Parent-child differences in psychological distress following childhood cancer treatment

Shelby A. Wilson

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Parent-Child Differences in Psychological Distress Following Childhood Cancer Treatment

by

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Thesis

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Abstract

While the prognosis for pediatric cancer is improving, survivorship is accompanied by a number of potential long-term consequences. While not all childhood cancer survivors (CCS) and their parents experience psychological distress during survivorship, research does indicate that at least some do experience significant problems that warrant intervention. The current study was a retrospective analysis of an existing cross-sectional dataset that examined associations between psychological distress and other late effects in CCS and their parents. Neurocognitive late effects (NCLE) and parent/child distress were found to predict both parent and child psychological distress. Time since diagnosis was found to be related to parental distress, and behavior problems were associated with child distress. The present study contributes to the current understanding of how families of CCS function during survivorship and indicate that interventions aimed at addressing child NCLE and psychological adjustment in children and parents will likely improve overall family functioning.

Keywords: childhood cancer survivors, parents, late effects, psychological distress
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Psychological Distress in Families of Childhood Cancer Survivors:
Exploring the Differences Between Child and Parent

With pediatric cancer becoming an increasingly survivable disease over the past few decades, survivorship has become an important area of focus for pediatric cancer patients and their families, researchers, and clinicians. Identifying, preventing, and then treating any negative symptoms experienced in the months and years following treatment completion is important for promoting healthy adjustment following a significant, stressful life event. Much research has been dedicated to exploring the long-term impact cancer has on survivors, such as psychological distress and neurocognitive late effects and many correlates have been identified. However, less research has focused on comparing the factors predictive of child versus parental psychological distress, and the trajectories of the child symptoms may be strikingly different from the parents’ trajectories over time. Improving our understanding of how parents and children may be similar or different would better inform clinical intervention in the survivorship phase.

**Pediatric Cancer**

**Prevalence**

It is estimated that one out of every 285 children in the United States will be diagnosed with cancer before their 20th birthday (American Cancer Society, 2014). Over the past several decades, there has been a slight increase in the incidence of pediatric cancer, with a 0.6% increase occurring every year from 1975 to 2012 (Siegel, Miller, & Jamal, 2015). In 2016, it was estimated that approximately 10,380 children would be diagnosed with cancer (Miller et al., 2016; Siegel, Miller, & Jamal, 2016). Over half of these cases would consist of only three diagnoses: leukemia, which accounts for 30% of pediatric cancer diagnoses, brain and other nervous system cancers (26%), and soft tissue sarcoma (7%; Siegel et al., 2016).
CHILD-PARENT DIFFERENCES IN PSYCHOLOGICAL DISTRESS

Treatment

Cancer treatments that are available today include surgery, chemotherapy, radiation therapy, and stem cell transplant. In some cases, a combination of medical therapies is used to best treat the cancer. While these treatments are often effective, they are also associated with a number of adverse short- and long-term effects. Surgery is often chosen to treat solid tumors. When surgery is performed, the tumor may be removed entirely or in part. Common problems immediately following surgery include pain as well as the risk of infection (National Cancer Institute, 2015b).

Chemotherapy involves the administration of one or more medications, often including high doses of drugs such as steroids and methotrexate, to slow or stop the growth of cancer cells (Castellino, Ullrich, Whelen, & Lange, 2014; National Cancer Institute, 2015a). Acute side effects of the various chemotherapeutic agents include nausea, fatigue, and hair loss (National Cancer Institute, 2015a). Chemotherapy for acute lymphoblastic leukemia (ALL) as well as tumors of the brain, head, and neck, in particular, is associated with a number of negative effects on the central nervous system (CNS). Acute CNS effects include seizure and aseptic meningitis as well as post-lumbar puncture headaches for intrathecal administration (Castellino et al., 2014; Rusch, Schulta, Hughes, & Withycombe, 2014). Months or years after the end of treatment, cognitive dysfunction, such as attention and processing speed deficits, can emerge as late CNS effects, as this system is targeted by methotrexate (Castellino at el., 2014). Thus, while the survival rates for ALL (91%) and CNS cancer (74%) patients are fairly positive, survivors of these cancers are particularly vulnerable to neurocognitive late effects (NCLE; Siegel et al., 2016).
Radiation therapy utilizes high-energy radiation waves or particles to reduce tumor size, eliminate cancer cells, or prevent recurrence. The acute side effects of irradiation vary based on the dose and field of treatment but in general can include skin irritation and fatigue. Fibrosis, memory loss, and infertility are possible chronic effects, with higher doses being associated with more severe side effects (Lawrence, Ten Haken, & Giaccia, 2008). Cranial irradiation, radiation directed at the brain, in particular is a risk factor for cognitive late effects, such as memory problems (Castellino et al., 2014). Therefore, brain tumor survivors are at greater risk of NCLE.

Lastly, stem cell transplant is the intravenous administration of hematopoietic, blood-forming, stem cells taken from a healthy individual, to a cancer patient. This procedure is primarily used to replace the stem cells destroyed by chemotherapy and/or radiation therapy, but in a few types of cancer, stem cell transplant can be used to directly treat cancer (National Cancer Institute, 2015c). This therapy also has the potential for adverse effects, such as graft-versus-host disease, a sometimes fatal disease that can occur as an acute or chronic condition (Barton-Burke et al., 2008).

Survivorship

Fortunately, most pediatric cancer patients will live to be cancer survivors, with some variation in survival rates between specific cancer types. It is estimated that there are at least 100,000 and perhaps as many as 420,000 childhood cancer survivors (CCS) in the United States today (Miller et al., 2016; Robison & Hudson, 2014). The survival rate for all pediatric cancer patients in 2016 is estimated to be 83% (DeSantis et al., 2014; Siegel et al., 2015; Siegel et al., 2016). This rate is 25% higher than it was just 40 years ago (Miller et al., 2016). Survival rates for specific cancer types vary, ranging from 61% for (osteosarcoma) to 97.5% (retinoblastoma) (DeSantis et al., 2014; Miller et al., 2016). Today’s more positive outlook for children diagnosed
with cancer is attributable to developments in technology that facilitate earlier detection, advances in treatment that allow for guided treatment protocols that result in better prognosis, and greater participation in clinical trials (Miller et al., 2016; Siegel et al., 2016).

**Psychological Distress**

Findings regarding the experience of psychological distress in pediatric cancer populations are varied. The immediate impact of cancer diagnosis and treatment on child and parent distress is mostly clear. Studies show that, perhaps unsurprisingly, both parents and children report notable levels of distress after the child has received a diagnosis of cancer. This distress, including symptoms of anxiety and depression, is generally found to be most severe immediately following diagnosis, with some symptoms persisting up to a year later (Grootenhuis & Last, 1997; Myers et al., 2014; Norberg & Boman, 2008). However, findings on the long-term psychological sequelae are less consistent. For the purpose of this study, the following review of psychological distress focuses on anxiety and depressive symptomology experienced by both child and parent during survivorship.

**During Treatment**

**Child distress.** Receiving a diagnosis of cancer and subsequently undergoing treatment is certainly a stressor. For example, children may report significant anxiety immediately following cancer diagnosis as well as some symptoms of depression up to one year following diagnosis (Myers et al., 2014). However, this initial distress may not persist, as demonstrated in many studies of children undergoing treatment. In a 2005 review paper, Patenaude and Kupst concluded that most studies show that pediatric cancer patients do not experience poor adjustment but instead have adjustment very similar to healthy control and other comparison groups. More recently, a study of 153 pediatric cancer patients found that only 4.5% of children
reported clinical symptomology of anxiety and depression (Compas et al., 2014). This falls within the estimated prevalence rates of anxiety and depression for all children (Beesdo, Knappe, & Pine, 2009; Chavira, Stein, Bailey, & Stein, 2004; Costello, Erkanli, & Angold, 2006).

**Parental distress.** In contrast, research does consistently show that many parents of children undergoing cancer treatment experience considerable distress. In one recent study, parents rated their current distress levels on a distress thermometer, and 46.2% reported considerable distress (Pierce et al., 2016). Similarly, a meta-analysis of 29 papers found both mothers and fathers to report significantly greater distress than mothers of healthy children (Pai et al., 2007). Parents specifically report higher levels of anxiety and depression than control groups, as supported in multiple review papers on parents of pediatric cancer patients (Haegen & Luminet, 2015; Norberg & Boman, 2008; Vrijmoet-wiersma, Egeler, Koopman, Norberg, & Grootenhuis, 2009). This distress seems to be most severe in the first few years following the diagnosis and lessens with time (Norberg & Boman, 2008).

**During Survivorship**

A majority (83%) of childhood cancer patients survive the disease; however, the survivorship period following completion of treatment presents its own set of challenges and opportunities for growth for childhood cancer survivors (CCS) and parents (Arpawong Oland, Milam, Ruccione, & Meeske, 2013; Ljungman et al., 2014). This section will focus on the psychological difficulties experienced by CCS and their parents after completion of cancer treatment.

**Child distress.** First, child psychological distress during survivorship will be discussed. Research generally shows that most childhood cancer survivors experience fairly typical levels
of psychological distress, with some experiencing more serious levels. Survivors are at particular risk for developing symptoms of depression.

**General distress.** In studies that measure psychological distress generally, results usually show that that most childhood cancer survivors do not experience serious levels of distress (Gianinazzi et al., 2013; Glover et al., 2003; Hudson et al., 2003; Zebrack et al., 2004). The exact incidence of psychological distress in survivorship varies greatly from study to study; this is likely due to the use of different measures and cut-off scores indicative of significant distress as well as to variation between study samples in survival time. As discussed above, most studies consider individuals to be survivors if they have lived five or more years post-diagnosis. However, actual time since diagnosis varies between studies, and is sometimes not reported (e.g., Glover et al., 2003).

The prevalence of general psychological distress in samples of CCS range from 11% to 47%, with these two extremes being found in pediatric brain tumor (BT) survivors (Frangis et al., 2009; Zebrack et al., 2004). In one report from the longitudinal multi-site Childhood Cancer Survivor Study (CCSS), which included 1101 adult survivors of pediatric BTs who received chemotherapy or radiation therapy, 11% of participants were found to be at risk for psychological distress (Zebrack et al., 2004). In smaller study of adult survivors of pediatric BT \( (n = 45) \) who received radiation therapy only, 47% reported emotional impairment (Frangis et al., 2009). Other studies have found sample prevalence rates between these two extremes, including a study of 407 adolescent cancer survivors (13%), 9935 adults from the CCSS (17.2%), and 555 adult ALL survivors who received CNS treatment (24%; Gianinazzi et al., 2013; Glover et al., 2003; Hudson et al., 2003). In one study of survivors \( (n = 324) \) of ALL, “emotional difficulties”
were the third most reported negative effect of treatment (Haddy, Mosher, & Reaman, 2009, p. 601).

Many of these and other studies compared cancer survivors with other groups, such as healthy population norms or their own healthy siblings. Using healthy siblings as controls is particularly useful in roughly controlling for environmental and social factors, as siblings are more likely to be raised in similar environments than other matched controls. Although studies do not suggest that most childhood cancer survivors experience significant psychological distress as determined by normed measures, as discussed above, they do indicate poorer functioning for survivors when compared to healthy sibling control groups. In a review of papers from the CCSS, survivors were found to report more general distress than their healthy siblings, but not more emotional distress in particular (Zeltzer et al., 2009). Similarly, results from the Swiss Childhood Cancer Study indicate that survivors experience higher levels of somatization as well as greater severity of general distress than healthy sibling controls (Gianinazzi et al., 2013). Hudson and colleagues (2003) found CCS to have greater odds of experiencing poor mental health than healthy siblings and survivors of CNS cancer to have the highest rates (17.2%) of poor mental health. Similarly, Patenaude and Kupst (2005) identified brain tumor (BT) survivors, CNS cancer survivors, and survivors who had intensive CNS treatment to be at greatest risk of poor psychosocial outcomes. In summary, it seems that, while most CCS experience relatively normative levels of emotional distress, they may experience higher levels of distress within normative ranges.

**Anxiety and depression.** The two specific types of distress focused on in the current study are anxiety and depression. Comparison of studies is difficult due to differences in definition and measurement of these two constructs. Some studies use criteria from the
Diagnostic and Statistical Manual of Mental Disorders (DSM) to define and measure anxiety or depression, while others use general measures of symptoms or feelings of anxiety or depression. For the purpose of this paper, general symptoms of anxiety and depression as well as diagnoses of anxiety or depressive disorders as classified in the DSM-5 are considered. It should be noted that, while criteria specification varies between DSM editions, the differences are small, and therefore, findings will be aggregated for both parsimony and clarity. While there is extensive literature examining post-traumatic stress in CCS, such a review is beyond the scope of the current study.

