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Oncology summer camp attendance and self-esteem and internalizing and externalizing behaviors among pediatric cancer patients and siblings

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ONCOLOGY SUMMER CAMP ATTENDANCE AND SELF-ESTEEM AND INTERNALIZING AND EXTERNALIZING BEHAVIORS AMONG PEDIATRIC CANCER PATIENTS AND SIBLINGS

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ABSTRACT

Children with cancer are faced with unique physical and psychosocial challenges, which may result in decreased quality of life. A cancer diagnosis affects the entire family, and siblings in particular are at increased psychological risk. A growing amount of literature has documented positive outcomes associated with camp attendance for both children with cancer and their siblings. This study uses archival data from Camp Ronald McDonald for Good Times collected by Wellisch et al. (2006), and examines the relationship between summer camp attendance and self-esteem and internalizing and externalizing behaviors among cancer patients and siblings. Sixty-four (64) pediatric cancer patients and their siblings (patients = 30; siblings = 34) ranging from 7 to 18 years (M = 11.84; *SD* = 2.89) who attended a weeklong oncology camp completed the study. Data was collected prior to camp (Baseline), at the end of camp (Follow-up 1), and again 4–6 months later (Follow-up 2). Measures included the Children's Depression Inventory, a self-report measure that screens for depressive symptoms; the Social Adjustment and Competence Domain from the Youth Self Report, a measure that examines perceived social support; and a socio-demographic survey. Using repeated measures MANOVAs, we found no significant changes in level of self-esteem or externalizing behaviors over time. We did, however, observe a statistically significant change in levels of internalizing behaviors over time when considering the entire sample and when looking at patients versus siblings. Results showed a statistically significant reduction in levels of internalizing behaviors over time, when considering the entire sample. When examining patients versus siblings, we also found statistically significant differences in internalizing behaviors over time. While patients reported a marked decrease in internalizing symptoms, siblings' symptoms remained fairly consistent over time. While the researchers hypothesized that the camp intervention would result in increased self-esteem and decreased externalizing behaviors, results did not reveal significant findings. Implications for future research as well as strengths and limitations of this study are discussed.

Introduction

Over the past 40 years, the field of pediatric oncology has changed dramatically. A shift in methods of treatment during the 1990s led to a significantly higher survival rate, which may be upwards of 70-75% for all childhood cancers when combined (Ach et al., 2013; Conrad & Altmaier, 2009; Eiser, Hill, & Vance, 2000; Ellis, 2000; Fearnow-Kenney & Kliewer, 2000; Katz, Leary, Breiger, & Friedman, 2011; Schwartz & Drotar, 2009; Thompson, Gerhardt, Miller, Vannatta, & Noll, 2009).

Due to increased survivorship, there has been a shift in focus from solely treating cancer medically to also considering the psychosocial impact of having cancer. In fact, familial support, once virtually overlooked by the medical community, is now regarded as a unit of care to support the healing process (Eiser et al., 2000; Kazak, Christakis, Alderfer, & Coiro, 1994; Robinson, Gerhardt, Vannatta, & Noll, 2007; Woodgate, 1999; Wu, Prout, Roberts, Parikshak, & Amylon, 2011).

In addition to the typical challenges faced by children and adolescents as they progress through their development, those with pediatric cancer must cope with unique challenges in the physical and psychosocial areas of development (Chao, Chen, Wang, Wu, & Yeh, 2003; Decker, 2007; Wu et al., 2011). They are often faced with treatment that is complex, invasive, and onerous (Decker, 2007; Ellis, 2000), with treatment periods ranging from 6 months to several years. Painful procedures, hospitalizations, and an uncertain prognosis are common stressors that can pose a substantial threat to the adjustment of children (Sloper, 2000).

A cancer diagnosis and subsequent treatment not only affects the sick child but the entire family, particularly healthy siblings. Having an ill sibling often leads to adjustment in family routines, increased responsibility, and decreased physical and emotional availability of

family members. Additionally, siblings likely experience confusion, fear, anger, jealousy, shame, guilt and isolation related to the illness of their sibling. In fact, numerous studies have reported that siblings of children with chronic illness both (a) experience more adjustment or behavioral problems than the siblings of healthy children (Barrera, Fleming, & Khan, 2004; Goudie, Havercamp, Jamieson, & Sahr, 2013; Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003; Houtzager, Grootenhuis, Caron, & Last, 2004; Lahteenmaki, Sjöblom, Korhonen, & Salmi, 2004; Packman et al., 2008) and (b) experience stress similar to that of the ill child (Murray, 1995, 1998, 1999; Spinetta, McLaren, Fox, & Sparta, 1981).

Studies indicate that, despite the intense stress connected with a cancer diagnosis and treatment, most children, adolescents, and families are able to cope and adapt adequately. There is, however, a small subset of children and siblings that experience severe and lasting difficulties requiring additional psychological help.

Self-Esteem

The notion of self-esteem refers to the degree to which one values or likes oneself (Johnson, 2014). The self evolves through a cognitive-developmental maturation process (Harter, 1983) and continues to be influenced by the environment (Bracken, 1996). In fact, the process of liking oneself takes place across the lifespan and is influenced by internal beliefs, emotions, and social experiences (Evan, Kaufman, Cook, & Zeltzer, 2006). Self-esteem in childhood and adolescence is particularly important as it has been found to be a predictor of psychosocial adjustment in adulthood (Overbaugh & Sawin, 1992).

Self-esteem among children and adolescent cancer patients and survivors has been studied widely. Results of those studies have been mixed. While many of the studies to date have found that in spite of surviving a potentially life threatening illness, self-esteem among

this group appears to be comparable or even higher than their healthy counterparts (Anholt, Fritz, and Keener, 1993; Richie, 2001). Others have documented a decline in self-esteem in patients during adolescence (McCaffrey, 2006; Von Essen, Enskär, Kreuger, Larsson, & Sjödén, 2000) and/or a decline over time after the conclusion of treatment (Pendley, Dahlquist, and Dreyer, 1996; Von Essen et al., 2000). Self-esteem related to physical appearance has, in some studies, been found to be lower than healthy peers (Anholt et al., 1993; Pendley et al., 1996). This is not altogether surprising, due to the many physical changes survivors may experience, including hair loss, weight gain, and amputation. The literature on siblings of cancer patients has shown that they often experience psychological difficulties. However, there is little evidence supporting low levels of self-esteem due to the experience of having a sibling who is ill (Sidhu et al., 2006).

Internalizing and Externalizing Behaviors

Despite the numerous stressors encountered by pediatric and adolescent cancer patients, several studies have found little evidence of serious maladjustment among this population (Patenaude & Kupst, 2005). To the contrary, many studies have found that most survivors show good adjustment on psychological self-report measures and that their scores are not significantly different from those of norms, controls, or comparison groups (Eiser et. al, 2000; Kazak et al., 1997; Mackie, Hill, Kondryn, & McNally, 2000; Noll et al., 1999; Simms, Kazak, Golomb, Goldwein, & Bunin, 2002). These studies have often examined both internalizing symptoms of emotional distress such as depression, as well as externalizing symptoms of distress such as aggression, academic difficulties, and substance use.

While the majority of pediatric cancer patients demonstrate functioning equivalent to or even better than comparison groups, literature has consistently reported that patients who suffer

from late effects or those with a diagnosis of a brain tumor are more likely to exhibit internalizing and externalizing behaviors (Eilersten et al., 2011; Kazak et al., 1994). Some studies have also found a relationship between a cancer diagnosis during adolescence and higher rates of internalizing and externalizing behaviors, particularly among adolescent females (Kazak et al., 1994; Thompson et al., 2009).

There is growing evidence indicating that siblings of children with cancer experience an increase in internalizing symptoms such as depression and externalizing behavioral problems (Goudie et al., 2013). Studies have found that, much like cancer patients, adolescent siblings exhibit the poorest adjustment, particularly adolescent females (Barrera et al., 2004; Houtzager, et al., 2003; Houtzager et al., 2004).

Pediatric Oncology Camps

One intervention that has shown much promise is the pediatric oncology camp. A growing amount of literature has documented positive outcomes associated with camp attendance for both children with cancer and their siblings (e.g., lower distress, improved social competence and health-related quality of life, greater perceived peer acceptance; Meltzer & Rourke, 2005; Packman et al., 2005; Sidhu, Passmore, & Baker, 2006; Wu et al., 2011). One such facility is Camp Ronald McDonald For Good Times (CRMFGT), established in 1982 as a way to include children suffering from cancer and their siblings in a "normalizing" summer camp experience (Balen, Fielding, & Lewis, 1996; Wellisch et al., 2006).

While a number of studies suggest that these camps have a significant impact on patients' self-esteem, these conclusions often rely on anecdotal information. Preliminary studies suggest that social comparison among similar peers can have substantial effects on cancer survivors' self-esteem (Meltzer & Rourke, 2005), and that the camp experience may

have a positive impact on those with lower initial self-esteem (Torok, Kokonyei, Karolyi, Ittzes, & Tomcsanyi, 2006), though more studies are needed to better understand the effects of camp on self-esteem.

While self-esteem among siblings tends to be in the normative range, the literature does demonstrate that the camp experience can further increase a sibling's self-esteem (Murray, 2001; Packman, Fine, Chesterman, & Ion, 2004; Sidhu et al., 2006).

With regard to internalizing and externalizing symptoms, a growing amount of literature has documented positive outcomes associated with camp attendance for both children with cancer and their siblings. Studies have shown a decrease in symptoms of depression (Wellisch et al., 2006), and loneliness (Melzer & Rourke, 2005) as well as an increase in social satisfaction (Melzer & Rourke, 2005), overall feelings of hope for patients (Woods, Mayes, Bartley, Fedele, & Ryan, 2013), and significant improvements in emotional, social, academic, and psychosocial domains for siblings (Packman et al., 2005; Sidhu et al., 2006).

While a number of studies have documented positive outcomes (e.g., increased self-esteem and decreased internalizing and externalizing behaviors) for children with cancer and their siblings following a pediatric oncology camp intervention, more research is needed to understand the dynamic of self-esteem among and between patients and siblings. Additionally, findings from many of the studies examining internalizing and externalizing behaviors and the impact of camp attendance are mixed often due to inconsistent methodology (e.g., the exclusion of certain types of cancers, small sample sizes, and lack of baseline measures) as well as the fact that the population being studied is not a traditional clinical population (Gerhardt, Lehmann, Long, & Alderfer, 2015). Finally, more research is needed to identify which

populations are vulnerable to maladjustment and how participation in pediatric oncology camp organizations affects those vulnerabilities.

