor

Syracuse, NY

- Provide instruction and student engagement for **SEM 100: First Year Seminar**
- Deliver feedback and grading in person and online (through Blackboard) of reflection assignments
- Assist students using a variety of different mediums to become more familiar with resources and opportunities available through campus programming

##### Utica College

2015-2019

Psychology-Child Life Internship Coordinator

Utica, NY

- Instruct approximately 50-70 students a semester. Courses taught include:

**PCL 474: Psychosocial Care of Hospitalized Children and Adolescents**

**PCL 272: Practicum Seminar**

**PCL 475: Child Life Internship (online)**

**PCL 471: Introduction to Child Life Internship I**

**UCC 101: First Year Seminar**

**PCL 472: Introduction to Child Life Internship II**

**PCL 374: The Helping Relationship**

**PCL 460: Fieldwork Experience**

**PCL 507: Child Life Practicum (online)**

**PCL 504: Social & Historical Context of Child Life (online-Engage)**

- Supervise 30 students a year completing fieldwork experiences with the Livetext platform
- Guide approximately 120 students on academic, fieldwork, and career goals
- Network with other child life professionals to enhance student's learning opportunities

*Community service-* Served on 2 successful faculty search committees and served as a reader for a master's thesis for Occupational Therapy students



**Falk College- Syracuse University**

August 2017-May 2019

Teaching Assistant  
Syracuse, NY

- Support classroom instruction for **CFS 388: Human Sexuality, CFS: 202 Child Development, and CFS 435: Lust, Love, and Relationships**
- Facilitate in person and online (through Blackboard) discussion group sessions based on topics covered throughout the course
- Employ a variety of teaching styles to engage and assist students with applying knowledge in a more individualized context

**BMW Lab Preschool- Syracuse University**

August 2016- May 2018

Teaching Assistant/Substitute Teacher  
Syracuse, NY

- Deliver educational instruction assistance to approximately 15 preschool students ages 2-6 in an integrated classroom setting
- Assist the lead teacher with classroom preparation, planning, and curriculum development following a creative curriculum gold and Reggio-inspired based approach
- Model behaviors, techniques, and interventions (such as child-directed learning and play) for student teachers

**Springfield College**

2010- 2011

Graduate Fellow  
Springfield, MA

- Oversee the Undergraduate Americorps (ASLIS) and America Reads Programs
- Serve as a liaison for the Office of Multicultural Affairs and Volunteer Services
- Install multicultural events and awareness within the campus and community

**PROFESSIONAL EXPERIENCE****KU School of Medicine-Wichita****Standardized Patient**

2021- Present

Wichita, KS

- Cultivate and role-play characters to assist healthcare students and professionals with clinical skills, communication, and navigating demanding emotional experiences
- Participate in debriefs and provide thorough feedback to continue advancement of instructional learning opportunities

**Encompass Health & Hospice**

2020-2021

**Volunteer Coordinator**

Wichita, KS

- Facilitate program administration to maintain and comply with regulations pertaining to volunteer services for the Hospice population
- Recruit, orient, train, and coordinate hospice volunteers in order to provide meaningful services to patients and office personnel

**Hutchings Psychiatric Center**

2019-2020

Recreation Therapist for Children and Youth Crisis Respite and Inpatient units  
Syracuse, NY

- Plan and conduct individual and/or group programming for up to 30 youth residents ages 6-17 based on individual leisure and therapeutic goals
- Assess and evaluate programming for achieving therapeutic outcomes that support positive change
- Complete resident admission and discharge evaluations, including psychosocial assessments
- Collaborate with the treatment team to fulfill family-centered and trauma-informed practices

**Camp Kesem**

Summers 2018-Present

Mental Health Professional and Hotline Operator

New York/Remote

- Serve as a resource to any camp member that is experiencing psychosocial distress and communicate needs to other members of the administrative team
- Assist campers and counselors navigate any difficult and/or potential stressful situations that arise in order to facilitate successful camp experiences
- Maintain accessibility to campers and counselors in order to enhance communication and therapeutic relationships among all camp participants

**Caribbean Journal of Psychology- Syracuse University**

August 2017-May 2019

Editorial Assistant

Syracuse, NY

- Proofread research articles submitted for publication for preliminary edits and APA formatting
- Provide communications with board members and associates of the journal
- Maintain and correspond marketing materials related to promoting the journal