First, studies using single measures that combine symptoms of both are discussed. These studies examine symptoms of anxiety and depression as measured by general questionnaires not designed for diagnostic purposes. Therefore, there are no clinical cut-off scores that indicate specific diagnoses. Many studies support that survivors experience significant symptoms of anxiety and depression. First, studies using the Behavior Problem Index (BPI; Zill, 1985), a measure yielding several domains of behavior primarily used for research purposes, will be discussed. In a sample of 2,979 adolescents from the CCSS, survivors were found to be 1.5 times more likely to experience depression and anxiety than a sibling comparison group (Shultz et al., 2007). Symptoms of depression and anxiety were measured using the depression/anxiety subscale of the BPI, with scores 1.3 standard deviations above sibling scores indicating significantly more distress than the comparison group. A 2010 study by Krull and colleagues also used this subscale of the BPI and found similar results in a sample of 1,652 adolescent CCS. Using a cut-off of 10% or below the mean score from the BPI standardization sample, 17.1% of participants reported significant depression/anxiety compared with only 9.1% of the 406 sibling participants (Krull et al., 2010).
Elevated anxiety and depression have also been found in studies using other general measures. Twenty-nine parents of pediatric brain tumor survivors completed the Child Behavior Checklist (Achenbach, 1991), for younger children, or the Young Adult Checklist (Achenbach, 1991), for older children, an average of 6.6 years after completing treatment. These measures are used for screening purposes and have clinical cut-off points, but do not indicate specific diagnoses. Parents reported increased depression and anxiety in their children, with 68% reporting child emotional disturbances (Sands et al., 2005). In contrast, a review of 20 studies of childhood cancer survivors (Eiser, Hill, & Vance, 2000) as well as a more recent study of 159 CCS, which used the Behavior Assessment System for Children (BASC; Myers et al., 2014) found survivors to have normal levels of anxiety and depression when compared to scale norms or matched control groups. However, Eiser and colleagues (2000) discuss the lack of consensus in measurement of psychological outcomes across studies and note this issue as a limitation of the results.

_Anxiety_. Incidences of significant anxiety in CCS samples vary from well below the prevalence rate of anxiety symptoms for children in general (15% – 20%) and anxiety disorders in adults (18.1%), to slightly above (Beesdo, Knappe, & Pine, 2009; Chavira, Stein, Bailey, & Stein, 2004; Kessler, Chiu, Demler, & Walters, 2005). The lowest and highest sample incidence rates were both found in samples of pediatric BT survivors. On the low end, one study of childhood BT survivors found that only 3.2% of participants reported feeling anxious (Carpentieri et al., 2003). The generalizability of this study of adolescent survivors one to five years after treatment completion is limited by its small sample size (N = 32). In a review of 17 papers, for a total of 5320 pediatric BT survivors, Shah and colleagues (2015) found an incidence of 20%. On the high end, a study of 319 adolescents and young adult survivors of
pediatric BT from the CCSS found that 28% of survivors reported anxiety, as measured in an interview based on DSM-IV-TR symptoms of anxiety (Brinkman et al., 2013a). Brinkman and colleagues (2013a) provided little detail as to how anxiety was measured and only reported how many participants had anxiety and did not have anxiety, without specifying how the variable was dichotomized. Therefore, Shah and colleagues’ (2015) conclusion that 20% of BT survivors report anxiety based on a review of many studies is likely the best estimate of anxiety incidence for this subset of CCS.

Incidences of anxiety in samples of survivors of various types of childhood cancer fall between these two extremes. Several large studies of adult survivors of childhood cancer from the CCSS found 4.8% – 13.2% of participants to report significant anxiety (Brinkman et al., 2013b; Brinkman et al., 2013c; Hudson et al., 2003). Participants sampled in all three studies had been diagnosed with cancer at least five years prior to participation, and anxiety was measured using the BSI. While incidence rates of anxiety in CCS fall within general prevalence rates of anxiety, the severity of anxiety in CCS tends to be higher than in healthy individuals. Another report out of the CCSS, which sampled 7147 adult survivors, found CCS to have higher levels of anxiety than 500 siblings in a comparison group (Zeltzer et al., 2008). Similarly, in a study of preschool survivors of non-CNS cancer survivors, parent reports indicated higher levels of anxiety two months after treatment completion when compared with the sample on which a preschooler quality of life scale was normed (Maurice-Stam et al., 2008). Similar to findings on general distress, CCS seem to experience anxiety at a rate similar to the general child population. As many as 13% of CCS, and perhaps 20% or more of BT survivors specifically, experience some level of anxiety. These rates are very close 15% – 20% estimated prevalence of anxiety in
all children. While CCS may experience anxiety at similar rates as healthy individuals, the severity of their symptoms may be greater.

**Depression.** The overall estimated 12-month prevalence for the diagnosis of a mood disorder is 9.5% with an estimated range of 2.1%-5.6% for children (Center for Disease Control and Prevention, 2010; Costello, Erkanli, & Angold, 2006; Kessler et al., 2005). Many studies of CCS measure depression symptomology more generally, as opposed to examining diagnosed mood disorders, and do seem to support that CCS experience elevated levels of depressive symptomology. Studies of adult survivors of various childhood cancers from the CCSS demonstrate that more survivors experience symptoms of depression, based on a BSI T-score of 63 or higher, compared both to siblings and compared to what would be expected based on normal prevalence rates. In Brinkman and colleagues’ study (2013b) of 10,378 adult survivors and 3,206 siblings, 9.1% of CCS and only 6.0% of siblings were found to report significant depression. Earlier studies also found that, while most CCS did not report significant depressive symptomology, they did report higher levels than individuals in sibling comparison groups (Zebrack et al., 2002; Zeltzer et al., 2008).

Studies of childhood CNS cancer survivors find comparable, or higher, incidence rates. A small study of adolescent brain tumor survivors found that 6.5% of participants reported symptoms of depression (Carpentieri et al., 2003). A large CCSS study of adult survivors of childhood BT found a much higher incidence of depression, with 41% of participants reporting significant depressive symptomology (Brinkman et al., 2013a). Another large CCSS study of adult pediatric BT survivors found CCS to have higher scores on the BSI depression subscale than siblings (Zebrack et al., 2004). A recent review paper on childhood BT survivors found that 19% of the participants in 17 studies experienced depression, a percentage much higher than the
prevalence of depressive disorders in the normal population of both children and adults (Shah et al., 2015). Therefore, there does seem to be a consensus among studies that CCS do experience symptoms of depression both at a higher rate and at a greater severity than healthy individuals.

**Correlates and predictors of child psychological distress.** Child distress seems to attenuate over time. Specific concerns about cancer as well as general anxiety seem to decrease with time. A cross-sectional study found that shorter time since treatment was associated with more cancer-related concerns (Langeveld, Grootenhuis, Voute, de Haan, & van den Bos, 2004). Similarly, in a longitudinal study that found survivors to have higher than normal levels of anxiety two months after treatment, anxiety levels were found to normalize within two or three years of treatment ending (Maurice-Stam et al., 2008). Recently, Gunn and colleagues (2016) conducted a qualitative study of 21 pediatric cancer survivors who ended treatment five or more years before study participation. They found that, when reflecting on their cancer, survivors typically said that their cancer had little impact on their current lives (Gunn et al., 2016). This attenuation may not be consistent across all symptoms of distress. Okado and colleagues (2016) found time since diagnosis to be negatively associated with child anxiety, but not depression. Only one study identified in this review contradicted the above findings. Myers and colleagues did not find any significant differences in anxiety or depression across three time points after diagnosis: one month, six months, 12 months (2014). However, this may be due to the relatively short time since diagnosis, as the above studies examined distress two or more years after diagnosis. Therefore, greater presence of at least some types of child psychological distress seems to be associated with shorter time since diagnosis and treatment completion, and it may be normative that distress decreases as they accrue more years of being considered cancer-free.
Sociodemographic factors studied as correlates and predictors of psychological distress in CCS include sex, age at diagnosis, race and ethnicity, and annual income. The vast majority of studies conclude that, as in the general population, being female is a risk factor for poorer psychological outcomes in CCS (Barr et al., 2003; Butler, Rizze, & Bandillo, 1999; Gianinazzi et al., 2013; Hudson et al., 2003; Langeveld et al., 2004; Maurice-Stam et al., 2009b; Maurice-Stam, Oort, Last, & Grootenhuis, 2009; Shultz et al., 2007; Wenninger et al., 2013; Zeltzer et al., 2009). However, a few studies indicate that sex is not associated with psychological distress (Canning, Bunton, & Robison, 2014; Zebrack & Chesler, 2002). Psychological distress does seem to increase with age at diagnosis (Brinkman et al., 2013a; McDougal & Tsonis, 2009). The association between race and child distress is mixed, with some studies concluding that there is not an association and others indicating that individuals of ethnic minorities are at greater risk of distress than white individuals (Glover et al., 2003; Hudson et al., 2003; Schultz et al., 2007). Myers and colleagues (2014) specifically found Hispanic individuals to report greater anxiety, but not depression. Lastly, low income may be a risk factor for distress (Zeltzer et al., 2009). The above differences are likely due to differences in definition and measurement of distress as well as study samples.

Diagnosis may also be related to outcomes in psychological distress. While one study of adolescent survivors of pediatric cancer ($n = 74$) did not find diagnosis to be predictive of emotional distress, a larger study of 642 pediatric CNS cancer survivors found survivors of brain tumors to have higher levels of psychological distress than survivors of other CNS cancers (Canning et al., 2014; van der Geest et al., 2013). A large CCSS study ($n = 9535$) found survivors of Hodgkin’s lymphoma, sarcoma, and bone cancer to be at greater risk of distress than survivors of ALL (Hudson et al., 2003). Therefore, survivors of some cancers (i.e., brain tumor,
Hodgkin’s lymphoma, sarcoma, and bone cancer) may be more vulnerable to distress than others.

In examining the role of treatment, Canning and colleagues’ (2014)) small study found no association between treatment type and distress. Zebrack and colleagues (2002) only found association between treatment and depression for survivors of ALL, not Hodgkin’s Disease or Non-Hodgkin’s Lymphoma. They also found no association between cranial irradiation, in particular, and depression in survivors of ALL (Zebrack et al., 2002). Two studies of pediatric BT survivors who received radiation therapy only found that radiation dose, specifically, was not correlated with distress (Frangi et al., 2009; Radcliffe et al., 1996). In contrast, two studies of CCS of various cancers found cranial radiation and/or surgery to be risk factors for psychological distress (Butler et al., 1999; Zeltzer et al., 2009). Another study found survivors who received chemotherapy in addition to radiation therapy to have the worst psychological outcomes (Maurice-Stam et al., 2009a). Additionally, a review of 17 studies with various CCS samples found that cranial radiation therapy, with or without the addition of chemotherapy, was associated with greater risk of psychological distress (Shah et al., 2015).

Zebrack and colleagues (2002) found an association between intensive chemotherapy and depression in survivors of leukemia. Categorization of intensive chemotherapy was determined specifically for each chemotherapeutic agent based on standard regimen as well as actual number of doses received. Survivors of leukemia who received intensive chemotherapy were at greater risk of being symptomatic for depression. Kazak and colleagues (2010) also found young adult CCS who received the most intensive treatment, as measured by the Intensity of Treatment Rating scale, had higher levels of anxiety than CCS who received less intensive treatment. Thus, research suggests that the relationship between treatment and psychological distress is complex.
It seems clear that more intensive treatment is associated with greater distress. However, treatment type and diagnosis appear to interact, with some combinations of treatment and diagnosis being predictive of distress and other combinations not being associated with distress.

Finally, there is relatively less research on associations between child psychological distress, defined as symptoms of anxiety or depression, and specific late effects, such as neurocognitive late effects (NCLE), educational difficulties, and behavior problems. One study found adult CCS who reported learning or memory problems also reported elevated levels of global distress (Oancea et al., 2014). However, another study examined potential relationships between receiving special education and child anxiety or depression and found no significant associations (Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996).

Parental distress during survivorship. A number of studies have examined psychological distress in parents of children who have survived cancer. While studies seem to support that parents do experience significant distress while their child is a cancer patient, there is less empirical evidence that distress is present during survivorship. Similar to findings on survivors, studies of the parents of CCS also generally find that they do not experience clinically elevated levels of distress once their child is in the survivorship period. The research in this area, however, particularly within the last decade, is relatively scant. This represents a gap in the CCS literature, since poor parental functioning can be associated with poor parenting practices and poor child functioning (Deater-Deckard, 1998).