Focus and Scope of the Present Study

In light of the powerful role that the summer camp experience may serve for cancer patients and siblings, this study will examine the relationship between participation in a pediatric oncology summer camp experience and internalizing and externalizing behaviors, in addition to the level of self-esteem for both cancer patients and their siblings. Through the use of an archival data set collected at a pediatric oncology camp, this study will help enhance the existing literature base regarding self-esteem and internalizing and externalizing behaviors, as findings in the existing literature vary quite considerably. The current study will also attempt to both identify more vulnerable subgroups in this population and to examine the impact of the camp intervention.

Specifically, the study will examine how self-esteem changes across time in relation to the following demographics: patients versus siblings, children versus adolescents, and males versus females. These same variables will be considered as we examine internalizing and externalizing behaviors across time, both before and after the camp intervention.

Hypotheses

The following hypotheses are made concerning the present study:

1. Following participation in a weeklong oncology summer camp experience, self-esteem will increase across all groups (e.g., patients and siblings, males and females, and children and adolescents).
2. No other predictions regarding self-esteem are made for between group differences in change over time.

3. Internalizing and externalizing behaviors will decrease across all groups (e.g., patients and siblings, males and females, and children and adolescents).
4. Internalizing and externalizing behaviors will be greater at both baseline and over time for adolescent female siblings when compared to other campers.
5. No other predictions regarding internalizing and externalizing behaviors are made for between group differences in change over time.

Method

Participants

The present study utilized data from an archival research database collected in 2001 by Dr. David Wellisch of the Department of Psychiatry, UCLA School of Medicine. Patients with cancer diagnoses or their siblings, ages 7 to 18, attending Camp Ronald McDonald for Good Times for a 1-week summer session, were invited to participate. Six sessions were included in this study, all with the same programming. Four sessions consisted of patients and siblings, one had patients only, and one was siblings only. Sixty-four (64) children in total completed the study; thirty (30) or approximately 47% were patients and thirty-four (34) or 53% were siblings. Twenty-seven (27) males were represented (42.2%) and thirty-seven (37) females participated (57.8%). The participants' ethnic backgrounds included: Caucasian (63%), Latino (23%), African-American (6%), Asian (2%), Bi-racial (3%), and did not state or other (3%). Age breakdowns were as follows: ages 7-10 (32.8%), ages 11-13 (37.5%), ages 14-18 (29.7%).

Of the 30 patient campers who participated, 18, or 61%, were diagnosed with a form of leukemia or lymphoma. The remaining 12 patient campers, or 39%, had a diverse range of solid tumors, such as Wilm's tumors, sarcomas, and brain tumors. The range of time since diagnosis was from 9 to 166 months (13 years and 10 months), with the average time since diagnosis being 81 months (6 years and 9 months).

Fifty-one (51) of the participants had attended camp previously, representing 78.8% of the sample. The remaining 13 participants were new to camp, representing 21.2% of the sample. Of the patient campers, 24 of 30 previously attended camp (80.6%). Twenty-seven (27) of 34 siblings in the sample had previously attended camp (79.4%). Camp Ronald McDonald for Good Times was referred patients and siblings from approximately nine pediatric cancer hospitals and outpatient clinics across Southern California and Nevada.

Procedures

Institutional Review Board (IRB) approval was obtained both from the original research project and again for the current study. Permission to use it was obtained from Dr. David Wellisch, the primary investigator of the original study. Consent forms and test protocol were created in English and Spanish versions. Informed consent from a parent and assent from each participant was obtained prior to participation. All children who registered for a camp session were notified of the ability to participate in the study. Seventy-seven (77) participants consented for the study with two (2.5 %) who withdrew before the study was initiated. Attrition after the baseline was 5 additional children (6%). Five more children did not complete the final measures, while 1 had multiple baseline measures missing, which left a total of 64 participants in the study.

All data was entered from hard copy files into SPSS by a graduate-level research assistant. Researchers screened the data for patterns of missingness and discovered several missing values across multiple participants. First, there were two cases that appeared to have substantial data that was missing at random (MAR). Specifically, there were entire measures (e.g., CDI, SA) that were omitted either at baseline or 6-month follow-up. For this reason, researchers employed case deletion for these two participants. Several other cases had values missing, and for cases with three or fewer items missing on a measure, researchers handled this with mean imputation. Since all questions on the YSR pertained to social adjustment and there were no subdomains, measures with one to three missing values were imputed with the participant's average item score. A number of participants omitted one particular item on the YSR regarding the desire to be alone versus with other children. Researchers hypothesize that this question was omitted due to complicated phrasing and not because of the content of the

question. The CDI has five domains, therefore the means of each domain were derived for the participant and imputed for those missing values.

Baseline measurements were taken on the first day of the camp session, and children completed the measures in a private room. The CDI and YSR were used at this time. The first follow-up occurred on the last day of the weeklong camp session. In addition to the CDI and YSR, an additional measure was completed by campers, called the "Things you did at camp." Approximately 4-6 months after the first follow-up, campers were contacted via phone to determine if they would like to finish testing on the phone or through mail. Of the 64 participants, five (7.8%) chose to be interviewed via telephone and 59 (92.2%) opted for mail-in testing. It should be noted that the participants, who were minors, completed the measures in full. Parents did not fill out any type of assessment.

Measures

Researchers used three separate test protocol in the original study. They are as follows: Children's Depression Inventory (CDI); Youth Self Report (Social Adjustment section) from the Child Behavior Checklist; Things You Did at Camp.

The CDI is a self-report, 27-item measure used to screen symptoms of depression in children and adolescents. There are five major categories that are represented by the 27 items: Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia, Negative Self-Esteem. In addition to each category score, a total CDI score is also calculated. Participants rated measures of depression on a 3-point scale for each item as they considered their symptoms over the previous 2 weeks. The CDI was originally normed on data from 1,266 Floridian children and adolescents ages 7-16. It was further standardized in a clinical setting on various groups of children ($N = 134$). The test has good internal consistency and reliability (alpha = 0.86). Test-

retest reliability has been indicated by multiple studies of the CDI ranging from $r = 0.38 - 0.87$. The majority of the studies show $r = 0.65$ or higher (Kovacs, 1992).

The YSR, referred to here as the SA, is a standardized, self-report measure for children, which examines feelings and behavior. It is typically administered as part of the CBCL. Twenty (20) questions from the YSR related to social adjustment and competence were used. Children rated each item on a 4-point Likert scale. An additional item was added for the purposes of this study, to assess fear about attending camp. For total competence, stability *R*'s were 0.62 and for total problems, stability was 0.56.

Things You Did at Camp is a measure developed by the researchers to identify activities available to participants and the level of enjoyment received through participation in camp activities. The measure included 21 questions about possible camp activities. Children aged 7-12 rated their feelings about activities by circling a cartoon face with emotions of sadness, happiness, or neutrality. Children ages 13-19 rated their enjoyment of activities by placing a check mark next to one of the following options: I liked it a lot, It was OK, I didn't like it. For each participant, the total number of activities in which he/she participated was calculated and the mean score was obtained.

Methods of Analysis

Statistical analyses aimed to identify important changes across time for patients and siblings. A repeated measures multivariate analysis of variance (MANOVA) was used to examine the impact of age (child versus adolescent), gender (male versus female), cancer status (e.g., patient versus sibling), and time (baseline, first follow-up, and second follow-up) on self-esteem (derived from the Negative Self-Esteem domain from the CDI questionnaire). Main effects and interactions were examined to understand more about the effects of this type of

intervention. A repeated measures MANOVA was also used to examine the impact of age, gender, cancer status, and time on internalizing symptoms using the Negative Mood Domain from the CDI questionnaire. Finally, a scale for externalizing behaviors was created by summing the scores for 2 items from the SA scale, which are consistent with items from the Child Behavior Checklist (CBCL; Achenbach, 1991), a measure of externalizing behavior: (#2: "I argue a lot" and #6: " I often try to get a lot of attention"). Internal consistency and reliability were examined. Following this, a repeated measures MANOVA was used to examine the impact of age, gender, and time on externalizing behaviors. Statistical significance was reported when *P* values were less than 0.05. *P* values that fell between 0.05 and 0.10 were discussed, however, as they are considered to be approaching significance and can yield important information.

Results

Table B1 shows descriptive summaries of the samples of patients and siblings. The average age among patients was 11.57 (*SD* = 2.86); (range: 7–17) and 12.09 (*SD* = 2.93) among siblings (range: 7–18). Gender, age, and ethnicity were similarly distributed in the patient and sibling groups.

Self-Esteem

Repeated-measures MANOVAs were utilized to examine the impact of time (baseline, first follow-up, and second follow-up), age, gender, and cancer status on self-esteem scores. It was hypothesized that all groups (e.g., patients and siblings, males and females, children and adolescents) would experience improved levels of self-esteem following participation in a camp intervention. We found, however, no statistically significant main effects when looking at the entire sample, Wilks' $\lambda = .998$ $F(2, 50) = .147$, $p > .05$.

We also found no significant change in level of self-esteem over time for patients versus siblings, Wilks' $\lambda = .985$ $F(2, 50) = .392$, $p > .05$, indicating that the effect of the camp intervention on level of self-esteem was statistically similar across both groups (e.g., patients and siblings). There were also no statistically significant findings when considering the impact of age, gender, or interaction between these variables. Refer to Figure C1 for self-esteem means across time for patient status, age category, and gender.

Internalizing Behaviors

Repeated-measures MANOVAs were utilized to examine the impact of time (baseline, first follow-up, and second follow-up), age, gender, and cancer status on levels of internalizing behavior. It was hypothesized that all groups (e.g., patients and siblings, males and females, and children and adolescents) would experience a decrease in internalizing behaviors. It was also hypothesized that adolescent females would experience a greater change in internalizing

behaviors following the intervention across time; no other group differences were expected. Results showed a statistically significant main effect of the intervention over time (e.g., baseline to second follow-up) when considering the entire sample, Wilks' $\lambda = .876$ $F(2, 50) = 3.67$, $p = .036$, partial eta squared = .124 (see Table 4 for internalizing means). We also found a statistically significant two-way interaction when considering the intervention over time and cancer status, Wilks' $\lambda = .872$ $F(2, 50) = 3.66$, $p = .033$, partial eta squared = .128. Refer to Figure G1 for visual representation of internalizing behavior means for the interaction between time and cancer status. We found that patient's internalizing behaviors significantly reduced over time, while siblings experienced a slight decrease in internalizing symptoms at the first follow-up and a considerable increase at the second follow-up. In fact, when examining siblings internalizing symptoms from baseline to the second follow-up, they reported an increase in symptoms. There were no statistically significant findings when considering age, gender, or interaction between time, age and gender, broadly or when considering patients versus siblings. This suggests that these demographic categories are not predictive of a reduction in internalizing behaviors across time points. Refer to Figure E1 for internalizing behavior means across time for patient status, age category, and gender.

