Examination of oncology summer camp attendance, psychosocial adjustment, and perceived social support among pediatric cancer patients and siblings

Jenna N. Oppenheim

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EXAMINATION OF ONCOLOGY SUMMER CAMP ATTENDANCE, PSYCHOSOCIAL ADJUSTMENT, AND PERCEIVED SOCIAL SUPPORT AMONG PEDIATRIC CANCER PATIENTS AND SIBLINGS

A clinical dissertation presented in partial satisfaction of the requirements for the degree of Doctor of Psychology

by

Jenna N. Oppenheim

April, 2017

Robert deMayo, Ph.D., ABPP – Dissertation Chairperson
This clinical dissertation, written by

Jenna N. Oppenheim

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirement of the degree of

DOCTOR OF PSYCHOLOGY

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DEDICATION

I would like to dedicate this to the families, volunteers, and staff of Camp Ronald McDonald for Good Times. Your strength, resilience, and dedication to enhancing the lives of children is inspiring. I am so honored to be part of this community. Thank you for allowing me to share a piece of camp with the rest of the world. Until cancer is cured, there’s camp.
ACKNOWLEDGEMENTS

To my parents Debbie and Scott Oppenheim, grandparents Earle and Elaine Cohen, and sister Jaci Oppenheim: Thank you for your unwavering support of my education and in achieving my goals. I would not be where I am today without your constant love and encouragement. I am incredibly lucky to have your support as I pursue my dreams.

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To Dr. Natasha Thapar-Olmos: I am so fortunate to have learned from your expertise. Thank you for your patience when explaining statistics and methodology for this study.

To Dr. David Wellisch: Sincerest gratitude for not only allowing me to utilize data from your original study, but also for serving as part of my dissertation committee.

To Dr. Robert deMayo: Deepest thanks for agreeing to serve as my dissertation chair and for allowing me to pursue an area of research that is so close to my heart.

To Liz Stein: We did it!! I wouldn’t have wanted to take on this project with anyone else.
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ABSTRACT

Pediatric oncology patients and siblings are a population at-risk for negative psychosocial outcomes due to the various procedures, treatments, late effects, and family-based stressors associated with pediatric cancer. Pediatric oncology camps were designed to creatively address psychosocial gaps experienced by this steadily increasing population. Literature focusing on psychosocial adjustment of pediatric cancer patients and siblings is generally mixed or inconclusive, although there is some evidence suggesting increased psychosocial adjustment following camp participation. Research focusing on levels of perceived social support is limited. Although campers report social support as a main benefit of oncology camp participation, most studies are exploratory and yield inconsistent findings regarding demographic differences. In order to understand the effects of an oncology camp intervention on levels of psychosocial adjustment and perceived social support for pediatric cancer patients and siblings, an archival data set collected at a pediatric oncology camp (N = 64) was analyzed. There were 30 patients and 34 siblings in the sample, 37 females and 27 males, and with a mean age of 11.84 (SD = 2.89). Participants completed the Children’s Depression Inventory (CDI) and the Social Adjustment Domain (SA) from the Child Behavior Checklist – Youth Self-Report at three time points. Data was analyzed using repeated measures MANOVAs and results indicated that psychosocial adjustment increased significantly for adolescent females but not for other demographic groups. Additionally, perceived social support was found to increase for adolescent females but decrease for adolescent males, although other demographic groups did not appear to experience significant change over time. Strengths, limitations, and areas for future research are addressed as part of the discussion.
Introduction