General Distress. Like childhood cancer survivors, parents of CCS seem to experience typical levels of distress in studies that examine psychological distress generally. A study of 133 CCS parents found that the majority of parents (80%) reported low levels of negative feelings, as measured by a survey created to assess distress across a number of domains, including anxiety
and depression (Van Dongen-Melman et al., 1995). However, a notable subset of parents reported moderate to high levels of anxiety (42%) and depression (29%), and 49.6% of participants were categorized as having some psychological problems. A more recent study using the standardized BSI found low rates of emotional distress. Using a cut-off T-score of 63 or greater, Malpert and colleagues (2015) found that less than 4% of parents of ALL survivors who received chemotherapy only reported serious levels of distress. A small study of pediatric brain tumor survivors ($n = 38$) found that parents reported average parental distress, as measured by the parental-distress subscale of the Parenting Stress Index, compared to scale norms (Radcliffe, Bennett, Kazak, Foley, & Phillips, 1996). A recent systematic review of 12 articles including a total of 1045 parents of CCS found that parents typically reported normal levels of psychological distress, with a substantial subgroup (9% – 30%) of parents reporting clinical levels of distress (Ljungman et al., 2014). The parents who did report significant distress had less time since diagnosis and were parenting children with comorbid medical conditions (i.e., chronic conditions, burns). Thus, studies using general measures of distress indicate that most parents of CCS experience relatively normal levels of distress, with a subset of parents reporting more severe distress. Predictors of distress that may explain which parents fall into this subset will be discussed in a later section.

**Anxiety.** As mentioned above, the 12-month prevalence rate of anxiety disorders in adults is approximately 18.1% (Kessler et al., 2005). However, it is important to note that this estimate is based on DSM-IV classification, which included post-traumatic stress disorder and obsessive-compulsive disorder as anxiety disorders; prevalence rates based on the DSM-5 may be lower. Furthermore, symptoms of anxiety, rather than anxiety disorder diagnoses, are often
examined in studies of CCS parents. As with the review of child anxiety, parental anxiety are defined as symptoms of anxiety or anxiety disorders as classified in the DSM-5.

Incidence rates of significant anxiety symptomology in CCS parents consistently fall well below the estimated prevalence of 18.1%. Two moderately sized studies of parents of CCS ($n = 112, 133$) from the mid-1990s found 10% of participants to report high levels of anxiety, as measured by the State-Trait Anxiety Inventory (STAI; Speechley & Noh, 1992; Van Dongen-Melman et al., 1995). A more recent study of parents of ALL survivors that used the BSI found 7.1% of parents to report clinically significant levels of anxiety (Malpert et al., 2015). Similar results are found when parents of CCS are compared to controls and measure norms. Both Speechley and Noh (1992) as well as Radcliffe and colleagues (1995) found parents of CCS to report anxiety levels similar to parents of healthy children as well as the norms for the STAI.

**Depression.** Lastly, depression in parents of CCS follows the trends of general distress and anxiety, with parents reporting depressive symptomology less than the estimated 9.5% overall prevalence rate of depressive disorders (Kessler et al., 2005). Only 3% of parents were found to report high levels of depression on the Self-Reporting Depression Scale in one study (Van Dongen-Melman et al., 1995). Malpert and colleagues found the same incidence rate (3.1%) in a sample of parents of ALL survivors using the BSI to measure depression (2014). Again, comparison results supported these low incidence rates. Parents of CCS were found to have normal levels of depression both when compared to the norms for the Beck Depression Inventory and when compared to parents of healthy children (Radcliffe et al., 1995; Speechley & Noh, 1992).

**Correlates and predictors of parent psychological distress.** Unlike the childhood cancer survivors themselves, it is less clear whether or not psychological distress decreases or remains
constant during survivorship. Some studies have found that time since diagnosis and time since
treatment completion were not associated with parental distress (Pierce et al., 2016; Van
Dongen-Melman et al., 1995). A 2014 systematic review found mixed results, with some studies
reporting a decrease in psychological distress over time and others reporting no change
(Ljungman et al., 2014). However, two large reviews have concluded that distress decreases with
time (Haegen & Luminet, 2015; Pai et al., 2007). This may be due in part to differences in
definitions and measurement of distress (e.g., anxiety or depression). For example, a recent study
by Okado and colleagues (2016) found that time since diagnosis was negatively associated with
parental depression, but not anxiety.

Evidence suggests that there are some child factors that are associated with parental
distress and other factors that are not. The sex of the CCS does not seem to be associated with
parental distress (Pierce et al., 2016). Associations with child age at diagnosis are mixed.
Ljungman and colleagues’ (2014) review identified two studies that did not find an association
and one that found mothers of children diagnosed at an older age to report higher distress.
Additionally, the child’s specific cancer diagnosis, the treatment type, and the treatment intensity
were not found to be related to parent psychological distress (Pierce et al., 2016; Radcliffe et al.,
1996; Van Dongen-Melman, 1995). Child late effects have been found to be related. Deficits in
neurocognitive functioning, or neurocognitive late effects (NCLE), specifically impaired
executive functioning, are associated with parental distress (Malpert et al., 2015; Patel, Wong,
Cuevas, & Van Horn, 2013). Findings regarding special education are mixed, with some studies
indicating significant associations between the CCS receiving services (Kazak & Meadows,
1989) and others not finding such associations (Radcliffe et al., 1996). Lastly, greater child
behavior problems are predictive of greater parental emotional distress (Patel et al., 2013).
Parent Report of Child Distress

Many studies of child distress rely on parents’ report of their child’s experience, and it is important to examine the validity of such measures. First, it should be noted that parent and child distress are not always strongly correlated. In studies that used self-report measures of both parent and child distress, findings are mixed. In a sample of children currently diagnosed with cancer and their parents, parent and child distress (i.e., depression and anxiety) were found to be positively, but weakly correlated (Okado, Long, & Phipps, 2014). Findings are similarly mixed when parent reports of child distress are used. In a study of 239 parents of children with an anxiety disorder, parental anxiety and parent-report of child anxiety were not found to be significantly associated (Krain & Kendall, 2000). In contrast, in a study of 127 parents of childhood ALL survivors, parental anxiety was found to be significantly associated with child emotional functioning; these correlations, however, were weak to moderate in strength (Malpert et al., 2015; Patel et al., 2015).

When comparing parents’ report of child distress with children’s self-report of their distress, sometimes parents are found to overestimate their child’s distress. In a sample of parents of children with an anxiety disorder, Krain and Kendall (2000) found statistically significant differences between parent and child reports of child anxiety, with mother-reported anxiety, as measured by the State-Trait Anxiety Inventory for Children, being 4.43 points higher than child-reported anxiety. Similarly, one study of pediatric brain tumor survivors found that parents overestimated their children’s level of depression. Over 16% of parents reported that their children were depressed, while only 6.5% of their children reported feeling symptoms of depression (Carpentieri et al., 2003). However, many studies have found parent reports of child distress to be concordant with their children’s self-reports of their own distress, such as
depression and health-related quality of life, in childhood cancer survivor samples (Canning, Bunton, & Robinson, 2014; Roddenberry & Renk, 2007; Sands et al., 2012). Thus, it seems that parents’ perception and report of their child’s distress may be accurate or slightly overestimated. However, parent-report of children’s distress does not seem to simply be a reflection of their own distress. It seems to be at least fairly representative of the child’s experience.

**Other Long-Term Consequences**

In addition to the immediate side effects of treatment as well as short- and long-term emotional outcomes of pediatric cancer, childhood cancer survivors may face a number of other negative effects in the months and years following the end of treatment. These include neurocognitive late effects (NCLE), related academic difficulties, and behavioral problems. These late effects can occur as a result of treatment or the cancer itself (Haddy, Mosher, & Reaman, 2009).

**Neurocognitive Late Effects**

Some survivors of childhood cancer, especially pediatric brain tumor survivors, experience various types of NCLE months or even years after they have completed treatment (Castellino, Ullrich, Whelen, & Lange, 2014). It is estimated that 5% – 14% of ALL survivors and 40% – 100% of BT survivors experience some level of cognitive impairment during survivorship (Castellino et al., 2014; Frange et al., 2009; Haddy et al., 2009; Kahalley et al., 2014). Disturbances in neurocognitive functioning have been found to be the second most common negative late effect reported by ALL survivors (Haddy et al., 2009).

Survivors of all cancer types can potentially experience slowed processing speed, attention difficulties, executive functioning (EF) weaknesses, and problems with visual-motor integration (Bonner, Hardy, Willard, & Gururangan, 2009; Castellino et al., 2014; Kahalley et
al., 2013; Sands et al., 2012; Winter et al., 2014). Interestingly, in a small study of pediatric BT survivors, parents reported attention problems in their children, but the children themselves did not report such difficulties, suggesting possible lack of insight (Carpentieri et al., 2003).

Significant processing speed deficits, especially in psychomotor processing speed, are more prevalent in pediatric BT survivors than ALL survivors, with 41.3% of BT survivors having significant discrepancies between processing speed and general ability, compared to 14% of ALL survivors (Kahelley et al., 2014; Sands et al., 2012). Impairment in executive functioning, including working memory deficits, is reported in survivors of all cancer types (Castellino et al., 2014; Robinson et al., 2014). However, variation between survivors of different cancers exist.

When comparing BT survivors to ALL survivors, BT survivors experience a broader range of EF deficits, suggesting global dysfunction, whereas ALL survivors experience more specific EF deficits (i.e., rapid naming; Winter et al., 2014).

While some studies of general intellectual ability exist, the generalizability of the results is limited due to small sample size. Regan and Reeb (1998) found that general intellectual ability seemed to remain intact in a small study of 11 ALL survivors. Other small studies of pediatric BT and other CNS cancer survivors suggest that these survivors’ intellectual functioning may be slightly lower than healthy children, in the Low Average range of the Wechsler Abbreviated Scale of Intelligence (Regan & Reeb, 1998; Robinson et al., 2014; Sands et al., 2012). One 2008 study found a dramatic decline in the IQ of 35 male survivors of pediatric BT, with IQ scores declining two to four points every year (Spiegler, Bouffet, Greenberg, Rutka, & Mabbott, 2008).

Risk factors for NCLE can be divided into three categories, as done in a review of 257 studies by Castellino and colleagues (2014): child factors, cancer factors, and treatment factors. While one study of BT and ALL survivors found males to be at greater risk of processing speed-
general reasoning ability discrepancies (Kahelley et al., 2013), Castellino and colleagues’ (2014) large review study of all NCLE found females to be at greater risk of cognitive dysfunction. Additional child risk factors include younger age at diagnosis and lower SES (Castellino et al., 2014; Kahalley et al., 2013). Cancer factors that put survivors at greater risk of NCLE include a diagnosis of brain tumor or leukemia involving the CNS (Castellino et al., 2014). Lastly, chemotherapy, especially intrathecal administration, and cranial irradiation, especially at higher doses, place CCS at higher risk of NCLE (Castellino et al., 2014; Regan & Reeb, 1998).

Castellino and colleagues’ (2014) review of 257 studies provides particularly compelling evidence that survivors of BT, ALL, and other CNS cancers are at higher risk of late effects than survivors of other cancers.

Findings on the progression of neurocognitive sequelae vary. Many studies purport that longer time since diagnosis and treatment completion is a risk factor for greater NCLE, especially in survivors who previously received cranial irradiation (Askins & Moore, 2008; Castellino et al., 2014; Kahelley et al., 2013; Spiegler et al., 2008). The outlook for survivors who did not receive cranial irradiation is only slightly better. Copeland and colleagues (1996) found modest declines in neurocognitive functioning several years after diagnosis. Additionally, a small study of survivors treated for brain tumor in infancy found that the children who were treated with chemotherapy or surgery experienced an increase in neurocognitive functioning over time (Copeland, deMoor, Moore, & Alter, 1999). As with psychological distress and time since diagnosis, the relationship between NCLE and time seems to be closely related to diagnosis and treatment.
Academic Difficulties

Closely related to NCLE are the learning and school problems that childhood cancer survivors may face. One study of ALL survivors found that nearly 10% of patients at a survivorship clinic reported learning difficulties (Haddy et al., 2009). These difficulties can include deficits in reading, spelling, math, and overall achievement (Brown et al., 1996; Copeland et al., 1998). Pediatric BT survivors in particular demonstrate weaknesses in nonverbal learning (Bonner et al., 2009). In addition, studies have found that 22% – 38% of pediatric BT survivors and 26% of pediatric ALL survivors reported being retained a grade (Foreman et al., 1999; Kahelley et al., 2013). To address these academic difficulties, many survivors receive special education services. One study found that one fourth of childhood cancer survivors utilized special education services, compared to only 8% of siblings (Mitby et al, 2003). Similarly to NCLE, risk factors for special education utilization include diagnosis before age six, CNS cancer diagnosis, intrathecal chemotherapy, cranial irradiation, and higher doses of radiation (Mitby et al., 2003). Fortunately, it seems that special education services are effective for CCS. While survivors of childhood ALL, CNS tumors, non-Hodgkin lymphoma, and BT are significantly less likely to graduate from high school than their siblings overall, those who receive special education graduate at the same rate as their siblings (Mitby et al., 2003).