Externalizing Behaviors

Regarding externalizing behaviors, the sums of scores across time for two items from the SA scale were calculated to measure the externalizing variable. The items were consistent with items from the CBCL. With these two items, Cronbach's $\alpha = .554$. Given this low alpha score, findings should be interpreted with caution. Repeated measures MANOVAs were used to examine the effect of time (baseline, first follow-up, and second follow-up), age, gender, and cancer status on levels of externalizing behavior. It was hypothesized that all groups (e.g.,

patients and siblings, males and females, and children and adolescents) would experience a decrease in externalizing behaviors. It was also hypothesized that adolescent females would experience a greater change in externalizing behaviors following the intervention across time; no other group differences were expected. Results indicated that there was no main effect of time on externalizing behaviors when considering the sample as a whole, Wilks' $\lambda = .952$ $F(2, 49) = 1.24$, $p > .05$. During further analysis, we found an interaction of the effect of time and age on externalizing behavior that was approaching statistical significance Wilks' $\lambda = .898$ $F(2, 49) = 2.775$, $p = .072$, partial eta squared = .102. Refer to Figure H1 for visual representation of externalizing behavior means for the interaction between time and age. We found no main effects when examining the impact of time moderated by gender, or when examining patients versus siblings when considering demographic variables. Refer to Figure F1 for externalizing behavior means across time for patient status, age category, and gender.

Discussion

In order to investigate the relationship between summer camp attendance and self-esteem, internalizing, and externalizing behaviors for cancer patients and their siblings, this study utilized archival data from Camp Ronald McDonald for Good Times collected by Wellisch et al. (2006). While self-esteem and negative mood were examined in their study, the researchers considered the impact of multiple demographic variables (age and gender) on self-esteem and internalizing, behaviors both to identify vulnerable subgroups in this population and to examine the impact of the camp experience. Externalizing behaviors is a unique variable that was not studied in the original article and findings will be discussed below.

The first variable examined was self-esteem. While we had predicted that participation in summer camp would result in all campers experiencing an improvement in self-esteem, this hypothesis was not supported by our data. We found no significant change in self-esteem following the camp intervention for patients versus siblings, nor when considering age and gender. It is important to note that the sample overall did not endorse poor self-esteem. In fact, at baseline, 45 out of 64 campers (71%) endorsed no self-esteem difficulties, and at the second follow-up, 49 out of 64 campers (78%) endorsed a "0" out of 15, indicating no self-esteem deficits (see Figure D1 for self-esteem frequencies). Therefore, lack of significant findings is likely due to floor effects, thereby making it difficult to identify changes in self-esteem. Additionally, because we used a clinical measure (CDI) on a population that is not traditionally a clinical population, it is likely that the measurements were not sensitive enough to detect change.

When examining the means across time, we did see a very slight elevation in self-esteem for patients from baseline to the second follow-up. Interestingly, we found that siblings

experienced a slight decrease in self-esteem from baseline to the second follow-up, although none of these findings were statistically significant. We also found that adolescent female siblings endorsed the highest level of difficulty with regard to self-esteem at baseline, which stayed consistent over time. However, it is important to note again that these findings were not significant and any endorsement of self-esteem difficulties was at the mild level.

With regard to internalizing symptoms, we hypothesized that symptoms would decrease across all groups over time. We found that levels of internalizing behaviors for all campers significantly changed over time when considering the entire sample. When examining the means for the entire sample, we confirmed that levels of reported internalizing symptoms decreased over time. We also found a statistically significant interaction between cancer status (patient versus sibling) and time. When examining the means, it appears that at baseline, patients endorsed lower mood (or greater internalizing symptoms) than siblings. Over time, however, patients' mood levels improved quite considerably, and continued to improve at the 4- to 6-month follow-up. This finding suggests that the effects of camp participation are long-lasting in nature for patients. Siblings reported fewer internalizing symptoms at baseline when compared to patients. Following the weeklong summer camp experience, siblings experienced fewer internalizing behaviors. However, at the 4-6 month follow-up, the levels of internalizing symptoms reported by siblings increased and were actually higher than their baseline measurements. Based upon these findings, patients experienced an improvement in overall mood following the camp intervention, while siblings experienced lower mood ratings.

It was also hypothesized that internalizing symptoms would be greater at baseline and over time for adolescent female siblings when compared to other campers. This hypothesis was not supported by our sample. When examining the internalizing means across time for the

various demographic groups, male adolescent patients actually reported the highest level of internalizing behaviors at baseline. This is quite surprising, as other studies have reported that males endorse fewer internalizing symptoms than females (Kazak et al., 1994). Across time, however, levels of internalizing behaviors for this group decreased quite considerably, and at the second follow-up, they actually reported the lowest level of internalizing behaviors when compared to all other campers. While this finding certainly supports the benefits of the camp intervention for this demographic, findings should be interpreted with caution, as this subgroup was comprised of only 5 campers. With regard to female adolescent siblings, this subgroup endorsed the second highest levels of internalizing behaviors (following male adolescent patients), and while their scores decreased slightly from baseline to the first follow-up, they increased at the second follow-up, staying fairly consistent with levels reported at baseline. This finding indicates that following the camp intervention, adolescent female siblings may have experienced an improvement in mood, but these changes were not maintained at the 4- to 6-month follow-up.

Finally, in order to study externalizing behaviors, the researchers created a new construct using two items from the Social Adjustment scale that were consistent with items from the CBCL, a measure of externalizing behaviors. Results indicated that this scale only had low internal consistency, and therefore all findings should be interpreted with caution. Similar to the internalizing variable, we hypothesized that externalizing behaviors would decrease across all groups over time following the camp intervention. This hypothesis was not confirmed, as there were no significant changes in externalizing behaviors across time for the entire sample or when considering the effect of the different demographic variables (e.g., cancer status or gender). We found that when considering externalizing behaviors over time

and age, there was a borderline significant interaction, indicating that the age category may be predictive of a change in externalizing behaviors over time. In looking more closely at the means, children at baseline reported fewer externalizing behaviors than adolescents, and these levels stayed fairly consistent across time. While, adolescents endorsed a greater level of externalizing behaviors at baseline, this reduced considerably across time. The implication of this finding is that over time, following the camp intervention, adolescent campers endorsed a decrease in both attention-seeking behavior and arguing with others.

We also hypothesized that adolescent female siblings would endorse higher levels of externalizing behaviors at baseline and across time when compared to all other campers. This hypothesis was not supported by the data. Female adolescent siblings did not endorse high levels of externalizing behaviors when compared to other campers. Additionally, over time, this group saw a decline in externalizing symptoms following the camp intervention.

Limitations

This study was not without its limitations. First, the scale created for externalizing behaviors used only two items from the SA scale, and yielded low internal consistency, making any findings difficult to interpret. Future studies could benefit from using a scale that more accurately measures externalizing behaviors, such as the CBCL externalizing scale. The study did not include a control group, thereby making it difficult to know conclusively if the changes observed were due to the intervention or simply a natural result of time. The sample size of the group was relatively small (n = 64), making it difficult to make inferences about pediatric cancer patients and their siblings. Similarly, the study is not representative of the population as the data was collected from a single camp in Southern California. Finally, the study relied on

self-report measures of campers as young as 7 years old, with no collateral involvement from parents or staff.

Strengths

One of the primary strengths of the current study is the contribution of knowledge regarding the relationship between summer camp attendance and self-esteem, internalizing, and externalizing behaviors among pediatric cancer patients and their siblings. Although the Wellisch et al., (2006) study examined the same population, the current study provides information regarding the impact of camp on externalizing behaviors, a variable not examined in the original study. The current study also examined the impact of demographic variables, including cancer status (e.g., patients versus siblings), age, and gender, with the hope of being able to identify and serve more vulnerable subgroups.

Implications for Future Research

One of the goals of the study was to identify patients or siblings vulnerable to distress – in the hopes that those findings can in the future help identify subgroups with particular vulnerability. We did find that at baseline, patients exhibited significantly more internalizing symptoms than did their siblings. In fact, male adolescent patients endorsed the highest levels of internalizing symptoms at baseline. This finding is important in that this potentially vulnerable population may have been previously overlooked.

For that reason then, it would be helpful to conduct follow-up studies examining distress among this particular subgroup. According to our study, adolescent male patients exhibited a considerable decline in internalizing behaviors following the camp experience. In order to better understand why this decline occurred, follow-up studies would be useful.

Among healthy siblings, following the camp intervention, levels of internalizing symptoms remained fairly consistent with baseline reports, although they increased at the second follow-up. In order to better understand the relationship between internalizing symptoms for this population over time, studies utilizing a longitudinal design could be very helpful.

Results from our study also demonstrated that patients and siblings do not experience deficits with regard to self-esteem. It is possible that the clinical assessment tool that was used with this non-clinical population was not sensitive enough to detect change. Hence, we recommend examining this population utilizing a more comprehensive measure of self-esteem, including not just deficits in self-esteem but areas in which individuals may experience positive feelings about the self. Additionally, previous studies have reported that among patients, self-esteem decreases as time since treatment increases. Because this finding is so critical, follow-up studies using a longitudinal design are warranted.

With regard to externalizing behavior, the camp intervention did appear to result in a reduction of externalizing symptoms among siblings, but this was not observed among patients. As mentioned earlier, we created a tool to measure externalizing symptoms, but the construct had relatively low reliability. Findings reported on externalizing behaviors among siblings and patients have been mixed and therefore, follow-up studies utilizing a more reliable construct, such as the CBCL externalizing scale, should be conducted.

While a number of studies have reported that healthy siblings experience notable degrees of distress and maladjustment, others do not report such findings. Furthermore, the camp intervention in this study did not appear to be as effective for siblings as it was for patients. Follow-up studies, both qualitative and quantitative, may be useful to help better

understand the experience of the sibling and identification of subgroups at risk for psychosocial difficulties so that we may better serve them.

In fact, there has been a focus developing evidence-based standards in medical settings for healthy siblings, cancer patients, and parents. These standards include screening tools in order to identify distress early on and psychosocial interventions in order to prevent maladjustment and to promote positive coping and wellbeing (Gerhardt et al., 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015; Zegaczewski, Chang, Coddington, & Berg, 2016). While these standards are new and more research is needed to understand their effects, they show much promise with early identification and intervention contributing to positive quality of life outcomes and adjustment for the entire family.