The ways in which pediatric cancer is approached and treated has changed dramatically since the 1970s, upon the introduction of oncologists specifically trained to treat pediatric forms of the disease (Bessell, 2001; Conrad & Altmaier, 2009; Meadows, 2001). Prior to the 1970s, morbidity and mortality rates for children diagnosed with pediatric cancer were high, and few achieved remission or any type of long-term cure (Bessell, 2001; Chao, Chen, Wang, Wu & Yeh, 2003; Ellis, 2000). Historically, these children were treated from a strictly medical standpoint, without consideration of the psychosocial impact of having cancer, likely due to the low survival rates. Additionally, family members were not often included in the healing process, despite their own psychosocial difficulties related to having a child with cancer (Eiser, Hill, & Vance, 2000; Kazak, Christakis, Alderfer, & Cirollo, 1994; Steele, Mullins, Mullins, & Muriel, 2015; Robinson, Gerhardt, Vannatta, & Noll, 2007; Woodgate, 1999; Wu, Prout, Roberts, Parikshak, & Amylon, 2011). In the 1990s, a shift in medical treatment methods led to significantly higher survival rates, which may currently be upwards of 70-75% for all pediatric cancers when combined (Ach et al., 2013; Conrad & Altmaier, 2009; Eiser et al., 2000; Ellis, 2000; Farnow-Kenney & Kliwer, 2000; Katz, Leary, Breiger, & Friedman, 2011; Schwartz & Drotar, 2009; Thompson, Gerhardt, Miller, Vannatta, & Noll, 2009). Despite this increase in survival, pediatric cancer patients are still often subjected to a variety of painful, stressful, and lengthy treatments that leave them with both short- and long-term consequences (Ach et al., 2013; Bessell, 2001; Conrad & Altmaier, 2009; Eiser et al., 2000; Ellis, 2000; Katz et al., 2011; Meadows, 2001; Robinson et al., 2007; Schwartz & Drotar, 2009). Research demonstrates the following psychosocial stressors may be attributed to pediatric cancer including the following: cognitive delays, emotional dysregulation, behavioral problems, frequent family separation, financial distress, parental stress,
poor social skills, lack of an understanding and supportive community, anxiety about recurrence or other medical complications, low self-esteem, and overdependence or extreme independence (Beckwitt, 2014; Fearnow-Kenney & Kliewer, 2000; Kim & Yoo, 2010; Martiniuk, Silva, Amylon, & Barr, 2014b; Phipps, 2007; Rumsey & Harcourt, 2007; Steele et al., 2015). Despite these documented difficulties, prior to 2015, there existed no evidence-based psychological standards of care for pediatric oncology patients (Steele et al., 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015).

In the late 1970s and early 1980s, pediatric oncology camps arose as a potentially innovative way to address the increasing numbers of children with cancer who were surviving their disease and were otherwise excluded from other camping organizations due to their unique medical difficulties (Balen, Fielding, & Lewis, 1996; Laing & Moules, 2014; Wellisch, Crater, Wiley, Belin, & Weinstein, 2006; Wu et al., 2011). At the time, most children who attended camp did not survive their disease and the intention behind a camp experience was to provide a purely fun and memorable experience (B. Crater, personal communication July 29, 2014). As previously described, medical advancements have led to higher survival rates at present, which has subsequently led to a shift in the ways pediatric oncology camps approach programming (B. Crater, personal communication July 29, 2014). As such, the focus of many oncology camp programs now includes growth outcomes to help children reduce the impact of short- and long-term psychosocial difficulties and consequences that arise due to a diagnosis of pediatric cancer (B. Crater, personal communication July 29, 2014; Martiniuk et al., 2014b).

This attempt to provide a normalizing summer camp experience, however, is often restricted to patients and does not include opportunities for siblings to participate despite the number of stressors and vulnerabilities they face (Zegaczewski, Chang, Coddington, & Berg,
Research demonstrates that siblings may also exhibit poor psychosocial adjustment following a pediatric cancer diagnosis, as determined by a variety of factors such as demographics, type of cancer diagnosis, and existing personality structure (Houtzager, Grootenhuis, Hoekstra-Weebers, Caron, & Last, 2003; Houtzager et al., 2004; Zegaczewski et al., 2016). Despite this, prior to 2015, there were no established, evidence-based standards of psychosocial care when considering this vulnerable population of children (Gerhardt, Lehmann, Long, & Alderfer, 2015). Research documents that participation in sibling support groups, including therapeutic groups and camps, may help achieve this unmet need (Gerhardt et al., 2015).