Behavioral Problems

Child behavior problems may also emerge throughout survivorship. One small study of childhood ALL survivors found no significant differences in problem behavior between childhood cancer survivors and healthy controls (Campbell et al., 2009). However, other studies have found elevated rates of problem behavior in CCS. One study of survivors of cancer diagnosed at preschool age by Maurice-Stam and colleagues found that survivors under the age
of 5 years engaged in more problem behavior two months after treatment ended than the scale norms, as measured by the TNO-AZL Preschool Quality of Life (2008). Specific problems identified in reports out of the CCSS include elevated rates of externalizing behavior and antisocial behavior (Krull et al., 2010; Shultz et al., 2007).

**Current Study**

While it is clear that not all childhood cancer survivors and their parents experience long-term psychological distress during survivorship, research does indicate that at least some do experience considerable problems that warrant intervention. Many predictors of child and parent psychological distress have been identified. However, there is limited research on whether or not learning and school problems are predictive of child or parental distress and if NCLE and behavior problems are predictive of parental distress. Much of the research on psychosocial correlates of special education services that does exist is 20 or more years old. Virtually no research has examined whether or not NCLE and problem behaviors are related to child distress in CCS samples. In addition, while some research does demonstrate correlations between child and parent distress, it is not clear whether or not the sources of distress are the same for children and their parents. Being aware of differences in stressors for cancer survivors compared with their parents would be useful in designing family interventions that are effective for both the child and his or her parents.

The current study aims to explore and clarify associations between psychological distress in survivorship and other possible late effects - NCLE, learning and school problems, and behavior problems - in both CSS and their parents. Hypotheses were made based on the current literature.

The specific aims of this study were to:
1. Examine associations between psychological distress and child biological factors (i.e., age at diagnosis, diagnosis, time since diagnosis, and NCLE).
   a. It was hypothesized that age at diagnosis will predict child psychological distress, with older age being associated with greater distress.
   b. No a priori hypothesis regarding age at diagnosis as a predictor of parent psychological distress was made, as existing evidence is mixed.
   c. It was hypothesized that diagnosis will predict child psychological distress, with high risk diagnoses being associated with greater distress than low risk diagnoses.
   d. It was hypothesized that diagnosis will not be associated with parent psychological distress.
   e. It was hypothesized that time since diagnosis will predict child psychological distress, with shorter time since diagnosis being associated with greater distress.
   f. No a priori hypothesis regarding time since diagnosis as a predictor of parent psychological distress was made, as existing evidence is mixed.
   g. It was hypothesized that NCLE will predict both parent and child psychological distress, with greater NCLE predicting greater distress in both parents and children.

2. Examine associations between psychological distress and parent and child psychosocial factors (i.e., child problem behavior, school functioning, parent or child psychological distress).
a. It was hypothesized these psychosocial variables will account for significant proportion of the variance in child and parent distress in addition to that accounted for by the child biological variables.

b. No a priori hypothesis regarding problem behavior as a predictor of child psychological distress was made, as existing evidence is limited.

c. It was hypothesized that problem behavior will predict parent psychological distress, with greater problem behavior being associated with greater parent distress.

d. No a priori hypotheses regarding school functioning as a predictor of parent or child psychological distress were made, as existing evidence is mixed.

e. It was hypothesized that parent psychological distress will predict child psychological distress, with greater parent distress being associated with greater child distress.

f. It was hypothesized that child psychological distress will predict parent psychological distress, with greater child distress being associated with greater parent distress.

**Method**

**Participants**

A sample of 100 parents of childhood cancer survivors, ages 6 to 18, were recruited through social media and online support groups. After completing an online informed consent form, participants completed a demographics questionnaire as well as a number of questionnaires regarding their child’s functioning, their own functioning, and the functioning of their family as a whole. See Table 1 for a summary of participant characteristics.
Materials

**Demographics.** Participants completed a demographics questionnaire and provided non-identifiable information about themselves as well as their child that survived cancer (Appendix A). Additional information about their child’s diagnosis and age at diagnosis was also provided. Age at diagnosis was measured by having parents indicate at which age their child was first diagnosed with cancer (e.g., 0 – 2, 3, 4, etc.). Because age at diagnosis was measured categorically with ages 0 to 2 being grouped, three variations of the variable were created: one with ages 0 to 2 set at 6 months, one ages 0 to 2 set to 1 year, and one ages 0 to 2 set at 2 years. Regression analyses predicting child and parent distress were run with all three variations of the variable in separate regression analyses. The three models for both child and parent distress were substantively the same, with no notable difference in beta weights between the models (Tables 2 – 3). Therefore, age at diagnosis for the category of 0 to 2 years old was set at one year old for the statistical analyses presented hereafter.

Diagnosis was dichotomized as high risk or low risk. Analyses were conducted with two variations of this dichotomy. One previous study that also dichotomized diagnosis into high and low risk categorized CNS cancer, including BT, and any leukemia as high risk (Shultz et al., 2007). However, many studies (e.g., Canning et al., 2014; Castellino et al., 2014; Siegal et al., 2016; van der Geest et al., 2013) agree that survivors of BT, other CNS cancers, and ALL are at higher risk of both psychological and neurocognitive late effects than survivors of other cancers. Therefore, regression analyses were conducted using both dichotomizations for predicting both child and parent distress. Both models predicting child distress as well as both models predicting parent distress were substantively the same, with no notable difference in beta weights between the models (see Tables 4 – 5). For simplicity, regression analyses presented here utilize the latter,
Table 1

**Participant Characteristics (N=100)**

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Parent Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Parent Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>96 (96.0)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (4.0)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>94 (94.0)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (6.0)</td>
</tr>
<tr>
<td>Annual Household Income(^a)</td>
<td></td>
</tr>
<tr>
<td>$10,000-$49,000</td>
<td>19 (19.0)</td>
</tr>
<tr>
<td>$50,000-$99,000</td>
<td>38 (38.0)</td>
</tr>
<tr>
<td>$100,000 or above</td>
<td>34 (34.0)</td>
</tr>
<tr>
<td><strong>Child Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Child Sex</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>50 (50.0)</td>
</tr>
<tr>
<td>Male</td>
<td>50 (50.0)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>92 (92.0)</td>
</tr>
<tr>
<td>Other</td>
<td>8 (8.0)</td>
</tr>
<tr>
<td>Age at diagnosis(^b)</td>
<td></td>
</tr>
<tr>
<td>0-5</td>
<td>60 (60.0)</td>
</tr>
<tr>
<td>6-11</td>
<td>31 (31.0)</td>
</tr>
<tr>
<td>12-18</td>
<td>9 (9.0)</td>
</tr>
<tr>
<td>Current Age</td>
<td></td>
</tr>
<tr>
<td>6-11</td>
<td>54 (54.0)</td>
</tr>
<tr>
<td>12-18</td>
<td>46 (46.0)</td>
</tr>
<tr>
<td>Diagnosis(^c)</td>
<td></td>
</tr>
<tr>
<td>High risk</td>
<td>63 (63.0)</td>
</tr>
<tr>
<td>Low risk</td>
<td>37 (37.0)</td>
</tr>
</tbody>
</table>

\(^a\) Ten participants (9.0%) indicated that they did not know their income or would prefer not to say.

\(^b\) Age at diagnosis was measured categorically by having parents indicate at which age their child was first diagnosed with cancer (e.g., 0-2, 3, 4, etc.). Age at diagnosis with the value for ages 0-2 set at 1 year.

\(^c\) Diagnosis was categorized as high or low risk, with CNS cancers, including BT, and ALL being considered high risk and all other cancers (e.g., acute myeloid leukemia, sarcoma, carcinoma) considered low risk; 0 = low risk, 1 = high risk.
CHILD-PARENT DIFFERENCES IN PSYCHOLOGICAL DISTRESS

Regression Analysis Predicting Child Distress with Three Variations of Age at Diagnosis (N = 100)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>B (SP)</th>
<th>SE</th>
<th>B (SP) 6 months 1 year 2 years</th>
<th>2-year changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child's age at diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis ≤ 2 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis &gt; 2 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School performance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School performance ≤ 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School performance &gt; 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School concerns ≤ 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School concerns &gt; 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent psychological distress</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent psychological distress ≤ 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent psychological distress &gt; 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *p < 0.05, **p < 0.01, ***p < 0.001.
### Table 3: Regression Analysis: Predicting Parental Distress With Three Portions of Age at Onset (N = 100)

<table>
<thead>
<tr>
<th>Age (in Years)</th>
<th>Distress Score</th>
<th>Beta (SE)</th>
<th>T Value</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2</td>
<td>5.0</td>
<td>0.9</td>
<td>5.6</td>
<td>0.00</td>
</tr>
<tr>
<td>3-5</td>
<td>4.5</td>
<td>0.8</td>
<td>4.5</td>
<td>0.00</td>
</tr>
<tr>
<td>6-9</td>
<td>4.0</td>
<td>0.7</td>
<td>4.0</td>
<td>0.00</td>
</tr>
<tr>
<td>10-12</td>
<td>3.5</td>
<td>0.6</td>
<td>3.5</td>
<td>0.00</td>
</tr>
</tbody>
</table>

**Note:**
- Distress scores above 4.5 are considered high risk.
- Age at diagnosis was calculated as age at diagnosis minus age at which child was first diagnosed with cancer.
dichotomization, with CNS cancers, including BT, and ALL being considered high risk and all other cancers (e.g., acute myeloid leukemia, sarcoma, carcinoma) considered low risk. See Table 4 for a comparison of models with both dichotomizations and Table 1 for descriptive statistics. Lastly, time since diagnosis was calculated by subtracting the child’s age at diagnosis, which was calculated as described above, from their current age (\( M = 6.52, SD = 3.94 \)).

School Information. Information regarding parent and teacher concerns about the survivor’s behavior and school performance was provided by parents. In addition, any learning disabilities and special education services being received were reported by parents (Appendix B). For the current study, school functioning includes parent rating of the child’s school performance (item 1), parent and teacher concerns (items 2 – 3), receipt of special education services (item 4), and whether the child had been retained a grade (item 5). Parents rated their child’s school performance as excellent, good, average, poor, or failing. Higher scores indicated better performance. Parents also reported on concerns about their child’s school performance. A list of nine areas of concern (e.g., math, reading) were provided. Parents selected which areas they as well as their child’s teacher had concerns about. For the current study, school concerns were dichotomized as either yes, parents and/or teachers had at least one concern, or no, neither parents nor teachers had concerns. Lastly, children were classified as either receiving special services (e.g., special education class, 504 plan) or not. See Table 6 for a summary of school information.

Behavior Problems Index (BPI). Child behavior problems were computed by summing the first 18 items of the BPI (Zill, 1985; Appendix C). This is a 28-item survey that produces six subscales: anti-social behavior, anxiety and depression, hyperactivity, stubbornness and parental conflicting behavior, immature and dependent behavior, social withdrawal and peer conflicting
Child-Parent Differences in Psychological Distress

<table>
<thead>
<tr>
<th>Note: 10 &gt; d*</th>
<th>5 &gt; d**</th>
</tr>
</thead>
<tbody>
<tr>
<td>School Services</td>
<td>School Services</td>
</tr>
<tr>
<td>School Problems</td>
<td>School Problems</td>
</tr>
<tr>
<td>Behavioral Problems</td>
<td>Behavioral Problems</td>
</tr>
<tr>
<td>Time Stress Diagnosis</td>
<td>Time Stress Diagnosis</td>
</tr>
<tr>
<td>Academic Diagnosis</td>
<td>Academic Diagnosis</td>
</tr>
<tr>
<td>Psychological Factors</td>
<td>Psychological Factors</td>
</tr>
</tbody>
</table>

Step 1: Psychological Factors

- Child所用
do: 32
- Parent所用
do: 32

Regression analysis for Diagnosed (High or Low Risk) Predicting Child Distress (N = 100)

Table 4
## Child-Parent Differences in Psychological Distress

### Psychological Distress

<table>
<thead>
<tr>
<th>Step</th>
<th>Psychological Domain</th>
<th>Child</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>School Performance</td>
<td>0.5</td>
<td>0.7</td>
</tr>
<tr>
<td>2</td>
<td>Behavior Problems</td>
<td>0.3</td>
<td>0.4</td>
</tr>
<tr>
<td>3</td>
<td>Time since Diagnosis</td>
<td>0.2</td>
<td>0.3</td>
</tr>
<tr>
<td>4</td>
<td>Initial Diagnosis</td>
<td>0.1</td>
<td>0.2</td>
</tr>
<tr>
<td>5</td>
<td>Biological Factors</td>
<td>0.6</td>
<td>0.8</td>
</tr>
</tbody>
</table>