Finally, as the majority of patients and siblings faced with pediatric cancer do not experience significant maladjustment, current studies are moving towards examining the nature and mechanisms supporting resiliency and positive adjustment in spite of multiple stressors. Researchers are just beginning to examine the effects of optimism (Williams, Davis, Hancock, & Phipps, 2010), hope, and repressive adaptation (Phipps, 2007). Developing a better understanding of the factors contributing to resilience among children with cancer has great potential to extend to other pediatric, adolescent, and even adult populations faced with significant stressors.

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APPENDIX A

Review of the Literature

Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Anholt U.V., Fritz, G.K., & Keener, M. (1993). Self-concept in survivors of childhood and adolescent cancer. Journal of Psychosocial Oncology, 11(1), 1-16.	Cancer group (n=63), ages 6- to 18-years-old comparison group (n=120) - Children with brain tumors excluded	Quantitative	To investigate the impact of cancer on the self-concept of pediatric oncology survivors. In comparing self-esteem among this group to a matched control group, researchers hypothesized that: 1) global self-esteem in both groups would be similar; and, 2) the cancer groups self-esteem would be less positive related to body image/physical appearance	Self-report measures (Piers Self-Concept Scale) and Physical Impairment Rating Scale. The Oncologist Rating Form was completed by an oncologist familiar with the children in the cancer group.	Researchers found that global self-concept in pediatric and adolescent cancer survivors was similar to the global self-concept of healthy children. However, researchers found that the cancer group had a lower self-concept with regard to physical appearance. Greater time since treatment, lower self-concept regarding physical appearance.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Barrera, M., Fleming, C. F., & Khan, F. S. (2004). The role of emotional social support in the psychological adjustment of siblings of children with cancer. Child: Care, Health and Development, 30(2), 103–11.	72 siblings of children being treated for cancer, ranging in age from 6-18-years-old, who were participating in a larger sibling intervention project. The sample consisted of two groups of siblings of children being treated for cancer: siblings referred for behavior problems (n= 47) and a comparison group of non-referred siblings (n= 25). Forty-two were female, and 30 were male. The mean age was 10.31 years (SD = 2.71).	Quantitative (Cross-Sectional)	To examine the role of emotional social support in the psychological adjustment of these siblings. The researchers also examined any potential relationships among the sibling's age, gender, emotional social support, and psychological adjustment.	Siblings completed the following measures: the CDI, the STAIC, the YSR, and the Sibling Perception Questionnaire. One parent of each sibling completed the following measures: the STAIC-Parent Form, and the CBCL, and provided demographic information.	Referred adolescent females reported significantly higher depression scores and were perceived as more anxious than referred adolescent males, and non-referred adolescent females. Non-referred younger siblings with high social support were perceived by their parents as having the fewest behavioral problems. High level of social support appears to play a protective role in psychological adjustment of siblings of pediatric cancer patients, with age and gender as modifying factors.
Bauld, C., Toumbourou, J. W., Anderson, V., Coffey, C., & Olsson, C. a. (2005). Health-risk behaviors among adolescent survivors of childhood cancer. Pediatric Blood & Cancer, 45(5), 706–15.	306 individuals (153 adolescent cancer survivors and 153 healthy peers). The ages of individuals in the sample ranged from 13-to-24-years, with a mean age of 18.2. The mean age of diagnosis was 6.2-years.	Quantitative	To investigate risky externalizing behaviors (i.e. smoking, alcohol and illicit drug use, and sexual risk taking) among adolescent cancer survivors compared to their healthy peers.	Self-Report measure: The Health Behavior Questionnaire (HBQ).	The study found that in general adolescent survivors engaged in health-risk behaviors at a lower prevalence rate than healthy peers. There were, however, exceptions including an increased risk of pain reliever use (for non-medical purposes) among younger survivors, and an increased risk of alcohol use among older survivors.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Chao, C. C., Chen, S. H., Wang, C. Y., Wu, Y. C., & Yeh, C. H. (2003). Psychosocial adjustment among pediatric cancer patients and their parents. Psychiatry and Clinical Neurosciences, 57, 75-81.	24 patients (ages 8-17; 14 male, 10 female) and 18 parents; Pediatric Hem/Onc Department at Children's Hospital in Taiwan	Quantitative	To study the psychosocial difficulties faced by children with cancer and their families, including child depressive symptoms	Self-report measures	Children and parents have a better relationship post-diagnosis, with no more depressive symptoms than a normative group.
Conrad, A. L., & Altmaier, E. M. (2009). Specialized summer camp for children with cancer: Social support and adjustment. Journal of Pediatric Oncology Nursing, 26(3), 150-157. doi: 10.1177/1043454209334418	25 children; week long summer oncology camp (patients)	Quantitative	Exploration of types of social support received while attending a specialized summer camp	Self-report measures	Females reported higher emotional/informational support (EIS) than males, however boys and girls both reported feeling more of all types of support than other children reported generally
Decker, C. L. (2007). Social support and adolescent cancer survivors: A review of the literature. Psycho-Oncology, 16, 1-11. doi: 10.1002/pon.1073	Reviewed 17 research studies.	Literature Review	Review of literature related to social support in adolescent cancer survivors.	Online databases: CINAHL, Medline, PsychINFO, SSCI, CANCERLIT.	Parents, mothers especially, are adolescent cancer survivors' main support system. Support from same-aged peers also significant, including both healthy and similarly affected by pediatric cancer. Learning about cancer was preferred when obtained from another peer with cancer. Additionally, older children valued peer support more than younger children, however both age groups valued family support.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Gerhardt, C. A., Lehmann, V., Long, K. A., & Alderfer, M. A. (2015). Supporting siblings as a standard of care in pediatric oncology. Pediatric Blood and Cancer, 62, S750-S804. doi: 10.1002/pbc.25821	Literature review of 125 studies published about siblings of pediatric cancer patients. 74 quantitative studies, 32 qualitative studies, and 19 literature reviews were used.	Literature Review	Support a recommendation for siblings of pediatric cancer patients to receive psychosocial intervention, as well as provide information to parents/providers regarding the needs of siblings.	Online search of Medline, CINAHL, and PsycInfo over the last 20 years. Search terms included the following terms: siblings, childhood, cancer, psychosocial outcomes.	Siblings of pediatric cancer patients are at risk for psychosocial difficulties and researchers found they would benefit from being identified to receive psychosocial intervention. Ultimately, found moderate support to support strong recommendation of easy access to intervention for these children.
Goudie, A., Havercamp, S., Jamieson, B., & Sahr, T. (2013). Assessing functional impairment in siblings living with children with disability. Pediatrics, 132(2), 476–83.	6,564 siblings identified as residing in households with only typically developing children and 245 siblings living in a household with at least 1 child with a disability.	Quantitative (retrospective secondary analysis)	To examine differences in functional impairment in siblings of children with disability compared with a peer group of siblings residing with siblings without disability.	Self-report measure (Youth CIS)	Results indicated that siblings of children with disability were more likely to experience interpersonal difficulties as well as psychopathology, and problems at school.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Houtzager, B. A., Grootenhuis, M. A., Hoekstra-Weebers, J. E. H. M., Caron, H. N., & Last, B. F. (2003). Psychosocial functioning in siblings of pediatric cancer patients one to six months after diagnosis. European Journal of Cancer, 39, 1423-1432. doi: 10.1016/S0959-8049(03)00275-2	66 siblings (61% female, age range from 7-18, from 49 different families). Two children's hospitals in Netherlands.	Quantitative	Study the extent of psychosocial risk factors in siblings of pediatric oncology patients over time.	Self-report measures, including: The Youth Self Report (YSR), the Dutch Children's AZL/TNO Quality of Life Questionnaire (DucatQoL), and The State-Trait Anxiety Inventory for Children (STAI-C).	Psychosocial distress decreases over time, however in the first few months post-diagnosis, psychosocial functioning is impaired. Children endorse physical and somatic complaints more than adolescents. Emotional and social decreases in quality of life. Adolescent females endorse more internalizing problems, withdrawal, and somatic complaints, while adolescent males endorsed emotional and social difficulties. Adolescents at highest risk for psychosocial maladjustment in the first 6 months post-diagnosis.
Houtzager, B.A., Grootenhuis, M.A., Caron, H.N., & Last, B. F. (2004). Quality of Life and Psychological Adaptation in Siblings of Pediatric Cancer Patients, 2 years after Diagnosis. Psycho-Oncology, 499–511.	The sample was comprised of 49 families, and consisted of 66 siblings, with 26 boys and 40 girls, aged 7-18 years, The children in the study had a variety of types of cancer including: leukemia, lymphoma, solid tumors, and brain tumors.	Quantitative (prospective)	To investigate the prevalence of psychosocial problems in siblings of pediatric cancer patients 2-years after the diagnosis of the illness.	Self-report measures, including: The Youth Self Report (YSR), the Dutch Children's AZL/TNO Quality of Life Questionnaire (DucatQoL), and The State-Trait Anxiety Inventory for Children (STAI-C).	The results indicate that acute emotional distress appears to normalize in most siblings. However, the emotional distress of having a brother or sister with cancer may continue beyond diagnosis for a subgroup. Researchers found that the 7-11-year-old siblings experienced a lower overall quality of life when compared to the available reference groups. The adolescent group, however, reported impaired emotional problem behavior, which was expressed in internalizing problems. In fact, approximately one third of the teenaged siblings reported internalizing problems such as depression, anxiety or social withdrawal.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Kazak, A. E., Christakis, D., Alderfer, M., & Coiro, M. J. (1994). Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. Journal of Family Psychology, 8(1), 74-84.	59 long-term cancer survivors (ages 10 to 15) recruited from a tumor registry at Children's Hospital of Philadelphia. Individuals in the sample had been off treatment and free of disease for at least 5 years. Included ALL, AML,and non-Hodgkins lymphoma survivors.	Quantitative (short-term longitudinal)	To examine adjustment, including behavior problems, psychological distress, social issues, and family dynamics/functioning.	Self-report measures and parent-report measures	Overall adjustment levels did not have clinically significant differences compared to peers. Males reported significantly less anxiety and hopelessness compared to females and children/adolescents with learning issues were more at-risk for problems with adjustment as a long-term survivor.
Lähteenmäki, P. M., Sjöblom, J., Korhonen, T., & Salmi, T. T. (2004). The siblings of childhood cancer patients need early support: a follow up study over the first year. Archives of Disease in Childhood, 89(11), 1008–13.	33 siblings of cancer patients (ages 3 to 17), and 357 healthy controls.	Quantitative	To examine the life situation of 33 siblings of cancer patients and 357 healthy controls, 3 months post diagnosis and at a 1-year follow-up.	Self-report measures. Parents completed the Huttunen's test and Conners' Parent Rating Scales. The children completed the STAI-C and CDI.	Researchers found that siblings ages 3-7 exhibited conduct problems and psychosomatic problems as well as a mixed group of behavioral problems at baseline (3-months after the initial diagnosis), yet these symptoms diminished at the 1-year follow up. among the school-aged children (8-17), siblings had conduct, learning, and psychosomatic problems, as well as impulsive-hyperactive and behavioral symptoms at baseline and the 1-year follow-up. Among this older sibling group, symptoms remained unchanged at follow-up.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
McCaffrey, C. N. (2006). Major stressors and their effects on the well-being of children with cancer. Journal of Pediatric Nursing, 21(1), 59–66.	Participants were 6 children with cancer. Of the sample, 3 children were undergoing chemotherapy treatment; while the other three were in remission. Two of the children (ages 5 and 11 years) were diagnosed with Acute lymphoblastic leukemia, two with Ewing's sarcoma (ages 14 and 15 years), one with non-Hodgkin's lymphoma (age 8 years), and one with Osteogenic sarcoma (age 15 years).	Qualitative (exploratory)	Researchers conducted an in-depth, exploratory study to identify the major stressors experienced by children diagnosed with cancer.	During the course of the study, focus group discussions and individual interviews were conducted with the 6 children in the study, their parents (n=6), and hospital professionals (n=23). During these groups and interviews, information was collected regarding major stressors and their corresponding effects on overall well-being.	This study identified medical procedures, fear of dying, and lack of self-esteem as the major stressors affecting the well-being of children with cancer. A decline in self-esteem, particularly as the children age, was a universal finding.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Meltzer, L. J., & Rourke, M. T. (2005). Oncology summer camp: Benefits of social comparison. Children's Health Care, 34(4), 305-314.	34 adolescents with cancer; week long summer oncology camp	Quantitative	To examine social comparisons made amongst adolescents with cancer who attend an oncology summer camp and the benefits of those comparisons.	The following self-report measures were administered: demographic information, a measure assessing peer comparison, which asked, "How different do you feel from other kids?" and "How different do you feel from other kids at camp?" Self-Perception Profile for Adolescents (SPPA; Harter, 1998) and Children's Loneliness and Social Satisfaction Questionnaire (CLSS; Asher, Hymel, & Renshaw, 1984).	-Even once off-treatment, adolescent survivors (5 years post rx) experience benefits from social comparing oneself to other cancer patients and survivors, especially when concerning latent effects. -The study found that adolescent's self-esteem was higher when they compared themselves to camp peers versus home peers. Further, when adolescents used a more similar comparison group (e.g. other campers), they perceived greater peer acceptance; were happier with their physical appearance; and generally happier with themselves. Adolescents who felt more different from their peers at home reported a greater sense of loneliness and isolation. -Researchers found that adolescents reported feeling more similar to their peers at camp than their peers at home. Further, this perceived similarity to adolescents with cancer was related to positive psychosocial outcomes. They reported greater perceived self-competence in the following domains: physical appearance, global self worth, and social acceptance. Researchers also found that those adolescents who reported feeling more different from their peers at home reported more loneliness and social isolation.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Murray, J. S. (2001). Self-Concept of Siblings of Children With Cancer. Issues in Comprehensive Pediatric Nursing, 24(2), 85–94.	The study consisted of 50 healthy siblings ages 6- to 12-years, with an average age of 9.58. 54% (n=27) were male and 46% (n=23) were female. 22 siblings attended camp, while 28 did not.	Quantitative (descriptive, exploratory design)	The researcher examined self-concept in siblings of children with cancer who attended summer camp.	In addition to demographic information, the Personal Attribute Inventory for Children (PAIC; Parish, 1976) was administered to the sample.	The researcher found that siblings who attended camp had statistically significant higher scores on the PAIC self-concept scale than siblings who did not attend camp.
Noll, R. B., Gartstein, M. A., Vannatta, K. Correll, J., Bukowski, W. M., Davies, H. (1999). Social, emotional, and behavioral functioning of children with cancer. Pediatrics, 103(1), 71-78.	76 children requiring chemotherapy or receiving it at that time (with the exception of children with brain tumors), ages 8 to 15, compared with 76 healthy peers.	Quantitative (case controlled design)	The researchers evaluated whether children with cancer would experience more social problems and difficulties than a case control group	Self-report measures	Researchers found that teachers of children with cancer perceived them as being more sociable, while both teachers and peers reported that they were less aggressive, and peers rated them as having greater social acceptance. Researchers found no significant differences on measures of depression, anxiety, loneliness, or self-concept. There were also no significant differences in mother or father perceptions of behavioral problems, social functioning or emotional well-being.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Packman, W., Fine, J., Chesterman, B., & Ion, M. D. A. (2004). Camp Okizu: Preliminary Investigation of a Psychological Intervention for Siblings of Pediatric Cancer Patients, 33(3), 201–215.	77 siblings ages 6 to 17 attending camp Okizu. The average age of campers was 11.7-years-old, with 42 girls, and 35 boys. In terms of demographics, 75.3 % of the sample identified as Caucasian, 14.3% identified as Latino, 3.9% identified as African American, 1.3% as Asian, and 5.2% as Other.	Quantitative (pre- post and follow-up design)	Researchers examined whether attendance at a summer camp for siblings of children with cancer has an effect on their self-esteem	The following measures were administered 1) Questionnaire assessing demographics ; 2) The UCLA PTSD Index for DSM-IV (Rodriguez, Steinbery, & Pynoos, 1998); 3) Revised Children's Manifest Anxiety Scale; 4) Pediatric Quality of Life Inventory (PedsQL; Varni, 1999); 5) Rosenberg Self-Esteem Scale; 6) Human figure drawing; and, the 7) the Codington Life Events Scale (CLES; Coddington, 1972).	Self-esteem scores decreased significantly on the Rosenberg Self Esteem Scale. Also, of note, posttraumatic stress and anxiety decreased significantly, while quality of life significantly increased.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Packman, W., Mazaheri, M., Sporri, L., Long, J. K., Chesterman, B., Fine, J, & Amylon, M. D. (2008). Projective drawings as measures of psychosocial functioning in siblings of pediatric cancer patients from the Camp Okizu study. Journal of Pediatric Oncology Nursing, 25(1), 44-55.	Siblings of pediatric cancer patients (n=77), ages 6 to 17. Camp Okizu in Novato, CA for a 1-week long camp session. 18 children were bereaved siblings.	Quantitative	To assess levels of emotional distress and adjustment following participation in an oncology camp session for siblings of pediatric cancer.	Projective drawings	Siblings had significant decrease in emotional distress following camp intervention. Also found decreased levels of distress in the child's family unit following the child's participation in camp.
Packman, W., Greenhalgh, J., Chesterman, B., Shaffer, T., Fine, J., Vanzutphen, K., ... Amylon, M. D. (2005). Siblings of pediatric cancer patients: The quantitative and qualitative nature of quality of life. Journal of Psychosocial Oncology, 23(1), 87-108.	77 siblings ages 6 to 17 attending camp Okizu. In terms of demographics, 42 campers were girls, and 35 boys. 75.3 % of the sample identified as Caucasian, 14.3% identified as Latino, 3.9% identified as African American.	Mixed methods	To assess the pediatric health-related quality of life among siblings (ages 6-17 years) of cancer patients attending summer camp.	Self-report measures on quality of life and perceptions of the parents with the Pediatric Quality of Life Inventory (PedsQL) were collected. Siblings and parents also expressed their perceptions and concerns using their own words. Siblings were encouraged to express their own feelings about the camp experience.	Found that siblings reported significant improvements in quality from pre- to-post camp. In fact, the t-test results indicate that four of the domains–emotional, social, school, and psychosocial–contained statistically significant differences at pre- to post-camp. Researchers found that parents did not report any significant improvements in the sibling's quality of life. However, when the researchers controlled for bereaved parents, they found significant improvements in children's quality of life.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Pendley, J .S., Dahlquist, L. M., & Dreyer, A. (1996). Body image and psychosocial adjustment in adolescent cancer survivors. Journal of Pediatric Psychology, 22(1), 29-43.	The sample included 9 female and 12 male adolescent cancer survivors, ages 11- to 21-years-old recruited from the Texas Children's Hospital Cancer Center database. On average, the adolescents had completed cancer treatment approximately 17 months prior to beginning the study.	Quantitative (cross-sectional)	To examine body image and social adjustment in adolescents who had completed cancer treatment.	Self-Report measures (Self-Image Questionnaire for Young Adolescents, Body Cathexis Scale, Self-Perception Profile for Adolescents, Body Image Avoidant Questionnaire , Situational Inventory for Body Image Distress, and Self-Report Likert Rating of Body Image). Research assistants also completed the Objective Ratings of Attractivenes s.	This study found no differences on body image scores between cancer survivors and the healthy control group. However, within the cancer group, adolescents who had been off treatment longer, reported lower self-worth and more negative body image perceptions; though were not rated as less attractive by observers. These findings suggest that cancer survivors may be at an increased risk for psychosocial difficulties after treatment ends.
Ritchie, M. A. (2001). Self-esteem and hopefulness in adolescents with cancer. Journal of Pediatric Nursing, 16(1), 35–42.	45 adolescents with cancer from 2 pediatric oncology clinics. The sample was divided into 3 groups, including: early adolescents from 12- to 14-years-old (n=16), middle adolescents 15- to 16-years-old (n=19), and late adolescents, from 17 to young adulthood (n=10).	Quantitative (Correlational)	The study examines the relationships among the stages of adolescence, gender, self-esteem, and hopefulness among adolescents with cancer.	Self-report measures (Coopersmith Self-Esteem Inventory and Hopefulness Scale for Adolescents)	No differences were found in terms of self-esteem for adolescents with cancer and their healthy peers. Also, researchers found no differences in terms of gender for self-esteem