**Gulf Coast Regional Medical Center**

2013-2015

Certified Child Life Specialist

Panama City, FL

- Established and developed the child life position and program at the 20 bed Pediatric department, 18 bed NICU unit, and 4 bed PICU unit
- Create, organize, and compose policies for volunteers and an activity room for patients ages 0-18
- Empower children and their families to become active participants in their medical experiences
- Provide diagnosis teaching, medical play, and preparation to ease the fear, anxiety, and stresses of children and families during hospitalization
- Facilitate developmentally supportive play and psychosocial growth opportunities
- Promote and advocate for increased measures to decrease painful medical practices
- Deliver trainings and in-services to hospital staff and community members

**Little Luke's Preschool**

October-March 2012-2013

1:1 Aide/Substitute Teaching Assistant

Baldwinsville, NY

- Instill a supportive and caring environment on a 1:1 basis for 3 children with special needs
- Offer developmentally appropriate learning experiences and modifications based on diagnoses
- Deliver appropriate assistance with activities of daily living and scheduled therapies

**Water Planet**

May-August 2011-2013

Therapeutic Programs and Intern Coordinator

Panama City Beach, FL

- Develop therapeutic interventions for 2-20 children a month with various medical conditions and emotional, social, and physical disorders
- Manage and educate 3-4 intern staff a month on the dolphin-assisted activities, interactions, and therapeutic processes
- Lead and organize dolphin swim encounters and human-animal interaction experiences
- Schedule activities for families and children with emotional, social, and physical disorders

**YMCA**

2008-2013

Site Assistant/Social Skills Teaching Assistant/Lifeguard/Swim Instructor

Baldwinsville, NY

- Implement educational planning and programming into the before and after school curriculum
- Assist with the development and execution of social skills growth among 6-8 children
- Teach swim lessons to a variety of age groups and skill levels and provide developmental adaptations as needed

## EDUCATIONAL EXPERIENCE

### Hutchings Psychiatric Center

Fall 2018 and Summers 2008 & 2009

Fieldwork Student and Volunteer

Syracuse, NY

- Create and implement health and wellness programming for at-risk youth within the inpatient unit
- Develop rapport with 10-15 children and 10-15 adolescents in a psycho-educational setting
- Attend clinical rounds, patient care committee meetings, and group therapy sessions

### University of North Carolina Hospitals

Spring 2012

Pediatrics Recreational Therapy and Child Life Intern

Chapel Hill, NC

- Provide documentation for recreational therapy and psychosocial interventions conducted with the assigned units of a 24-bed general surgery inpatient pediatric floor and a 20-bed PICU
- Lead and facilitate age and developmentally appropriate procedural teachings and medical play based on the specific needs and goals of the child and family
- Design, apply, and present 2 special projects and demonstrate event management skills to benefit children undergoing hospitalization
- Support and integrate all practices that are conducive to a family-centered Care philosophy
- Assess, plan, implement, and evaluate recreational and diversion activities during hospitalization

### Rick's Place

Fall 2011

Child and Family Volunteer

Wilbraham, MA

- Provide bereavement support and teach healthy coping mechanisms to approximately 40 families
- Individually facilitate supportive group work with 6-8 children in grades 3-5
- Maintain a caring, safe, and accepted environment for children and families undergoing healing

### Brooklyn Hospital Center

Spring 2010

Child Life Volunteer

Brooklyn, NY

- Provide developmentally appropriate activities to individuals 0-18 years of age directly under the CCLS
- Assist the child life department with programming and organization for a 22-bed Pediatric floor and bed PICU unit

## SCHOLARSHIP

Bay, D. (2021). Hearing and Honoring the Voices of Limited English Proficiency Families- Children's Corner: Perspectives of Supportive Care. *Pediatric Nursing*, 47(5).

*Spotlight on Chicago: Child Life Archive Poster Presentation*. Association of Child Life Specialists Annual Conference- Chicago IL, April, 2019.

Bay, D. & Ramadoss, K. (2018). Certified Child Life Specialist's Role with Immigrant, Refugee, and Limited English Proficiency Patients and Families. Manuscript in Preparation.

*Advancing Healthcare Services by Empowering Immigrant, Refugee, and LEP Families through Child Life Services* Poster Presentation- National Council on Family Relations Annual Conference-Orlando, FL, November, 2017.

Bay, D. (2017). Family Expectations and Outcomes from Participation in Dolphin Assisted Activity Therapeutic Programming. Manuscript in Preparation.