### Table 5

Regression analysis for diagnosis (high vs. low risk) predicting parent distress (N = 100)

**Note:** 0.05 > d * 0.01 > d **
Table 6

School Functioning (N = 100)

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>School performance</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>29 (29.0)</td>
</tr>
<tr>
<td>Good</td>
<td>24 (24.0)</td>
</tr>
<tr>
<td>Average</td>
<td>27 (27.0)</td>
</tr>
<tr>
<td>Poor</td>
<td>17 (17.0)</td>
</tr>
<tr>
<td>Failing</td>
<td>3 (3.0)</td>
</tr>
<tr>
<td>Parent and teacher concerns</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>66 (66.0)</td>
</tr>
<tr>
<td>No</td>
<td>34 (34.0)</td>
</tr>
<tr>
<td>Receiving special services</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>45 (44.9)</td>
</tr>
<tr>
<td>No</td>
<td>55 (55.0)</td>
</tr>
</tbody>
</table>

behaviors. Respondents rate their agreement with a series of statements on a scale of 1 (“not true”) to 3 (“often true”). For the present study, only the first 18 items were used. The first 18 items contain items from all subscales, and the scale total of these items were found to be highly, positively correlated with the scale total for all BPI items ($r = .96, p < .001$). Although the distribution of this scale was positively skewed, neither square root nor logit transformation improved model fit. Therefore, the variable was left untransformed for the analyses reported here. Item scores are summed for a total score, which can range from 18 to 54, with higher scores indicating more behavior problems. Total scores ranged from 18 to 50 ($M = 26.72; SD = 7.14$). The level of problem behaviors identified in the current sample of CCS is notably higher than the mean found by Zill (1985) in a national survey ($M = 6.40, SD = 5.70$). Internal consistency of this measure as used in the current sample was adequate ($\alpha = .88$).

**Pediatric Oncology Quality of Life Scale (POQOLS):** Child emotional distress was computed by summing items of the Emotional Distress subscale of the POQOLS (Goodwin et al., 1994; Appendix D). The POQOLS is a 21-item measure of child quality of life and
behavioral and emotional functioning. The Emotional Distress subscale consists of eight items. Participants read a series of statements and rated how often each statement is true on a scale of 1 (“never”) to 7 (“very frequently”). The distribution of this scale was positively skewed. However, square root transformation did not improve model fit, and therefore the variable was left untransformed for the analyses reported here. Scale totals ranged from 6 to 31 with a mean of 15.27 ($SD = 5.73$). This was very similar to the subscale mean reported by Bijttebier and colleagues’ sample of children with a current cancer diagnosis (2011; $M = 15.40$, $SD = 6.75$). Higher scores indicate greater distress. It should be noted that internal consistency of this measure as used in the current sample was somewhat low ($\alpha = .69$). However, Goodwin and colleagues found high internal consistency ($\alpha = .85$) as well as inter-rater reliability between mother and father reports ($r = .87$) (1994). The measure was also found to have evidence of validity, as indicated by significant correlations with other measures of child behavioral adjustment and physical functioning (Goodwin et al., 1994).

**Childhood Cancer Survivor Study Neurocognitive Questionnaire (CCSS-NCQ).**

Neurocognitive late effects were measured using a modified version of the CCSS-NCQ (Krull et. al., 2008; Appendix E). The CCSS-NCQ is a 25-item self-report measure of NCLE for adult survivors of childhood cancer. Items were modified for parent-report of child NCLE. All items of the CCSS-NCQ (Krull et. al., 2008) were summed to yield a total NCLE score. Respondents rated how often a series of issues are a problem for their child on a scale of 1 (“never a problem”) to 3 (“often a problem”). The mean NCLE score for all participants was 47.20 ($SD = 10.86$), with scores ranging from 26 to 74, with higher scores indicating greater late effects. This measure has been shown to have adequate reliability, ranging from 0.77 to 0.84 for the subscales, as well as validity. Construct validity of the measure was supported by positive correlations with
the BPI, especially for the Task Efficiency subscale. Concurrent validity was supported by stronger association between the Emotional Tolerance subscale and the BSI than with the other CCSS-NCQ subscales. Lastly, discriminant validity was supported by statistically significant differences on subscale scores between CCS who received cranial radiation, CCS with additional neurologic conditions, healthy controls, and sibling controls (Krull et al., 2008). Internal consistency of this measure as used in the current sample was high ($\alpha = .93$).

**Parent Experience of Childhood Illness (PECI).** Parent emotional distress was computed by summing items of two subscales from the PECI: Guilt and Worry, and Unresolved Sorrow and Anger (Bonner et al., 2006; Appendix F). Together, these subscales consist of 19 items. The PECI is a 25-item parent-report measure that assesses parental adjustment associated with having a child with a medical condition. Respondents rate how often each statement is true on a scale of 0 (“never”) to 4 (“always”). Total scores ranged from 8 to 63 with a mean of 32.81 ($SD = 12.35$). Higher scores indicate higher levels of distress. Mean item scores on both the Guilt and Worry ($M = 1.88, SD = .76$) and the Unresolved Sorrow and Anger ($M = 1.76, SD = .72$) subscales were similar to those found in Bonner and colleagues’ sample of brain tumor survivors used to validate the measure ($M = 1.72, SD = .77; M = 1.51, SD = .82$) (2009). In their development of the measure, Bonner and colleagues found the PECI to have adequate internal consistency, with subscale internal reliabilities ranging from 0.72 to 0.89 (2006). The measure was also found to have adequate construct validity, as demonstrated by positive correlations with established measures of parental psychological adjustment. Internal consistency of this measure as used in the current sample was adequate ($\alpha = .93$).
**Procedure**

Data for this current study were obtained from an existing data set belonging to Dr. Catherine Peterson’s Pediatric Psychology Lab at Eastern Michigan University. These data were collected as part of a study that was previously granted exemption by Eastern Michigan University’s Human Subjects Review Committee on May 27, 2014 (UHSRC: #40508; Appendix G). Participants were recruited through social media and online support groups. They completed an online informed consent form and questionnaire containing the measures described above. Participants had the opportunity to have a $1.00 donation made by the research team to the charity of their choice. Data were collected from August 24, 2014 until December 13, 2015. Only non-identifiable information was collected, and data were stored on a secure server, only accessible by research team members. Permission to use this data was granted by Dr. Catherine Peterson. The current study was granted exemption on December 19, 2016 (UHSRC: #993824-1).

**Statistical Analyses**

Secondary analysis of the above described data was conducted. First, correlation analysis was used to assess the association between child psychological distress and parent psychological distress. Based on previous studies, it was expected that these two factors would have a positive correlation with the strength of the association being weak to moderate. Although child and parent psychological distress were measured using different scales, other studies have used similar methods. For example, Malpert and colleagues (2014) used the BSI to measure parent “emotional distress” and the Pediatric Quality of Life Inventory to measure “child emotional functioning” and found significant associations between the two (p. 1116).
Next, two hierarchical regression models were created to determine the predictors of child psychological distress and parent psychological distress. Both models included the same predictors, with the exception of child or parent distress. Parental distress was only included in the model predicting child distress, and child distress was only included in the model predicting parent distress. Child biological variables were added in step one of the models, and psychosocial variables were added in step two.

Results

Data were screened for data entry accuracy, outliers, and missing data. Data were found to be within range, and no univariate outliers were found. As noted above, the distributions of behavior problems and child psychological distress were positively skewed. However, transformation did not improve model fit, and therefore these variables were left untransformed. The distributions of all other variables were satisfactorily normal.

Correlation Analyses

Correlation analysis was used to examine the association between child and parent emotional distress, and analyses revealed a moderate, positive association \( r = .35, p < .001 \). This indicates that higher levels of child distress were associated with higher levels of parental distress. The moderate strength of the association suggests that these scales are likely measuring two related, but separate, constructs and that the parent-report measure of child distress is not simply another report of parental distress. See Table 7 for a summary of bivariate correlations between all variables. Longer time since diagnosis was weakly associated with greater NCLE \( r = .30, p < .01 \), greater behavior problems \( r = .24, p < .05 \), poorer school performance \( r = .33, p < .01 \), parent/teacher concerns \( r = .24, p < .05 \), and receipt of special school services \( r = -.27, p < .01 \). Greater NCLE was associated with greater problem behaviors \( r = .71, p < .001 \),
CHILD-PARENT DIFFERENCES IN PSYCHOLOGICAL DISTRESS

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</table>

Table 7: Correlation Matrix for Key Study Variables (N = 100)

Note: d_*** > d_** > d_+ > d_.*
poorer school performance ($r = -.67, p < .001$), parent/teacher concerns ($r = .47, p < .001$), and receipt of special school services ($r = -.40, p < .001$). Greater behavior problems were associated with poorer school performance ($r = -.46, p < .001$), parent/teacher concerns ($r = .28, p < .01$), and with receipt of special school services ($r = -.32, p < .01$). Lastly, poorer school performance was associated with no parent/teacher concerns ($r = -.56, p < .001$) and no receipt of school services ($r = .39, p < .001$), and parent/teacher concerns were moderately associated with receipt of school services ($r = .41, p < .001$).

**Regression Analyses**

Data were screened for outliers, normality of residuals, and linearity between predictor and criterion variables. No multivariate outliers were present and distributions of variables were satisfactorily normal. Adequate linearity and homoscedasticity of the variables and residuals were found. No evidence of collinearity, multicollinearity, or singularity was present.

First, a hierarchical multiple regression analysis was conducted to examine predictors of child psychological distress. It was hypothesized that age at diagnosis, diagnosis (i.e., high or low risk), time since diagnosis, NCLE, and parental distress would significantly predict child distress. See Table 8 for a summary of model results. In step one, child biological factors were added to the model. Greater NCLE was predictive of greater child psychological distress ($\beta = .43, p < .01$). Age at diagnosis, diagnosis (i.e., high or low risk), and time since diagnosis did not account for a significant proportion of the variance in child psychological distress. These child biological variables accounted for a significant proportion of the variance in child psychological distress, $F(4, 95) = 5.29, p < .01, R^2 = .18$. In step two, psychosocial factors were added to the model. After accounting for child biological factors, greater child problem behaviors ($\beta = .87, p < .01$) and greater parent psychological distress ($\beta = .24, p < .01$) were found to be predictive of
CHILD-PARENT DIFFERENCES IN PSYCHOLOGICAL DISTRESS

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<tr>
<th>Step 1: Psychological Diagnoses</th>
<th>Step 2: Psychological Diagnoses</th>
<th>Time since diagnosis</th>
<th>Age at diagnosis</th>
<th>NCE</th>
<th>Time since diagnosis</th>
<th>Age at diagnosis</th>
<th>NCE</th>
<th>Time since diagnosis</th>
<th>Age at diagnosis</th>
<th>NCE</th>
</tr>
</thead>
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<td>Diagnosed</td>
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<td>5 (4)</td>
<td>18.4 (2.9)</td>
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<td>18 (7)</td>
<td>5 (4)</td>
<td>18.4 (2.9)</td>
<td>Yes</td>
<td>18 (7)</td>
</tr>
<tr>
<td>Diagnosed</td>
<td>Diagnosed</td>
<td>18 (7)</td>
<td>5 (4)</td>
<td>18.4 (2.9)</td>
<td>No</td>
<td>18 (7)</td>
<td>5 (4)</td>
<td>18.4 (2.9)</td>
<td>No</td>
<td>18 (7)</td>
</tr>
</tbody>
</table>

Note: NCE = no change expected. Time since diagnosis and age at diagnosis are measured from the time of the initial diagnosis. P values for the difference between child and parent reports are shown in Table 8.
child distress. School performance, school concerns, and school services did not contribute to a significant proportion of the variance, although the contribution of school services receipt did approach significance ($p = .09$). NCLE did not remain a significant predictor in step two. The final model, including both biological and psychosocial factors, accounted for 60% of the variance in child psychological distress, $F(9, 90) = 15.00, p < .001$.

Next, a second hierarchical multiple regression analysis was conducted to examine the same variables as predictors of parent psychological distress. It was hypothesized that age at diagnosis, child problem behavior, and child distress would be predictive of parental distress. See Table 8 for a summary of model results. NCLE accounted for a significant proportion of the variance explaining parent distress, with greater NCLE being associated with greater distress ($\beta = .35, p < .01$). Shorter time since diagnosis was also found to predict greater distress ($\beta = -.35, p < .01$). Neither age at diagnosis nor diagnosis (i.e., high or low risk) were significantly predictive of distress. Together, these child biological factors accounted for 17% of the variance in parent psychological distress, $F(4, 95) = 4.68, p < .01$. Psychosocial factors were added in step two. Child psychological distress predicted parent psychological distress, with greater child distress being associated with greater parent distress ($\beta = .44, p < .01$). Although child problem behavior did approach significance ($p = .06$), problem behavior, school performance, school concerns, and school services were not found to be predictive of parent distress. NCLE and time since diagnosis did not remain significant predictors in step two. The final model accounted for 27% of the variance in parent psychological distress, $F(9, 90) = 3.60, p < .01$.