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Sidhu, R., Passmore, A., & Baker, D. (2006). The effectiveness of a peer support camp for siblings of children with cancer. Pediatric Blood Cancer, 47, 580-588.	26 siblings of pediatric cancer patients recruited from an Australian pediatric oncology unit. Ranged in age from 8-13 and 52% female.	Quantitative	-Examine the effects of a sibling-specific oncology camp aimed at reducing overall distress, increasing social skills, and providing medical information about cancer and its treatment. -Researchers also evaluated the effects of camp attendance among siblings to see whether changes in distress, social competence, and self-esteem occurred.	Three, standardized, self-report measures were administered to all siblings, including: The Self-Report of Personality (SPR) (BASC; Reynolds, 1992); the Self Perception Profile for Children (SPPC; Harter, 1985); and the Sibling Perception Questionnaire (SPQ; Carpenter & Sahler, 1991).	-Found that the camp experience was effective in providing campers with peer support and competencies, a space for self-expression, and gathering medically-relevant information. Also felt supported in the environment. -Self-concept did not appear to differ greatly from the normal population, but improvements were seen post intervention and again at follow-up. -Researchers found that the siblings reported less psychological distress and anxiety from pre- to post-camp. Specifically, measures of anxiety decreased, while self-concept, improved at post-intervention and again at follow-up.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Thompson, A. L., Marsland, A. L., Marshal, M. P., & Tersak, J. M. (2009). Romantic relationships of emerging adult survivors of childhood cancer, 774(December 2008), 767–774.	56 cancer survivors (ages 18 to 20) and comparison peers. The survivors had a mean age of diagnosis of 11.32, with time since diagnosis approximately 7.32 years. The average time between the initial and follow-up assessment was 5.93 years	Quantitative (longitudinal)	To examine the adjustment of families of children with cancer and their comparison peers. The study researched group differences and predictors of externalizing behavior and substance use among 18-20-year-old cancer survivors.	Data was collected from parents (i.e. demographic questionnaire, Child Behavior Checklist (CBCL; Achenbach, 1991) from the participant (i.e. the Antisocial Behavior Checklist (ASB), Drinking and Drug History), and from pediatric oncologists including information regarding treatment severity and late effects.	Researchers found that survivors were just as likely as peers to have tried alcohol, tobacco and illicit drugs (excluding marijuana). They also found that peers were twice as likely to have tried marijuana than survivors. They found no differences in terms of age of initiation of drinking, frequency or quantity of use. However, there was a modest effect size indicating that survivors may drink more at each episode than their comparison peers. Found that earlier peer acceptance and less aggressive social behavior had no relationship with later externalizing behavior. Researchers also found that survivors who were older at diagnosis had a greater risk for externalizing behavior and substance abuse.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Von Essen, L., Enskär, K., Kreuger, a, Larsson, B., & Sjödén, P. O. (2000). Self-esteem, depression and anxiety among Swedish children and adolescents on and off cancer treatment. Acta Paediatrica, 89(2), 229–36.	The study was comprised of 51 individuals, 16 of which were undergoing treatment and 35 who were not. The children and adolescents were recruited from pediatric oncology centers, and had been diagnosed with cancer no later than 1-month prior to the study	Quantitative (cross-sectional)	Researchers examined the level of self-esteem among children and adolescents (8- to 18-years-old).	Data was collected via self-report questionnaires, including: "I Think I Am" (ITIA; Ouvinen-Birgerstam, 1985), the Children's Depression Inventory (CDI; Kovacs, 1983), and Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds, 1985).	While researchers found that the younger sample (age 8 and 9) did not differ from their healthy peers, they did find that among the 10- to 18-year-old sample, self-esteem was lower, particularly as it relates to physical appearance and psychological well-being. These results suggest that post-treatment may be a particularly vulnerable time for children and adolescents in terms of their self-esteem.
Wellisch, D. K., Crater, B., Wiley, F. M., Belin, T. B., & Weinstein, K. (2006). Psychosocial impacts of a camping experience for children with cancer and their siblings. Psycho-Oncology, 15, 56-65.	The sample consisted of 66 children ages: 7- to-17-years-old, with 56.1% female and 43.9% male. Among the cancer patients (n=31), 19 had leukemia or lymphoma, and 12 had solid tumors. Time since diagnosis ranged from 9 to 166 months, with a mean of 81 months.	Quantitative (prospective)	Researchers sought to examine the relationship between mood and the camp experience and children with cancer and their siblings	Self-report questionnaires	This study found a marked change in affective symptoms occurred for patient campers over time, and those improvements were seen when measured 4 to 6 months after camp. This effect was not observed among the sibling group.