There is a growing amount of literature focusing on participation in pediatric oncology camp programs and positive outcomes (e.g., greater perceived peer acceptance, improved psychosocial adjustment) for children with cancer and their siblings, however results are often inconclusive or mixed (Gerhardt et al., 2015; Meltzer & Rourke, 2005; Packman et al., 2005; Sidhu, Passmore, & Baker, 2006; Woods, Mayes, Bartley, Fedele, & Ryan, 2013; Wu et al., 2011). This is frequently attributed to issues with methodology and understanding that pediatric cancer patients and their siblings are not a traditionally clinical population (Gerhardt et al., 2015). Further research is necessary to characterize the specific vulnerabilities that children with cancer and their siblings face and how participation in pediatric oncology camp organizations affects psychosocial adjustment and perception of social support.

Psychosocial Adjustment

Psychosocial adjustment, as defined by Alderfer et al. (2009), encompasses the following five domains: psychological adjustment, family functioning, social and school functioning, somatic complaints, and resilience. The available research on psychosocial adjustment
additionally incorporates life satisfaction, coping skills, protective factors (i.e., hope, empathy, family cohesion, humor), perceived social support, demographics (i.e., socioeconomic status), temperament, and demographics (Conrad & Altmaier, 2009; Fearnow-Kenney & Kliewer, 2000; Kazak et al., 1994; Kim & Yoo, 2010; Labay & Walco, 2004; Robinson et al., 2007; Varni & Katz, 1997; Wechsler & Sanchez-Iglesias, 2013). The breadth of this construct leads to heterogeneous findings in the existing literature base, particularly regarding pediatric cancer patients, as their psychosocial adjustment is often correlated with additional factors such as type of cancer, treatment, time since diagnosis, and late effects (K. Ahmed, personal communication, November 12, 2014; Alderfer et al., 2009; Katz et al., 2011; Kazak et al., 1994; Manne & Miller, 1998; Martiniuk, 2003; Varni & Katz, 1997; Woodgate, 1999).

Generally, available literature indicates inconsistent findings regarding psychosocial adjustment of pediatric cancer patients (Chao et al., 2003; Kazak et al., 1994; Kim & Yoo, 2010; Manne & Miller, 1998). Overall, females seemed to experience higher levels of distress and maladjustment compared to males, and adolescents generally were more prone to psychological maladjustment and distress; however, pediatric cancer patients and siblings are not often regarded as a clinical population when considering psychosocial adjustment (Kazak et al., 1994; Manne & Miller, 1998). When considering siblings of pediatric cancer patients, there is a wealth of research suggesting these children experience adjustment difficulties, although not consistently at the clinical level (Alderfer et al., 2009; Gerhardt et al., 2015; Houtzager et al., 2003; Labay & Walco, 2004). Available literature revealed adolescent females exhibited the highest levels of psychosocial distress and that siblings generally are at risk for psychosocial maladjustment (Alderfer et al., 2009; Gerhardt et al., 2015; Houtzager et al., 2003).
Research focusing specifically on oncology camps and their impact on psychosocial adjustment for pediatric cancer patients yields findings that are generally inconclusive (Conrad & Altmaier, 2009). There is some evidence that cancer patients who attend an oncology camp have better psychosocial adjustment in the weeks to months following the intervention, but may not immediately show improvement, owing to the emotional experience of a camp session ending (Martiniuk et al., 2014b; Wellisch et al., 2006). Overall, an increase in health-related quality of life was indicated in some of the research, but other physical, social, and cognitive aspects of adjustment are largely unknown and undocumented (Epstein, Stinson, & Stevens, 2005). In contrast, studies investigating siblings’ participation in an oncology camp experience consistently reveal lowered emotional distress and psychosocial maladjustment (Gerhardt et al., 2015; Packman et al., 2008; Prchal & Landolt, 2009; Sidhu et al., 2006).

**Perceived Social Support**

Social support, as defined by Fuemmeler, Mullins, and Carpentier (2006), is the nature of the relationships one engages in with others, and can consist of four specific types of support: emotional, instrumental, informational, and appraisal. Perceived social support represents a combination of the four types of support, as well as how much and how often a child perceives he or she receives support from others (Fuemmeler et al., 2006). The present study defines perceived social support as perceived friendships with others and the level of satisfaction the child receives from the support given.