**Post Hoc Analyses**

To further explore possible association between school functioning and psychological distress, correlation analysis was conducted. See Table 9. Analyses revealed a significant
A correlation between one item of the Emotional Distress subscale of the POQOLS and all three indicators of school functioning (i.e., school performance, school concerns, and special services). Greater child distress was associated with poorer school performance ($r = -.41, p < .001$), no school concerns ($r = -.20, p < .05$), and receipt of special education services ($r = .33, p < .001$). In addition, significant correlations were observed between several items from the Guilt and Worry and Unresolved Sorrow and Anger subscales of the PECI. Items with significant associations indicated that greater parental distress was weakly associated with poorer school performance ($r = -.20$ to $-.28, p < .05$) and parent/teacher concerns about school ($r = -.23$ to $-.27, p < .05$). Correlation coefficients of two items indicated that greater parental distress was associated with not receiving services ($r = -.33$ and $r = -.24, p < .05$), while one indicated the converse ($r = .22, p < .05$).

**Discussion**

With survivorship in pediatric cancer patients becoming increasingly common, understanding factors related to poor outcomes during survivorship has become an important area of focus for pediatric psychologists. The current study explored predictors of child and parent psychological distress in a sample of parents of childhood cancer survivors. First, child biological factors were examined. Contrary to hypotheses and previous findings, age at diagnosis, diagnosis (high or low risk), and time since diagnosis were not predictive of child psychological distress. This suggests that CCS may experience similar levels of general psychological distress throughout survivorship regardless of how old they were when first diagnosed and regardless of whether their diagnosis placed them at high or low risk of NCLE. Discrepancies between current and previous findings may be due to methodological, measurement, and sample differences. Age at diagnosis has previously been found to be
Table 9

Correlations Between Indicators of School Functioning and Parent and Child Psychological Distress (N = 100)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>School Concerns</th>
<th>School Performance</th>
<th>Parent Concerns</th>
<th>Parent Psychological Distress</th>
</tr>
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<tbody>
<tr>
<td>Poor</td>
<td>0.33</td>
<td>-0.20</td>
<td>-0.41</td>
<td>-0.23</td>
</tr>
<tr>
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<td>-0.23</td>
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<tr>
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<td>-0.23</td>
<td>-0.23</td>
<td>-0.23</td>
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</tbody>
</table>

Note: *p < 0.05, **p < 0.01, ***p < 0.001

<table>
<thead>
<tr>
<th>Item</th>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child has demanded more help with daily tasks than he/she needs.</td>
<td>01</td>
<td></td>
</tr>
<tr>
<td>School concerns were discussed with either yes, parents and/or teachers had at least one concern, or no, neither parents nor teachers.</td>
<td>01</td>
<td></td>
</tr>
<tr>
<td>School performance was measured by parent rating: 1 = Extravagant, 2 = Poor, 3 = Average, 4 = Good, 5 = Excellent</td>
<td>01</td>
<td></td>
</tr>
</tbody>
</table>

Table 9

Correlations Between Indicators of School Functioning and Parent and Child Psychological Distress (N = 100)
associated with suicidal ideation specifically in BT survivors (Brinkman et al., 2013a) and with measures focused more on physical functioning (McDougal & Tsonis, 2009). It may be that age at diagnosis is related to particular types of child emotional and physical functioning, but not others, resulting in a lack of association with a general measure of psychological distress.

Measurement-related limitations also may explain why no significant associations with diagnosis were found. Studies that have found an association between diagnosis and distress looked at specific types of cancer (e.g., Canning et al., 2014; Hudson et al., 2003). While other studies have categorized cancer diagnoses into high risk and low risk for NCLE, this may not be a useful categorization for predicting psychological distress. It may be useful to look at differences based on specific diagnosis, as done in the studies mentioned above, or to categorize diagnoses found to be associated with greater distress (i.e., brain tumor, Hodgkin’s lymphoma, sarcoma, and bone cancer) as high risk and diagnoses associated with relatively less distress (i.e., ALL, other CNS) as low risk (Hudson et al., 2003; van der Geest et al., 2013). Measurement may have also played a role in the current findings on time since diagnosis as well. Longer time since diagnosis has been found to be related to fewer cancer-related concerns (Langeveld et al., 2004) and less anxiety, but not depression (Okado et al., 2016). Therefore, a general measure of psychological distress may not capture these nuances. Furthermore, Maurice-Stam and colleagues’ (2008) longitudinal study found child anxiety to be elevated two months after treatment and normalized after two years. This suggests that the relationship between time since diagnosis and distress is not perfectly linear and may not be able to be captured in a linear regression. Additionally, time since diagnosis may need to be measured in smaller increments (e.g., months rather than years).
Consistent with hypotheses and with Oancea and colleagues’ (2014) study of adult survivors of childhood cancer, NCLE was found to be a significant predictor of child psychological distress, with greater NCLE predicting greater distress. Associations between deficits in neurocognitive functioning and heightened anxiety have been observed in the general child population (Visu-Petra, Ciairano, & Miclea, 2006). For example, weaknesses in executive functioning (Emerson, Mollet, & Harrison, 2004; Toren et al., 200) as well as attentional difficulties (Angold, Costello, & Erkanli, 1999; Jarrett & Ollendick, 2008) may be related to childhood anxiety, and slowed processing speed may be associated with depressive symptomology in children (Favre et al., 2009). This suggests that neurocognitive and psychological functioning are likely at least somewhat intertwined. In addition, it is possible that a decline from previous functioning could contribute to distress in CCS. While children may lack insight into the emergence of specific cognitive deficits, they may nonetheless notice difficulty completing tasks that they did not previously experience. Thus, understanding NCLE is critical to understanding the child’s overall functioning. Furthermore, because the present study indicates that NCLE is such a strong predictor of psychological distress, clinicians should pay close attention to any indication of neurocognitive impairment in CCS patients. Proactive screening for NCLE would help facilitate early intervention, which is critical (Askins & Moore, 2008; Castellino et al., 2014s) for both neurocognitive deficits and psychological adjustment.

Age at diagnosis was not found to predict parental psychological distress. No a priori hypothesis was made as to whether these variables would be associated due to mixed findings in previous studies. However, two out of three studies identified in Ljungman and colleagues’ 2014 review found no association. Thus, the current study adds evidence that the age at which a child was first diagnosed with cancer may not be related to their parent’s experience of distress during
survivorship. As hypothesized, high or low risk diagnosis was not predictive of parental distress. This is consistent with previous studies that found no association between specific cancer diagnosis and parental distress (Pierce et al., 2016; Radcliffe et al., 1996) and suggests that diagnoses associated with greater risk of NCLE may not be related to parent psychological distress. It may be that the survivor’s actual functional outcomes (i.e., child NCLE) is more closely tied to parents’ current emotional response than anticipated outcome (i.e., receiving a diagnosis with high risk of negative outcomes). Some parents of children diagnosed with high-risk cancers may be able to view survivorship as a positive outcome rather than seeing the late effects as a negative outcome and are subsequently able to cope more effectively through positive reappraisal (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Folkman, Lazarus, Gruen, & DeLongis, 1986). Conversely, some parents of survivors of low-risk cancers who expected a positive survivorship outcome may not be as readily able to positively reappraise unanticipated late effects.

Two factors that were found to predict parent distress were time since diagnosis and child NCLE. Previous findings on time since diagnosis were mixed, and therefore no a priori hypothesis was made. The present finding that shorter time since diagnosis is associated with greater distress is consistent with Haegen and Luminet’s (2015) review of 92 papers, which found a negative association between time since diagnosis and several indicators of distress (e.g., stress, anxiety, depression) in parents of CCS. As previously mentioned, discrepancies in findings may be due to differences in conceptualization and measurement of psychological distress, as demonstrated by recent findings that higher levels of depression, but not anxiety, are associated with shorter time since diagnosis (Okado et al., 2016). As hypothesized, greater NCLE were predictive of greater distress in parents. This adds to evidence found in previous
studies that parents of children with more neurocognitive deficits tend to experience more
distress than parents of children with higher neurocognitive functioning (Malpert et al., 2015;
Patel et al., 2013).

When comparing models of child biological factors predicting child and parent
psychological distress, some similar associations were found. Age at diagnosis and high or low
risk diagnosis were not found to predict distress in children or parents. Given the strong
association found between NCLE and both child and parent distress in this study, it is surprising
to find a lack of association between child distress and diagnosis considered high risk for NCLE.
Nonetheless, the current findings on the relationship between distress and NCLE suggest that
current and ongoing cognitive and functional deficits in the child are a very important issue to
address for the wellbeing of both CCS and their parents.

The current findings highlight the importance of addressing NCLE proactively and with
ongoing support for both child and parent psychological wellbeing. Changes in the treatment
regimens for both chemotherapy and radiotherapy aimed at maximizing effectiveness while
minimizing neurotoxicity have helped to prevent later negative cognitive effects (Askins &
Moore, 2008; Castellino et al., 2014). After treatment completion, psychological intervention for
NCLE may be warranted. A growing body of evidence provides support for the use of cognitive
remediation, an intervention originally adapted for CCS by Bulter (1998; Askins & Moore, 2008;
Castellino et al., 2014). Improvements include increased focused attention and academic
performance. As mentioned above, early intervention may have the best outcomes (Askins &
Moore, 2008; Castellino et al., 2014). Unfortunately, this intervention is not widely accessible as
insurance coverage varies between providers (Castellino et al., 2014). Preliminary findings on a
parent-directed intervention developed by Patel and colleagues (2014) suggest that such an
intervention is highly feasible and is associated with some improvements in academic functioning. Psychopharmacological intervention is also becoming available for NCLE. Stimulant medication (e.g., methylphenidate hydrochloride) in particular, has been shown to increase sustained attention, cognitive flexibility, and processing speed (Askins & Moore, 2008; Castellino et al., 2014; Colkin et al., 2010). In addition, emerging evidence suggests that recombinant human growth hormone may lead to improvements in some areas of cognitive functioning, such as sustained attention and cognitive-perceptual performance, in CCS (Castellino et al., 2014).

One predictor that differed between the child and parent distress models was time since diagnosis. Lower levels of parent psychological distress were found to be related to longer time since diagnosis, while no association was found with child psychological distress. This may suggest that parents are more likely to experience relief from symptoms of distress as they gain more distance from the time at which their child was diagnosed, which is consistent with some previous findings (e.g., Haegen and Luminet, 2015), while children’s levels of distress, which may in fact be normative (e.g., Glover et al., 2003; Hudson et al., 2003), remain more stable. However, it may be more appropriate and useful to examine changes in more specific symptoms of distress (e.g., anxiety, depression) over time, as demonstrated by Okado and colleagues (2015).

The second aim of this study was to examine psychosocial predictors of child and parent psychological distress. As predicted, greater parent psychological distress predicted greater child psychological distress. This is consistent with other studies that identified significant correlations between the two (e.g., Malpert et al., 2015; Okado et al., 2014). This also aligns with Peterson and Drotar’s (2006) model of neurodevelopmental late effects and family functioning, which
hypothesized a bidirectional relationship between child and parental psychological adjustment. Given the lack of empirical findings in CCS, no directional hypotheses were made regarding whether or not child problem behaviors would predict child distress. Greater problem behaviors were found to be related to greater psychological distress. This is not surprising, given that the measure of problem behaviors included internalizing behavior (e.g., “Is too fearful or anxious”). Additionally, both the BPI and PECI rely on parent report, and parents experiencing distress may over-report child dysfunction. Thus, there is likely some shared variance between these two measures due to their reliance on a single informant.

As expected, indicators of school functioning (i.e., performance, parent/teacher concerns, services) were not found to be predictive child psychological distress. This is consistent with the one previous study that explored associations between receipt of special education services and child anxiety and depression and found none (Radcliffe et al., 1996). However, it should be noted that a weak, but significant, negative correlation existed between child psychological distress and child academic performance ($r = -.21, p < .05$). This suggests that how the child is performing in school is not completely unrelated to their psychological functioning. Associations between these two variables have been found in the general child population, with many studies finding higher levels of anxiety to predict lower academic performance. Based on a meta-analysis of 126 studies, the population effect size of this association is small ($r = -.21$) (Seipp, 1991). Thus, there may be a weak, bidirectional relationship between anxiety and academic performance in children in general. Lastly, it may be unsurprising that child distress was not found to be associated with receipt of special education services. While it could be posited that receipt of special services would be indicative of greater impairment, cognitive and psychological, special education services should help mitigate that impairment. Additionally,
some children who are experiencing academic difficulty may not be receiving needed services, resulting in continued impairment, while other children who are not receiving services may be functioning well and not require additional assistance. Thus, receipt of special education services may not be a strong and clinically relevant indicator of academic performance.