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Woods, K., Mayes, S., Bartley, E., Fedele, D., & Ryan, J. (2013). An Evaluation of Psychosocial Outcomes for Children and Adolescents Attending a Summer Camp for Youth With Chronic Illness. Children's Health Care, 42(1), 85–98.	102 children (ages 8-19), with various medical conditions including cancer (36.9%), and kidney disease (21.4%), from a Midwestern children's hospital. The median age of the sample was 13.1, with 55% male and 45% female.	Quantitative	To evaluate the psychosocial outcomes for children and adolescents attending a summer camp specifically designed for children with chronic illnesses.	Self-report measures, including a demographic questionnaire, the Pediatric Quality of Life Inventory (PedsQL), and the Children's Hope Scale (CHS),	Found that youth in the sample demonstrated overall higher levels of hope after participation in the camp. Increased hope may be an important factor in preventing depression and anxiety. Surprisingly, no significant changes were found in the health related quality of life from pre- to post-camp.
Wu, Y. P., Goldhof, G. J., Roberts, M. C., Parikshak, S., & Amylon, M. D. (2013). Initial examination of a new questionnaire assessing perceived social support in summer camp and home environments for children with cancer and their siblings. Children's Health Care, 42(1), 67-84. doi: 10.1080/02739615.2013.753817	65 cancer patients or survivors, 85 siblings, 19 of whom were bereaved; week long summer oncology camp	Quantitative	To assess validity for a new measure (Children's Assessment of Perceived Social Support; CAPSS), which would determine perceived support in the home and camp environments with regard to cancer and non-cancer related issues	Self-report measures	Children perceived different levels of support given depending on type of support needed and the setting. Cancer patients experienced different support received from friends at home versus friends at camp on cancer-related and non-cancer related issues, while siblings did not experience differences in type of support received in the different environments

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Study	Sample/Setting	Type	Purpose	Data Collection Method	Major Findings
Wu, Y. P., Prout, K., Roberts, M. C., Parikshak, S., & Amylon, M. D. (2011). Assessing experiences of children who attended a camp for children with cancer and their siblings: A preliminary study. Child Youth Care Forum, 40, 121-133. doi: 10.1007/s10566-010-9123-5	89 families w/ pediatric cancer (78 mothers, 9 fathers, 56 patients, 73 siblings, 8 of whom were bereaved); week long summer oncology camp	Program Evaluation; Qualitative and Quantitative	To determine what aspect of a summer oncology camp produces satisfaction in campers and parents, improving existing services for families	Self-report measures	Parents and campers were most highly satisfied with aspects related to the camp's mission, such as recreation, respite, and peer support.
Zegaczweski, T., Chang, K., Coddington, J., & Berg, A. (2016). Factors related to healthy siblings' psychosocial adjustment to children with cancer: An integrative review. Journal of Pediatric Oncology Nursing, 33(3), 218-227. doi: 10.1177/1043454215600426	Comprehensive literature review of studies related to psychosocial adjustment. 12 total studies were included and were obtained through search of Cumulative Index to Nursing & Allied Health Literature and PubMed. Search terms included: siblings, pediatrics, children, neoplasms, and psychosocial adaptation.	Literature Review	Identify commonalities of healthy siblings of pediatric cancer patients with attention specifically paid to psychosocial adjustment.	Online search of CINAHL and PubMed.	Found that perceived social support from family and friends made at summer camps, as well as contextual factors (e.g., family's ability to adapt, overload, etc.) were significantly predictive of psychosocial adjustment levels.

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APPENDIX B

Characteristics of Sample

Table B1.

Characteristics of Sample

Variable	Patients (n = 30) (47%)	Siblings (n = 34) (53%)	Total (n = 64) (100%)
Gender			
Female	17 (55%)	20 (57%)	37 (56%)
Male	13 (45%)	14 (43)	27 (44%)
Ethnicity			
Caucasian	17 (57%)	23 (68%)	40 (63%)
Latino	7 (23%)	8 (24%)	15 (23%)
Other	6 (20%)	3 (8%)	9 (14%)
Age			
Mean (SD)	11.57 (2.9)	12.09 (2.9)	11.84 (2.89)
Child (ages 7-12)	18 (60%)	20 (59%)	38 (59%)
Adolescent (ages 13-18)	12 (40%)	14 (42%)	26 (41%)

*Totals may not add up to 100% due to rounding

APPENDIX C

Self-Esteem Means

Table C1.

Self-Esteem Means

Variable	Group	*n*	Time 1 *M* (SD)	Time 2 *M* (SD)	Time 3 *M* (SD)
Cancer Status	Patients	26	0.23 (0.51)	0.35 (0.85)	0.15 (0.37)
	Siblings	33	0.55 (0.87)	0.55 (0.94)	0.61 (1.52)
	Total	59	0.41 (0.75)	0.46 (0.90)	0.41 (1.18)
Gender and Cancer Status	Male Patients	12	0.42 (0.67)	0.50 (1.17)	0.08 (0.29)
	Male Siblings	14	0.29 (0.47)	0.29 (0.61)	0.50 (1.61)
	Female Patients	14	0.07 (0.27)	0.21 (0.43)	0.21 (0.43)
	Female Siblings	19	0.74 (1.05)	0.74 (1.10)	0.68 (1.49)
	Male Total	26	0.35 (0.56)	0.38 (0.90)	0.31 (1.19)
	Female Total	33	0.45 (0.87)	0.52 (0.91)	0.48 (1.18)
Age and Cancer Status	Child Patients*	17	0.24 (0.44)	0.53 (1.01)	0.18 (0.39)
	Child Siblings	19	0.37 (0.68)	0.37 (0.76)	0.16 (0.37)
	Adolescent Patients**	9	0.22 (0.67)	0.00 (0.00)	0.11 (0.33)
	Adolescent Siblings	14	0.79 (1.05)	0.79 (1.12)	1.21 (2.19)
	Child Total	36	0.31 (0.58)	0.44 (0.88)	0.17 (0.38)
	Adolescent Total	23	0.57 (0.95)	0.48 (0.95)	0.78 (1.78)
Gender, Age, and Cancer Status	Male Child Patients	7	0.43 (0.53)	0.86 (1.46)	0.14 (0.38)
	Male Child Siblings	9	0.11 (0.33)	0.11 (0.33)	0.00 (0.00)
	Female Child Patients	10	0.10 (0.32)	0.30 (0.48)	0.20 (0.42)
	Female Child Siblings	10	0.60 (0.84)	0.60 (0.97)	0.30 (0.48)
	Male Adolescent Patients	5	0.40 (0.89)	0.00 (0.00)	0.00 (0.00)
	Male Adolescent Siblings	5	0.60 (0.55)	0.60 (0.89)	1.40 (2.61)
	Female Adolescent Patients	4	0.00 (0.00)	0.00 (0.00)	0.25 (0.50)
	Female Adolescent Siblings	9	0.89 (1.27)	0.89 (1.27)	1.11 (2.09)
	Male Child Total	16	0.25 (0.45)	0.44 (1.03)	0.06 (0.25)
	Female Child Total	20	0.35 (0.67)	0.45 (0.76)	0.25 (0.44)
	Male Adolescent Total	10	0.50 (0.71)	0.30 (0.67)	0.70 (1.89)
	Female Adolescent Total	13	0.62 (1.12)	0.62 (1.12)	0.85 (1.77)

*Child (ages 7-12)
**Adolescent (ages 13-18)

APPENDIX D

Self-Esteem Frequencies

Table D1.