**HONORS AND AWARDS**

Southwestern College Women's Soccer Student Athlete Faculty Recognition Award	2022
Syracuse University Dissertation Fellowship	2022
Syracuse University- Human Development and Family Science- <b>Dean Edith Smith Dissertation Grant</b>	2020
Syracuse University-Human Development and Family Science- <b>Alice Sterling Honig Award</b>	2019
Syracuse University Graduate Student Organization Travel Grant	2017-2019
Southeast Recreational Therapy Symposium Scholarship Recipient	2012

**REVIEWER FOR JOURNAL**

Children and Schools	2022
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**CONFERENCE PRESENTATIONS**

The New York State Therapeutic Recreational Association (NYSTRA) Virtual Conference- "The use of Zine Workshop Programming for Individuals Coping with Mental Health Concerns"	2021
Hutchings Psychiatric Center Recreation Therapy Conference- "Integration of Coping Skills Development with Mindfulness and Yoga Programming"	2019
Association of Child Life Professional Annual Conference- "Ethical Practices of Shaping an Interdisciplinary Global Fieldwork Course"	2019
<b>Keynote Speaker:</b> Hutchings Psychiatric Center Recreation Therapy Conference- "Cultural Humility and the Family"	2018
Future Professoriate Program Conference- "Let's Play to Learn: Incorporating Play in College Classrooms"	2018
Florida Association of Child Life Professionals Conference Presenter "Starting a One-Person Program"	2015

**INVITED TALKS AND WORKSHOPS**

Southwestern College Faculty Teaching Day: <i>Trauma-Informed Teaching and Learning</i>	2021
SUNY Educational Opportunity Center (EOC), Syracuse- "Why Mindfulness and Yoga?"	2019
Utica College's 18 <sup>th</sup> Annual Teaching Day- "Mindfulness and Other Strategies for Creating Trauma Sensitive Practices in College Classrooms"	2019
Association of Child Life Professionals Webinar "What Can I Do as a Child Life Specialist to Empower Immigrant, Refugee, and Limited English Proficiency Families?"	2018
Utica College Research Presentation "Expectations and Outcomes from Participation in Dolphin Assisted Activity Therapeutic Programming"	2016
Child Life Council Annual Conference- Student Networking Event Panel Speaker	2015
Utica College Faculty Research Day- "One-Person Child Life Program: Survey Results and Feedback"	2015
Panama City News Channel 7 Interview "Helping Children with Medical Experiences"	2014
Southeast Recreational Therapy Symposium "Dolphin Assisted Activities Therapeutic Programs"	2014
Lighthouse Retreat Center Volunteer Training "Childhood Cancer 101"	2014

**PROFESSIONAL AFFILIATIONS**

<b>Association of Child Life Professionals</b>	Current
<b>National Council for Therapeutic Recreation</b>	Current
<b>Future Professoriate Program- Syracuse University</b>	Current
<b>National Council on Family Relations</b>	2016-2017
<b>Playmaker Training- Life is Good</b>	2014

**LEADERSHIP AND COMMUNITY INVOLVEMENT**

<b>Calm Connections-<i>Director of Programming</i></b>	2019-Present
Syracuse City Schools Yoga Instructor	Summer 2019
Hutchings Psychiatric Center Children and Youth Inpatient Yoga Instructor	Summer 2019
<b>Association of Child Life Professionals Committee Member</b>	2016-Present
Archives Management Group Chair	2020-2021
Archives Management Group Chair-elect	2019-2020
Archives Management Group Member	2018-2019
International Committee Member	2016-2018
<b>Camp Kesem- Syracuse University</b>	
Advisory Board Member	2017-2020
Intake Volunteer	2018-2019
<b>Child Disaster Services- Child Life Specialist Training</b>	2018
Hurricane Michael Deployment-Panama City, FL	2018
<b>Red Cross Volunteer- Disaster Preparedness</b>	2016- 2017
<b>Junior League Member of Panama City, FL</b>	2014-2015
<b>North Carolina Recreational Therapy Association (NCTRA)</b>	
<b>Student and Professional Issues Forum</b>	2012
Session Moderator	
<b>Up 'til Dawn (Society to benefit St. Jude Children's Research Center)</b>	2008-2010
Entertainment Chair/Sponsorship Chair	
<b>Alpha Omicron Pi Sorority</b>	2007-2009
Philanthropic Chair and Conflict Resolution Representative	

**INTERNATIONAL EXPERIENCES**

<b>India-</b> Syracuse University: South Asia Culture: Family, Food, and Health Care Systems	2019
<b>South Africa-</b> Syracuse University: Implementation and Evaluation of Health Education	2018
<b>Dominican Republic-</b> Utica College Interdisciplinary Fieldwork Course Facilitator	2016-2017
<b>Albenga, Italy-</b> Au Pair Experience	2013
<b>Seville, Spain-</b> Wells College Semester Study Abroad Program- (All classes taught in Spanish)	2009-2010
<b>Israel-</b> Expanding Your Horizons (EYH) Wagner College- Two-week Religious Studies course	2007