Psychosocial predictors of parent psychological distress were also investigated. Contrary to hypotheses, child problem behaviors were not found to predict parental distress. This is surprising given the strong evidence that exists linking problem behavior and parenting stress not only in parents of CCS (Patel et al., 2013), but also parents of children in general (e.g., Hall & Graff, 2012; Neece, Green, & Baker, 2012). It could be that child problem behavior is related only to parenting stress specifically and not psychological distress more generally, as measured in the present study. No indicators of school functioning were found to predict parent distress. This is consistent with Radcliffe and colleagues’ (1996) finding that parental distress was not associated with special education placement. While this is inconsistent with earlier findings by Kazak and Meadows (1989) that parents of CCS receiving tutoring or special education services were more likely to experience distress, that study contained only a small sample of CCS (n = 35). Although academic functioning did not predict parental distress, some weak associations were noted. Poor academic performance and receipt of special education were associated with higher levels of distress. As mentioned above, a weak association between parents’ distress and child special education services may exist in part because children who are receiving special services are benefitting from assistance, while other children are functioning well academically without them. Associations between parental distress and all the indicators of academic functioning (i.e., school performance, parent/teacher concerns) may be weak as a result of measurement, as it seems unlikely that poor academic functioning would have no effect on
parental distress. The PECI, which was used to measure parental distress, is a measure of parent experience specific to their child’s chronic illness. How the child is functioning in school may not be related to the parent’s illness-specific distress, but it may be related to distress more generally. Had a different measure of distress been used, perhaps a measure of perceived stress, school functioning may have been predictive of parental distress. Finally, higher levels of child psychological distress were found to predict higher levels of parent psychological distress, as expected. This provides further evidence that child and parent psychological functioning are related and that understanding how one is functioning is crucial for understanding the other.

Like the biological predictors of distress, some psychosocial factors were found to predict both child and parent psychological distress, and others were not. Child problem behavior was found to predict child distress, but not parent distress. Again, it is unsurprising that children’s internal experience of distress was found to be related to their external expression of behavior. As discussed above, the lack of evidence for an association between parental distress and child problem behavior may be due to an issue of measurement, as it has been well established that child problem behavior is a strong driver of parental distress. Thus, despite current findings, addressing behavior concerns in CCS is likely an important clinical objective for clinicians working with this population.

No indicators of school functioning (i.e., overall performance, parent and teacher concerns, and receipt of special services) were predictive of either child or parent psychological distress. Again, it seems unlikely that academic functioning is unrelated to child and parent psychological functioning. This is supported by weak negative correlations between parental and child distress and child school performance, a weak positive correlation between parental distress and school concerns, and several significant associations between some of the indicators of
school functioning and some items on the measures of parent and child psychological distress. Several items from the PECI were associated with child school performance and receipt of special education services. Greater parental distress on several items was associated with worse school performance, more parent/teacher concerns, and receipt of special education services. Greater child distress on one item of the POQOLS was associated with worse school performance, fewer parent/teacher concerns, and receipt of special education services. Thus, a measure of distress not specifically related to childhood illness may better capture predictive or directional relationships between academic functioning and psychological functioning in both parents and children. Given the limited literature on associations between school functioning and child and parent psychological distress, future studies may be warranted to further explore this relationship, especially in children. It may be more useful to look at more specific types of distress, as anxiety and depression have been linked with poor school performance in the general child population (e.g., Ialongo, Edelsohn, Werthamer-Larsson, Crockett, & Kellam, 1994; Fröjd et al., 2008).

Lastly, child and parent psychological distress were found to be associated, with higher levels of each predicting higher levels of the other. This suggests that any alleviation in symptoms in the parent may be accompanied by a decrease in child symptoms and vice versa, that what is good for one part of the family unit, may be good for another. Family interventions, addressing both parent and child needs, may be highly beneficial in alleviating the symptoms of each individual. Intervening on parental distress may be especially important since parenting stress, in particular, and poor parenting practices covary, as do poor parenting and poor child adjustment (Deater-Deckard, 1998). Perhaps the most supported intervention for parents of CCS is the Surviving Cancer Competently Intervention Program (SCCIP) developed by Kazak and
CHILD-PARENT DIFFERENCES IN PSYCHOLOGICAL DISTRESS

colleagues (1999). A randomized clinical trial of the SCCIP indicated that families receiving the intervention reported substantial declines in posttraumatic stress symptoms (Kazak et al., 2004). Interventions aimed at addressing other cancer-related issues may also have benefits for parental wellbeing, such as psychoeducation (Patel et al., 2013) and interventions specifically targeted for NCLE (Patel et al., 2014). Reductions in parental distress may be accompanied by reduction in poor child functioning, including psychological distress and behavior problems, further contributing to healthy family functioning (Gunlicks & Weissman, 2008).

While there were some differences in which psychosocial factors predict child and parent psychological distress, when examining the overall models, these factors do make a unique contribution even after accounting for child biological factors. Adding psychosocial factors to the model increased the variance accounted for by 42% for child distress and by 10% for parent distress. Clearly, these psychosocial factors are important in understanding the distress experienced by CCS and their parents during survivorship and perhaps even more so than biological factors. This is an encouraging finding since, while most biological factors cannot be modified (e.g., age at diagnosis, diagnosis), the psychosocial factors examined here may be modifiable. The modifiable factor that emerged as the most important in predicting child and parent psychological distress is the psychological distress of another part of the family unit. Upon additional comparison of the two overall models, it becomes clear that the factors identified here account for more of the variance in child psychological distress (56%) than parent psychological distress (20%). This is not surprising, considering that all but one of the factors examined here were child factors. However, this further emphasizes the discrepancy between knowledge about factors that drive child distress and parental distress as noted above. This makes sense given the many roles that parents must fulfill in addition to the specific role of being
a parent of a childhood cancer survivor. Factors beyond just child-specific variables, as examined here, warrant continued exploration in order to better understand parental distress. For example, other studies of CCS families have found family functioning before cancer diagnosis and treatment (Pai et al., 2007), social support (Kazak et al., 1997), and parent relationship to the child (i.e., mother versus father) (Ljungman et al., 2014) to be related to psychological distress in parents of CCS. Based on studies in other populations, socioeconomic status (e.g., Puff & Renk, 2014; Streisand, Swift, Wickmark, Chen, & Holmes, 2005) and coping style (Frydenberg, 2014) may also be associated factors. Examining these and other parent and family-level factors in parents of CCS will be important for gaining a better understanding of parental distress and risk factors for poor family functioning.

**Future Directions**

In the future, it may be useful for studies to be guided by a developmental approach. Given our understanding that children are constantly developing, it is important to understand their experiences within the context of their developmental history, current developmental stage, and ongoing development. A cancer diagnosis and subsequent treatment are certainly disruptive to development, both neurocognitively and psychosocially. There is evidence that there is an expected trajectory for psychological distress in CCS, with greater distress closer to the time of diagnosis and an attenuation of at least some symptoms over time and an eventual return to typical adjustment in, again, at least some areas (e.g., Maurice-Stam et al., 2008; Okado et al., 2016). However, it is also known that heterotypic continuity of many internalizing and externalizing behaviors exists (e.g., Beauchaine & McNulty, 2013). Thus, it is possible that certain symptoms of distress at one point in a child’s life may be related to other symptoms of distress later in childhood or even later in adulthood. Continued efforts should be made to look at
general distress and specific symptoms (e.g., anxiety, depression) and predictors of distress at different time points after treatment completion. For example, Okado and colleagues (2016) found that child and parent distress were more strongly associated at a longer time since diagnosis in their cross-sectional study. More findings from longitudinal studies, like the Childhood Cancer Survivor Study, will be crucial in exploring developmental pathways in CCS. Greater understanding of how distress and the factors that drive it change over time would be useful in informing interventions. Furthermore, while this study aimed to expand understanding of parent distress in parents of CCS, the discrepancy in variance accounted for by the two models further highlighted the need to identify other factors related to distress in parents. Substantial attention has been paid to understanding the experiences of CCS. Given the tremendous influence that parents have on their children’s functioning, greater attention on parental functioning is warranted.

**Limitations**

The limitations of the current findings should be considered. First, a cross-sectional online survey was used to collect the data analyzed here. Thus, changes in child and parental psychological distress from functioning before cancer diagnosis and treatment cannot be determined. All measures in the survey relied on parent-report, making responses inherently subjective to the parent’s experience. Parental ratings of child functioning may be influenced by parental functioning, possibly resulting in overestimation of child distress (Carpentieri et al., 2003). In addition, the sample consisted of self-selected participants who voluntarily completed this online survey, some of whom were already members of online groups for parents of CCS. The vast majority of participants were also White, middle to upper class, and mothers. Thus, the present findings may not generalize to minorities, lower socioeconomic status, and fathers or
other caregivers. Results of this study may be also limited by the measures utilized. The scales used to measure child and parent psychological distress were not equivalent measures designed to measure the same construct. Furthermore, only two of the measures (i.e., POQOLS, CCSS-NCQ) were specifically developed for use with cancer survivors. It is generally accepted that measures of distress developed for use on other populations may not perfectly capture the experience of CCS and their families (Kazak, 2005). Thus, although the PECI was created for parents of children with chronic illnesses, it may not capture the unique experiences of being the parents of a child who has survived cancer. The same may be true of measures of other constructs. For example, the Behavior Problem Index may not capture the challenging behavior specific to CCS. Lastly, the models predicting psychological distress in the current study do not statistically account for family socioeconomic status and related variables due to small sample size and accompanying lack of power to include many predictor variables. As mentioned above, it should be considered that socioeconomic factors have been found to predict psychological distress in CCS specifically (Zeltzer et al., 2009) and in both children and adults more generally (e.g., McLaughlin et al., 2010; Moreno-Peral et al., 2014).

**Conclusion**

Childhood cancer survivorship and understanding of potential late effects is an important area of focus for pediatric psychologists. While a great deal is known about the long-term psychological impact cancer has on survivors, less is known about predictors of trajectories of parent distress and possible differences in predictors from child distress. The current study examined the same factors as predictors of psychological distress in childhood cancer survivors and their parents, allowing for side-by-side comparison of variables related to psychological adjustment in families of CCS. Results indicated that neurocognitive late effects predict
psychological distress in both parents and children. In addition, child psychological distress predicts parental psychological distress, which in turn predicts child distress. These findings offer evidence for proposed associations between parental psychological adjustment, child psychological adjustment, and NCLE in Peterson and Drotar’s (2006) model of family functioning in families of CCS. Thus, the present study contributes to the current understanding of how families of childhood cancer survivors function during survivorship by supporting the need for interventions aimed at addressing parental and family adjustment to child NCLE, which may contribute to improvements in overall family functioning following the devastating experience of a child’s cancer diagnosis.
References


Kazak, A.E., Cant, M.C., Jensen, M.M., McSherry, M., Rourke, M., Hwang, W., Alderfer, M., Beele, D., Simms, S., & Lange, B.J. (2003). Identifying psychosocial risk indicative of
subsequent resource use in families of newly diagnosed pediatric oncology patients.

*Journal of Clinical Oncology, 21*, 3220–3225.


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Appendix A: Demographics Questionnaire

Please complete the following identifying information about yourself.

1. Please indicate your age
2. Please indicate your gender
3. Please indicate your relationship to your child
   a. Biological mother
   b. Biological father
   c. Adoptive mother
   d. Adoptive father
   e. Step-mother
   f. Step-father
   g. Foster mother
   h. Foster father
   i. Other, please specify _______
4. Please indicate your ethnicity/race
   a. American Indian/Alaska Native
   b. Asian
   c. Native Hawaiian/Other Pacific Islander
   d. Black/African American
   e. White
   f. Other
5. Please indicate how many people live in the home
6. Please indicate the number of other children in the home *during* your child’s treatment
   a. 1
   b. 2
   c. 3
   d. 4
   e. 5 or more
7. Please indicate your current marital status
   a. Married/living with partner
   b. Single
   c. Divorced
   d. Widowed
8. Please indicate your marital status *at the time of your child’s diagnosis with cancer* your child’s treatment
   a. Married/living with partner
   b. Single
   c. Divorced
   d. Widowed
9. Please indicate the highest grade of school that you have completed
   a. High school or less
   b. Vocational school
   c. Some college
d. College degree
e. Professional/post-graduate degree

10. Please indicate the highest grade of school that your spouse/partner/co-parent has completed
   a. High school or less
   b. Vocational school
   c. Some college
   d. College degree
   e. Professional/post-graduate degree
   f. N/A

Please complete the following identifying information about your child who was treated for cancer.