Children undergoing treatment for cancer often experience disruptions in their social relationships due to missing school, time spent in the hospital, reduced energy, and weakened immune systems (K. Ahmed, personal communication, November 12, 2014; Marsland, Ewing, & Thompson, 2006). Research identifies several themes regarding perceived social support and
pediatric cancer patients. First, perceived social support may be negatively correlated with stress and affectivity, although further methodically sound research is needed (Varni & Katz, 1997). Instrumental support, usually in the form of family and friends, was identified as highly important (Ishibashi, Ueda, Kawano, Nakayama, Matsuzaki, & Matsumura, 2010). Finally, pediatric cancer patients reported feeling shielded by parents and peers against emotionally harsh or insensitive comments from others (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).

There is a paucity of information regarding perceived social support for siblings of pediatric cancer patients, however available research highlights that the number of individuals available to a child and instrumental support are the two most important aspects of perceived social support for siblings (Alderfer et al., 2009; Prchal, Graf, Bergstraesser, & Landolt, 2012).

Pediatric oncology camps have been shown to play a large role in the development and maintenance of social relationships (Beckwitt, 2014; Conrad & Altmaier, 2009; Decker, 2007; Epstein et al., 2005; Gerhardt et al., 2015; Martiniuk et al., 2014a; Sidhu et al., 2006; Wu, Goldhof, Roberts, Parikshak, & Amylon, 2013; Zegaczewski et al., 2016). Pediatric cancer patients consistently name social support as one of the most influential factors of an oncology camp intervention (Beckwitt, 2014; Decker, 2007; Epstein et al., 2005; Martiniuk et al., 2014b). To this end, research indicates that camps provide a community where they can feel normalized and a part of a group where all members have a commonality (Laing & Moules, 2014). Studies have even described that relationships forged in a camp setting, through bonding and activities, were viewed by adult survivors of pediatric cancer as part of the normalizing process (Beckwitt, 2014). Both patients and siblings have been found to feel more supported by their peers following a camp intervention when compared to measures prior to camp (Beckwitt, 2014; Conrad & Altmaier, 2009; Laing & Moules, 2014; Sidhu et al., 2006; Wu et al., 2011; Wu et al.,
There are inconsistent findings regarding gender differences, however some studies indicate that females report higher levels of social support than males in the camp setting (Conrad & Altmaier, 2009; Decker, 2007). Finally, similar to patients, siblings endorse that having an opportunity to engage in socially supportive relationships with other siblings experiencing the same difficulties is a highly important aspect of pediatric oncology camp programs (Sidhu et al., 2006; Wu et al., 2011; Wu et al., 2013).

**Focus and Scope of the Present Study**

Existing literature indicates that there is a clear need to better understand the impact of pediatric oncology camp programs on the children they serve. Although pediatric cancer patients and siblings are not necessarily a traditionally clinical population, they have been consistently shown to have multiple vulnerabilities as a result of pediatric cancer. To this end, the objective of the present study is to examine the effects of participation in a pediatric oncology camp on psychosocial adjustment and perceived social support in pediatric cancer patients and their siblings. Through use of an archival data set collected at a pediatric oncology camp, this study will help enhance the existing literature base regarding psychosocial adjustment and perceived social support in the context of an oncology camp setting. These areas of study were chosen due to documented inconsistent findings and having minimal published data.