Self-Esteem Frequency Tables

Self-Esteem Frequency at Baseline

Total Score in SE Domain (0-15)	Frequency	Valid Percent	Cumulative Percent
0	45	71.4	71.4
1	12	19	90.5
2	4	6.3	96.8
3	2	3.2	100
Total (*n*=63)	63	100	

Self-Esteem Frequency at Time 2

Total Score in SE Domain (0-15)	Frequency	Valid Percent	Cumulative Percent
0	43	70.5	70.5
1	12	18.8	90.2
2	1	1.6	91.8
3	4	6.3	98.4
4	1	1.6	100
Total (*n*=64)	64	100	

Self-Esteem Frequency at Time 3

Total Score in SE Domain (0-15)	Frequency	Valid Percent	Cumulative Percent
0	49	77.8	77.8
1	10	15.6	93.7
2	1	1.6	95.2
3	1	1.6	96.8
6	2	3.1	100
Total (*n*=63)	63	100	

APPENDIX E

Internalizing Means

Table E1.

Internalizing Means

Variable	Group	*n*	Time 1 *M* (SD)	Time 2 *M* (SD)	Time 3 *M* (SD)
Cancer Status	Patients	17	1.54 (1.61)	0.92 (0.98)	0.69 (0.93)
	Siblings	20	1.18 (1.42)	1.00 (1.41)	1.33 (1.69)
	Total	37	1.34 (1.50)	0.97 (1.23)	1.05 (1.43)
Gender and Cancer Status	Male Patients	12	1.75 (1.54)	0.75 (0.87)	0.50 (0.67)
	Male Siblings	14	0.64 (1.01)	0.86 (1.35)	0.93 (1.38)
	Female Patients	14	1.36 (1.69)	1.07 (1.07)	0.86 (1.10)
	Female Siblings	19	1.58 (1.57)	1.11 (1.49)	1.63 (1.86)
	Male Total	26	1.15 (1.38)	0.81 (1.13)	0.73 (1.12)
	Female Total	33	1.48 (1.60)	1.09 (1.31)	1.30 (1.61)
Age and Cancer Status	Child Patients*	17	1.24 (1.68)	1.00 (1.06)	0.59 (0.71)
	Child Siblings	19	0.63 (1.01)	0.47 (0.90)	0.89 (1.10)
	Adolescent Patients**	9	2.11 (1.36)	0.78 (0.83)	0.89 (1.27)
	Adolescent Siblings	14	1.93 (1.59)	1.71 (1.68)	1.93 (2.16)
	Child Total	36	0.92 (1.38)	0.72 (1.00)	0.75 (0.94)
	Adolescent Total	23	2.00 (1.48)	1.35 (1.47)	1.52 (1.90)
Gender, Age, and Cancer Status	Male Child Patients	7	1.29 (1.50)	0.71 (0.95)	0.57 (0.79)
	Male Child Siblings	9	0.33 (0.71)	0.33 (0.71)	0.67 (0.87)
	Female Child Patients	10	1.20 (1.87)	1.20 (1.14)	0.60 (0.70)
	Female Child Siblings	10	0.90 (1.20)	0.60 (1.07)	1.10 (1.29)
	Male Adolescent Patients	5	2.40 (1.52)	0.80 (0.84)	0.40 (0.55)
	Male Adolescent Siblings	5	1.20 (1.30)	1.80 (1.79)	1.40 (2.07)
	Female Adolescent Patients	4	1.75 (1.26)	0.75 (0.96)	1.50 (1.73)
	Female Adolescent Siblings	9	2.33 (1.66)	1.67 (1.73)	2.22 (2.28)
	Male Child Total	16	0.75 (1.18)	0.50 (0.82)	0.63 (0.81)
	Female Child Total	20	1.05 (1.54)	0.90 (1.12)	0.85 (1.04)
	Male Adolescent Total	10	1.80 (1.48)	1.30 (1.42)	0.90 (1.52)
	Female Adolescent Total	13	2.15 (1.52)	1.38 (1.56)	2.00 (2.08)

*Child (ages 7-12)
**Adolescent (ages 13-18)

APPENDIX F

Externalizing Means

Table F1.

Externalizing Means

Variable	Group	*n*	Time 1 *M* (SD)	Time 2 *M* (SD)	Time 3 *M* (SD)
Cancer Status	Patients	25	4.56 (0.87)	4.60 (1.12)	4.40 (0.96)
	Siblings	33	4.48 (1.03)	4.52 (0.87)	4.79 (0.86)
	Total	58	4.52 (0.96)	4.55 (0.98)	4.62 (0.91)
Gender and Cancer Status	Male Patients	11	4.45 (0.82)	4.55 (1.21)	4.45 (0.93)
	Male Siblings	13	4.38 (1.04)	4.23 (1.01)	4.69 (1.03)
	Female Patients	14	4.64 (0.93)	4.64 (1.08)	4.36 (1.01)
	Female Siblings	20	4.55 (1.05)	4.70 (0.73)	4.85 (0.75)
	Male Total	24	4.42 (0.93)	4.38 (1.10)	4.58 (0.97)
	Female Total	34	4.59 (0.99)	4.68 (0.88)	4.65 (0.88)
Age and Cancer Status	Child Patients*	17	4.53 (0.80)	4.59 (1.18)	4.12 (0.93)
	Child Siblings	20	4.55 (1.10)	4.50 (1.00)	4.70 (0.92)
	Adolescent Patients**	8	4.63 (1.06)	4.63 (1.06)	5.00 (0.76)
	Adolescent Siblings	13	4.38 (0.96)	4.54 (0.66)	4.92 (0.76)
	Child Total	37	4.54 (0.96)	4.54 (1.07)	4.43 (0.96)
	Adolescent Total	21	4.48 (0.98)	4.57 (0.81)	4.95 (0.74)
Gender, Age, and Cancer Status	Male Child Patients	6	4.33 (0.82)	4.33 (1.51)	4.17 (0.98)
	Male Child Siblings	9	4.56 (1.13)	4.22 (1.20)	4.67 (1.12)
	Female Child Patients	11	4.64 (0.81)	4.73 (1.01)	4.09 (0.94)
	Female Child Siblings	11	4.55 (1.13)	4.73 (0.79)	4.73 (0.79)
	Male Adolescent Patients	5	4.60 (0.89)	4.80 (0.84)	4.80 (0.84)
	Male Adolescent Siblings	4	4.00 (0.82)	4.25 (0.50)	4.75 (0.96)
	Female Adolescent Patients	3	4.67 (1.53)	4.33 (1.53)	5.33 (0.58)
	Female Adolescent Siblings	9	4.56 (1.01)	4.67 (0.71)	5.00 (0.71)
	Male Child Total	15	4.47 (0.99)	4.27 (1.28)	4.47 (1.06)
	Female Child Total	22	4.59 (0.96)	4.73 (0.88)	4.41 (0.91)
	Male Adolescent Total	9	4.33 (0.87)	4.56 (0.73)	4.78 (0.83)
	Female Adolescent Total	12	4.58 (1.08)	4.58 (0.90)	5.08 (0.67)

*Child (ages 7-12)
**Adolescent (ages 13-18)

APPENDIX G

Internalizing Behaviors: Time by Cancer Status Interaction

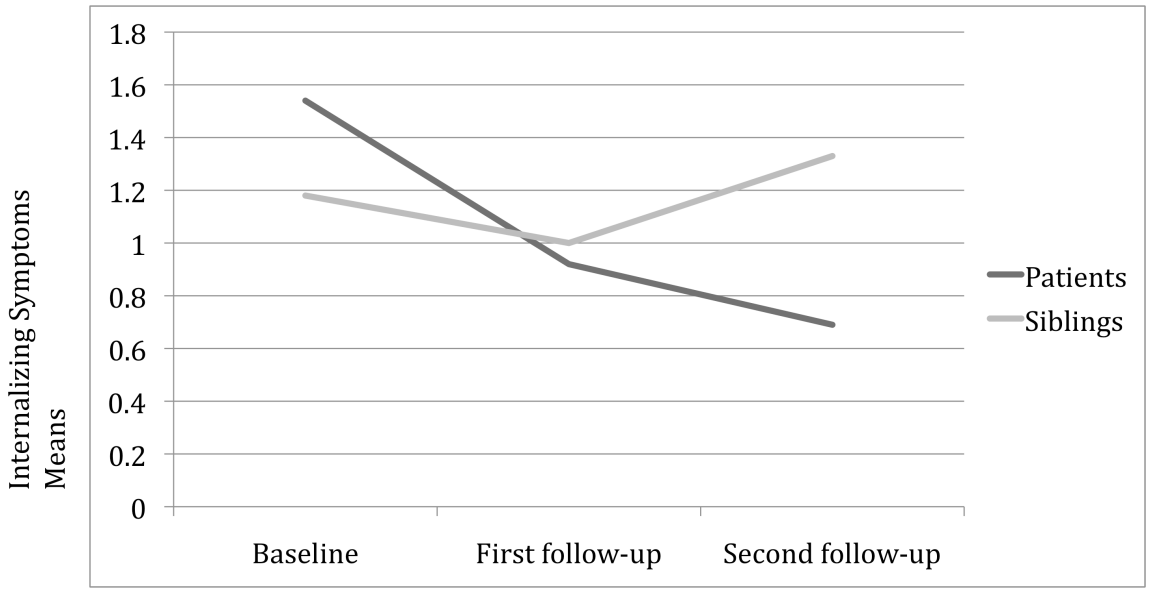

Figure G1. Internalizing behaviors: Time by cancer status interaction.