1. Please indicate your child’s current age and date of birth
2. Please indicate how old your child was when they were diagnosed.
3. Please indicate your child’s gender
4. Please indicate your child’s race/ethnicity
   a. American Indian/Alaska Native
   b. Asian
   c. Native Hawaiian/Other Pacific Islander
   d. Black/African American
   e. White
   f. Other
5. Please indicate your child’s current grade in school (or most recent grade completed, if summer)
6. Please indicate the type of school your child attends
   a. Public School
   b. Charter School
   c. Private- parochial or religious school
   d. Other private school
   e. Homeschool
7. Please indicate your child’s initial cancer diagnosis
8. Please indicate your child’s age at diagnosis
9. Did your child have surgery (other than infusion port/central catheter placement)?
   a. Yes/no
   b. If yes, location
10. Did your child have chemotherapy?
    a. Yes/no
       i. If yes, was chemotherapy intrathecal (i.e., given in spinal taps)
          1. Yes/no
11. Did your child have radiation?
    a. Yes/no
       i. If yes, location (e.g., tumor bed, brain, total body)
          1. How much
12. Did your child relapse?
a. Yes/no
   i. If yes, treatment received
      1. Check all that apply
         a. Chemotherapy, radiation, transplant
13. Did you child undergo a bone marrow/stem cell transplant?
   a. Yes/no
14. Please indicate when your child’s treatment ended (MM/YY).
Appendix B: General School Information/Behavior Questionnaire

1. How would you describe your child’s current school performance (his/her current grades)?

<table>
<thead>
<tr>
<th>Failing</th>
<th>Poor</th>
<th>Average</th>
<th>Good</th>
<th>Excellent</th>
</tr>
</thead>
</table>

2. Do you have concerns about your child’s school performance?
   a. Yes/No
   i. If yes, please select which areas concern you (select all that apply)
      1. Math
      2. Reading
      3. Writing/spelling
      4. Attention/focus
      5. Hyperactivity
      6. General behavior
      7. Gross Motor
      8. Fine Motor
      9. Other, Please specify

3. Have your child’s teachers had concerns about your child’s school performance?
   a. Yes/No
   i. If yes, please select which areas concern you (select all that apply)
      1. Math
      2. Reading
      3. Writing/spelling
      4. Attention/focus
      5. Hyperactivity
      6. General behavior
      7. Gross
      8. Fine Motor
      9. Other, Please specify

4. Does your child receive any special services at school?
   a. Yes/No
   i. If yes, please select all that apply
      1. Special education class/consultation/resource room access
      2. 504 plan
      3. Individual Education Plan (IEP)
      4. Individualized Behavior Plan
      5. Preferential classroom seating
      6. Speech/language services
      7. Occupational therapy
      8. Audio FM system
      9. Physical therapy
      10. Social skills group
      11. Counseling with social worker or psychologist
      12. Other, please specify
5. Has your child ever been held back?
   a. Yes/No
      i. If yes, what grade
6. Has your child ever been tested for learning problems?
   a. Yes/No/Not Sure
7. Have teachers raised concerns regarding your child’s behavior at school?
   a. Yes/No
      i. If yes, please check all that apply
         1. Overly active/fidgety in class
         2. Breaks rules
         3. Received detention/suspension
         4. Loses or forgets things
         5. Doesn’t listen/follow directions
         6. Aggressive/fights with other children
         7. Sent to principal/guidance counselor
         8. Other, please specify

2. Do you have concerns about your child’s study habits, such as attention, organization, or memory?
   a. Yes/No
      i. If yes, please check all that apply
         1. Trouble paying attention to schoolwork
         2. Finishing projects/chores
         3. Remembering chores/tasks/commands
         4. Remembering material for tests
         5. Keeping room organized
         6. Trouble paying attention to tv/movies or games
         7. Finishing multi-step instructions or tasks
         8. Remembering books/supplies for homework
         9. Solving multi-step problems in the correct order
         10. Finishing things he/she starts
         11. Switching between tasks/assignments
         12. Finishing homework/projects on time
         13. Taking longer than usual on homework
         14. Tasks taking longer than teacher expects
         15. Remembering how to solve math problems
         16. Struggling with memorizing math facts
         17. Struggling with spelling words
         18. Struggling with writing skills
         19. Poor or sloppy handwriting
         20. Struggling with reading skills
         21. Struggling with reading comprehension
         22. Trouble copying from the board
         23. Pain or fatigue when writing
         24. Other, please specify

3. Do you have concerns about your child’s interactions with other children his/her same age?
a. Yes/No
   i. If yes, please check all that apply
      1. Making new friends
      2. Keeping/sustaining friendships
      3. Making good decisions in social situations
      4. Understanding/keeping up in social situations
      5. Initiating conversations with peers
      6. Sustaining conversations with peers
      7. Initiating conversations with adults
      8. Sustaining conversations with adults
      9. Understanding turn-taking in conversations
     10. Making off-topic comments in conversations
     11. Understanding sarcasm, humor
     12. Seeming “immature” compared to peers
     13. Respecting personal space in social situations
     14. Other, please specify

4. Do you have concerns about how your child handles his/her emotions?
   a. Yes/No
      i. If yes, please specify
         1. Doesn’t handle challenges well
         2. Doesn’t handle change well
         3. Gets upset or tearful easily
         4. Gets frustrated quickly/easily
         5. Gets angry easily
         6. Gives up on things quickly
         7. Worries often
         8. Emotions lead to aches/pains (e.g., headaches)
         9. Worries about “little” things
        10. Other, please specify
Appendix C: Behavior Problem Index-Short Form (BPI-SF)

Here are some statements that describe behavior problems many children have. Please mark whether each statement is not true, sometimes true, or often true of your child during the past 3 months.

1 = Not True  2 = Sometimes True  3 = Often True

1. Has sudden changes in mood or feelings
2. Feels or complains that no one loves him/her
3. Is rather high strung, nervous, or tense
4. Cheats or tells lies
5. Is too fearful or anxious
6. Argues too much
7. Has difficulty concentrating, cannot pay attention for long
8. Is easily confused, seems to be in a fog
9. Bullies, or is cruel or mean to others
10. Is disobedient at home
11. Does not seem to be sorry after he/she misbehaves
12. Has trouble getting along with other children
13. Is impulsive, or acts without thinking
14. Feels worthless or inferior
15. Is not liked by other children
16. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions
17. Is restless or overly active, cannot sit still
18. Is stubborn, sullen, or irritable
Appendix D: Pediatric Oncology Quality of Life Scale (POQOLS)

Please answer the following questions about your child’s current feelings and activities.  
7 point likert scale: never, very rarely, rarely, occasionally, sometimes, frequently, very frequently

1. My child has anger outbursts
2. My child has expressed fear about the disease and its treatment
3. My child has been sad
4. My child has been able to participate in recreational activities (sports, games, etc).
5. My child has had less energy and has been easily tired out
6. My child has required active medical treatment
7. My child has been able to interact/play with friends completely normally
8. My child has complained of pain from medical procedures
9. My child has been embarrassed about physical changes (hair loss, weight change, etc.)
10. My child has been physically capable of performing as usual
11. My child has had trouble sleeping
12. My child has complained about physical pain from his/her cancer
13. My child has been bothered by other people treating him/her differently
14. My child has been satisfied with his/her recent physical activity
15. My child has played/visited with friends
16. My child has been able to attend school
17. My child has demanded more help with daily tasks than he/she needs
18. My child has been hostile
19. My child has spent time during the day resting
20. My child has had nausea or vomiting due to treatment
21. My child has needed extra help with daily living skills.
Appendix E: Childhood Cancer Survivor Study Neurocognitive Questionnaire (CCSSNQ)

Please answer the following questions about your child’s thinking and learning. Likert scale ranging from 1 (“Never a Problem”) to 3 (“Often a Problem”).

My child….
1. Gets upset easily
2. Takes longer to complete work
3. Does not think of consequences
4. Is disorganized
5. Forgets instructions easily
6. Has problems completing his/her work
7. Has difficulty recalling things learned before
8. Gets frustrated easily
9. Changes moods frequently
10. Finds different ways to solve a problem
11. Is impulsive
12. Forgets what he/she is doing in the middle of things
13. Has problems with self-motivation
14. Is an underachiever
15. Has trouble finding things in his/her bedroom
16. Is easily overwhelmed
17. Has trouble with multitasking
18. Blurts things out
19. Has a messy desk
20. Has trouble remembering things
21. Has trouble prioritizing activities
22. Reads slowly
23. Is slower than others
24. Does not work well under pressure
25. Has trouble solving math problem
Appendix F: Parent Experience of Childhood Illness Scale (PECI)

This questionnaire is concerned with thoughts and feelings related to parenting a child who is living with, or has experienced, a chronic illness. Read each statement and then try to determine how well it describes your thoughts and feelings over the past month.

<table>
<thead>
<tr>
<th>Statement</th>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>OFTEN</th>
<th>ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is painful for me to think about what my child might have been like had s/he never gotten sick.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I am at peace with the circumstances of my life.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I feel guilty because my child became ill while I remained healthy.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I worry about my child’s future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I feel ready to face challenges related to my child’s well being in the future.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I worry that I may be responsible for my child’s illness in some way.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I worry that at any minute, things might take a turn for the worse.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I worry about whether my child will be able to live independently as an adult.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I have regrets about decisions I have made concerning my child’s illness.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I think about whether or not my child will die.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
11. I am aware of the specific ways I react to sadness and loss. 0 1 2 3 4
12. I experience angry feelings when I think about my child’s illness. 0 1 2 3 4
13. I am afraid of this diagnosis occurring in another member of my immediate family. 0 1 2 3 4
14. I trust myself to manage the future, whatever happens. 0 1 2 3 4
15. I find it hard to socialize with people who don’t understand what being a parent to my child means. 0 1 2 3 4
16. When my child is playing actively, I find myself worried that s/he will get hurt. 0 1 2 3 4
17. I believe I will never be as completely happy or satisfied with my life as I was before my child became ill. 0 1 2 3 4
18. My hopes and dreams for my child’s future are uncertain. 0 1 2 3 4
19. I am jealous of parents who have healthy children. 0 1 2 3 4
20. I worry that my child’s illness will worsen/return. 0 1 2 3 4
21. Seeing healthy children doing everyday activities makes me feel sad. 0 1 2 3 4
22. I worry about something bad happening to my child when s/he is out of my care. 0 1 2 3 4
23. I can get help and support when I need it.  

24. I wake up during the night and check on my child.  

25. When I am not with my child, I find myself thinking about whether or not s/he is ok.
Appendix G: Institutional Review Board Letter of Exemption

RESEARCH @ EMU

UHSRC Determination: EXEMPT

DATE: December 19, 2016

TO: Shelby Wilson
Department of Psychology
Eastern Michigan University

Re: UHSRC: #993824-1
Category: Exempt category 4
Approval Date: December 19, 2016

Title: Psychological Distress in Families of Childhood Cancer Survivors: Exploring the Differences Between Child and Parent

Your research project, entitled Psychological Distress in Families of Childhood Cancer Survivors: Exploring the Differences Between Child and Parent, has been determined Exempt in accordance with federal regulation 45 CFR 46.102. UHSRC policy states that you, as the Principal Investigator, are responsible for protecting the rights and welfare of your research subjects and conducting your research as described in your protocol.

Renewals: Exempt protocols do not need to be renewed. When the project is completed, please submit the Human Subjects Study Completion Form (access through IRBNet on the UHSRC website).

Modifications: You may make minor changes (e.g., study staff changes, sample size changes, contact information changes, etc.) without submitting for review. However, if you plan to make changes that alter study design or any study instruments, you must submit a Human Subjects Approval Request Form and obtain approval prior to implementation. The form is available through IRBNet on the UHSRC website.

Problems: All major deviations from the reviewed protocol, unanticipated problems, adverse events, subject complaints, or other problems that may increase the risk to human subjects or change the category of review must be reported to the UHSRC via an Event Report form, available through IRBNet on the UHSRC website.

Follow-up: If your Exempt project is not completed and closed after three years, the UHSRC office will contact you regarding the status of the project.

Please use the UHSRC number listed above on any forms submitted that relate to this project, or on any correspondence with the UHSRC office.

Good luck in your research. If we can be of further assistance, please contact us at 734-487-3090 or via e-mail at human.subjects@emich.edu. Thank you for your cooperation.

Sincerely,

Alissa Huth-Bocks, Ph.D.
Chair
CAS Human Subjects Review Committee