APPENDIX H

Externalizing Behaviors: Time by Age Interaction

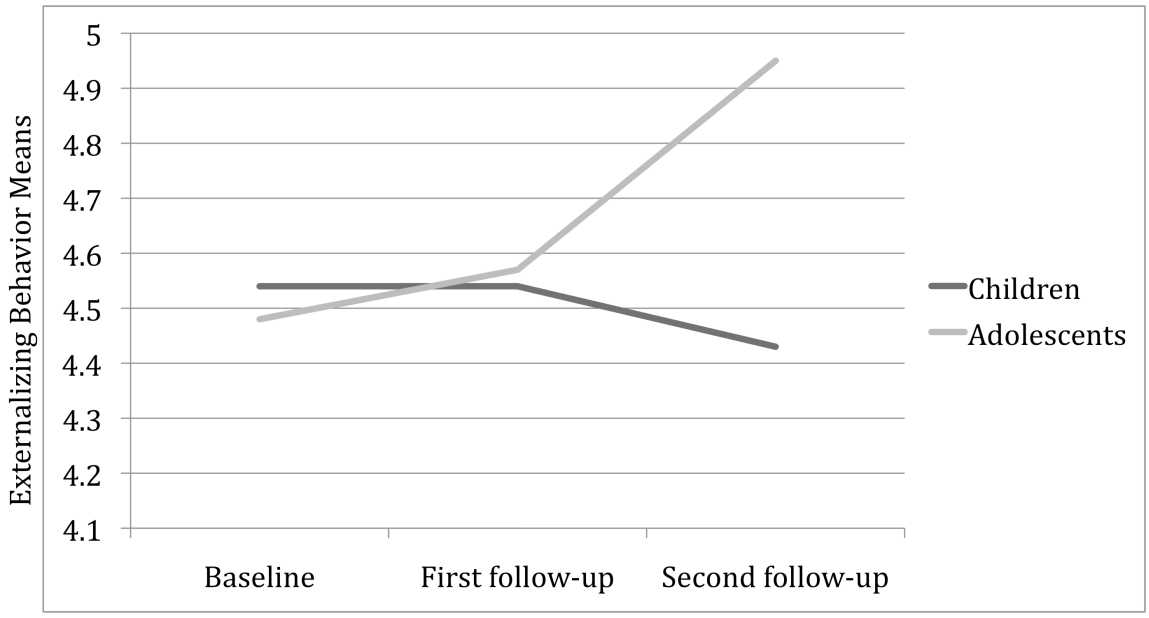

Figure H1. Externalizing Behaviors: Time by age interaction.

APPENDIX I

Children's Depression Inventory

Instructions:
Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick one sentence that describes you ***best*** for the past two weeks. After you pick a sentence from the first group, go on to the next group.

There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this **X** next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you ***best***.

Example:
- I read books all the time.
- I read books once in a while
- I never read books.

When you are told to do so, tear off this top page. Then, pick the sentences that describe you best on the first page. After you finish the first page, turn to the back. Then, answer the items on that page.

Remember, pick out the sentences that describe you best in the PAST TWO WEEKS.

Item 1:
- I am sad once in a while.
- I am sad many times.
- I am sad all the time.

Item 2:
- Nothing will ever work out for me.
- I am not sure if things will work out for me.
- Things will work out for me O.K.

Item 3:
- I do most things O.K.
- I do many things wrong.
- I do everything wrong.

Item 4:
- I have fun in many things.
- I have fun in some things.
- Nothing is fun at all.

Item 5:
- I am bad all the time.
- I am bad many times.
- I am bad once in a while.

Item 6:

- I think about bad things happening to me once in a while.
- I worry that bad things will happen to me.
- I am sure that terrible things will happen to me.

Item 7:

- I hate myself.
- I do not like myself.
- I like myself.

Item 8:

- All bad things are my fault.
- Many bad things are my fault.
- Bad things are not usually my fault.

Item 9:

- I do not think about killing myself.
- I think about killing myself but I would not do it.
- I want to kill myself.

Item 10:

- I feel like crying every day.
- I feel like crying many days.
- I feel like crying once in a while.

Item 11:

- Things bother me all the time.
- Things bother me many times.
- Things bother me once in a while.

Item 12:

- I like being with people.
- I do not like being with people many times.
- I do not want to be with people at all.

Item 13:

- I cannot make my mind up about things.
- It is hard to make up my mind about things.
- I make up my mind about things easily.

Item 14:

- I look O.K.
- There are some bad things about my looks.
- I look ugly.

Item 15:

- I have to push myself all the time to do my schoolwork.
- I have to push myself many times to do my schoolwork.
- Doing schoolwork is not a big problem.

Item 16:

- I have trouble sleeping every night.
- I have trouble sleeping many nights.
- I sleep pretty well.

Item 17:

- I am tired once in a while.
- I am tired many days.

- I am tired all the time.

Item 18:

- Most days I do not feel like eating.
- Many days I do not feel like eating.
- I eat pretty well.

Item 19:

- I do not worry about aches and pains.
- I worry about aches and pains many times.
- I worry about aches and pains all the time.

Item 20:

- I do not feel alone.
- I feel alone many times.
- I feel alone all the time.

Item 21:

- I never have fun at school.
- I have fun at school only once in a while.
- I have fun at school many times.

Item 22:

- I have plenty of friends.
- I have some friends but I wish I had more.
- I do not have any friends.

Item 23:

- My schoolwork is alright.
- My schoolwork is not as good as before.
- I do very badly in subjects I used to be good in.

Item 24:

- I can never be as good as other kids.
- I can be as good as other kids if I want to.
- I am just as good as other kids.

Item 25:

- Nobody really loves me.
- I am not sure if anybody loves me.
- I am sure that somebody loves me.

Item 26:

- I usually do what I am told.
- I do not do what I am told most times.
- I never do what I am told.

Item 27:

- I get along with people.
- I get into fights many times.
- I get into fights all the time.

APPENDIX J

Youth Self Report: Social Adjustment Questions

1. I act too young for my age. ____
   Sometimes I act too young for my age. ____
   Most of the time I act my age. ____

2. I argue a lot. ____
   Sometimes I argue. ____
   I don't argue. ____

3. I like animals. ____
   Sometimes I like animals. ____
   I don't like animals. ____

4. I depend on adults too much. ____
   Sometimes I depend on adults too much. ____
   I don't depend on adults too much. ____

5. I feel lonely most of the time. ____
   I feel lonely some of the time. ____
   I hardly ever feel lonely. ____

6. I often try to get a lot of attention. ____
   Sometimes I try to get a lot of attention. ____
   I never try to get lots of attention. ____

7. I often don't get along with other kids. ____
   Sometimes I don't get along with other kids. ____
   I usually get along with other kids. ____

8. I am willing to help others when they need help. ____
   Sometimes I am willing to help others when they need help. ____
   I rarely am willing to help others when they need help. ____

9. I am afraid to go to camp. ____
   I am a little afraid to go to camp. ____
   I am not afraid to go to camp. ____

10. I get teased a lot. ____
    I get teased a little. ____
    I don't get teased. ____

11. I would usually rather be alone than with others. ____
    Sometimes I would rather be alone than with others. ____
    I would usually rather be with others than alone. ____

12. Other kids usually don't like me. ____

Sometimes other kids don't like me. ____
Other kids usually like me. ____

13. I am often willing to help others when they need help. ____
I am sometimes willing to help others when they need help. ____
I am often unwilling to help others when they need help. ____

14. I almost always would rather be alone than with others. ____
I sometimes would rather be alone than with others. ____
I would rarely rather be alone than with others. ____

15. Other kids usually like me. ____
Sometimes I am liked by other kids. ____
I am not usually liked by other kids. ____

16. I can do many things better than most kids. ____
I can do some things better than most kids. ____
I can do very few things better than most kids. ____

17. I am usually pretty friendly. ____
Sometimes I am pretty friendly. ____
I am not usually very friendly. ____

18. I would rather be with older kids than with kids my own age. ____
I would rather be with kids my own age. ____
I would rather be with younger kids than kids my own age. ____

19. I am often self-conscious or easily embarrassed. ____
I am sometimes self-conscious or easily embarrassed. ____
I am rarely self-conscious or easily embarrassed. ____

20. I usually stand up for myself. ____
I sometimes stand up for myself. ____
I rarely stand up for myself. ____

21. I often like to make others laugh. ____
I sometimes like to make others laugh. ____
I rarely like to make others laugh. ____

APPENDIX K

IRB Approval Notice

PEPPERDINE UNIVERSITY

Graduate & Professional Schools Institutional Review Board

September 30, 2015

Jenna Oppenheim/Elizabeth Stein
6100 Center Drive – Suite 500
Los Angeles, CA 90045

Protocol #: P0715D04
Project Title: An Examination of Oncology Summer Camp Attendance and Psychosocial Functioning Among Pediatric Cancer Patients and Siblings

Dear Ms. Oppenheim and Ms. Stein:

Thank you for submitting your application, *An Examination of Oncology Summer Camp Attendance and Psychosocial Functioning Among Pediatric Cancer Patients and Siblings*, for expedited review to Pepperdine University's Graduate and Professional Schools Institutional Review Board (GPS IRB). The IRB appreciates the work you and your advisor, Dr. deMayo, completed on the proposal. The IRB has reviewed your submitted IRB application and all ancillary materials. As the nature of the research met the requirements for expedited review under provision Title 45 CFR 46.110 (Research Category 7) of the federal Protection of Human Subjects Act, the IRB conducted a formal, but expedited, review of your application materials.

I am pleased to inform you that your application for your study was granted **Full Approval.** The IRB approval begins today, **September 30, 2015,** and terminates on **September 30, 2016**.

Please note that your research must be conducted according to the proposal that was submitted to the GPS IRB. If changes to the approved protocol occur, a revised protocol must be reviewed and approved by the IRB before implementation. For ***any*** proposed changes in your research protocol, please submit a Request for Modification form to the GPS IRB. Please be aware that changes to your protocol may prevent the research from qualifying for expedited review and require submission of a new IRB application or other materials to the GPS IRB. If contact with subjects will extend beyond **September 30, 2016**, a **Continuation or Completion of Review Form** must be submitted at least one month prior to the expiration date of study approval to avoid a lapse in approval.

A goal of the IRB is to prevent negative occurrences during any research study. However, despite our best intent, unforeseen circumstances or events may arise during the research. If an unexpected situation or adverse event happens during your investigation, please notify the GPS IRB as soon as possible. We will ask for a complete explanation of the event and your response. Other actions also may be required depending on the nature of the event. Details regarding the timeframe in which adverse events must be reported to the GPS IRB and the appropriate form to be used to report this information can be found in the *Pepperdine University Protection of Human Participants in Research: Policies and Procedures Manual* (see link to "policy material" at http://www.pepperdine.edu/irb/graduate/).

Please refer to the protocol number denoted above in all further communication or correspondence related to this approval. Should you have additional questions, please contact me. On behalf of the GPS IRB, I wish you success in this scholarly pursuit.

Sincerely,

Dr. Judy Ho, Ph.D.
Chair, Graduate and Professional Schools IRB
Pepperdine University

cc: Dr. Lee Kats, Vice Provost for Research and Strategic Initiatives
Mr. Brett Leach, Regulatory Affairs Specialist
Dr. Robert deMayo, Faculty Advisor