Specifically, this researcher identified several possible questions to examine in order to better explore and understand how psychosocial adjustment and perceived social support are impacted by a pediatric oncology camp intervention. With regard to psychosocial adjustment, the present study will look at the differences across time (e.g., prior to and following a camp intervention) considering the following demographics: patients vs. siblings, children vs. adolescents, and males vs. females. Exploration of the following demographics across time will
also occur when investigating the impact of a camp experience on perceived social support: patients vs. siblings, males vs. females, and children vs. adolescents.
Hypotheses

Regarding perceived social support, multiple correlations were conducted to determine relatedness of CDI Items 20, 22, and 25 as well as SA Item 5. With these four items, Cronbach’s α = .497, indicating low reliability. Correlations revealed that CDI Item 25 (“Nobody really loves me; I am not sure if anybody loves me; I am sure that somebody loves me”) was the only question that was not significantly correlated with any of the other items, and therefore the decision was made to remove it from the overall construct of perceived social support. CDI Item 25 pertained more to feelings of perceived love, which may not mesh with the overall construct of perceived social support, and was therefore not correlated significantly with the other items. CDI Item 22 (“I have plenty of friends; I have some friends but I wish I had more; I do not have any friends”) and SA Item 5 (“I feel lonely most of the time; I feel lonely some of the time; I hardly ever feel lonely”) were significantly negatively correlated (p < 0.01), as were CDI Item 20 (“I do not feel alone; I feel alone many times; I feel alone all the time”) and SA Item 5 (“I feel lonely most of the time; I feel lonely some of the time; I hardly ever feel lonely”) (p < 0.05). It is expected that these items were negatively correlated, as a higher score on CDI items is reflective of maladjustment and a lower score on SA items indicates maladjustment. CDI Items 20 (“I do not feel alone; I feel alone many times; I feel alone all the time”) and 22 (“I have plenty of friends; I have some friends but I wish I had more; I do not have any friends”) were significantly positively correlated (p < 0.05). In summary, the three-item scale (e.g., CDI Items 20 and 22 and SA Item 5), are significantly correlated and appear to measure a related construct, Cronbach’s α = .648.
Considering available research and results from similar types of studies examining psychosocial adjustment and perceived social support, the following hypotheses are made concerning the present study:

1) Following participation in a weeklong oncology summer camp experience, psychosocial adjustment will increase across all groups (e.g., patients and siblings, males and females, children and adolescents).

2) Adolescent females will have lower levels of psychosocial adjustment at baseline and following the camp intervention when compared to child and adolescent males and child females.

3) No other predictions regarding psychosocial adjustment are made for between group differences in change over time.

4) Perceived social support will increase across all groups (e.g., patients and siblings, males and females, children and adolescents).

5) Adolescents will experience a greater increase in perceived social support across time compared to children.

6) No other predictions regarding perceived social support 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 were mixed patients and siblings, one was 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%), Hispanic/Latino (23%), African-American (6%), Asian (2%), Biracial (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, with the average time since diagnosis being 81 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 from both the original research project and again for the current study. Permission to use the data 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 five 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, 1-week follow-up, or 4 to 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 fewer than three items missing on a measure, researchers handled this with mean imputation. Since all questions on the SA pertained to social adjustment and there were no subdomains, measures with fewer than three missing values were imputed with the participant’s average item score. A number of participants omitted one particular item on the SA regarding the desire to be alone versus with other children. Researchers hypothesize that this question was omitted due to complicated phrasing rather than 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 SA questionnaires 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 SA, 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 completed a demographic questionnaire, but did not fill out any type of assessment.

Measures

Researchers used three separate test protocols in the original study. They are as follows:
Children’s Depression Inventory (CDI), Social Adjustment Domain (SA) from the Child

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, and 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 past 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 Social Adjustment (SA) questionnaire is a standardized, self-report measure for children, which examines feelings and behaviors. It is typically administered as part of the CBCL. Twenty (20) questions from the SA 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 the original study, to assess fear about attending camp. For total competence, stability $R$s were 0.62 and for total problems, stability was 0.56.

For the purpose of the present study, the researcher-developed “Things you did at camp” measure was not included.

**Statistical Analysis**

Statistical analyses were selected for each variable in order to best identify changes in functioning following participation a weeklong session of camp. A repeated measures multivariate analysis of variance (MANOVA) was used to examine the impact of gender, age, cancer status, and time (independent variables) on psychosocial adjustment. Main effects and interactions were examined to understand more about the effects of this type of intervention. Regarding perceived social support, multiple correlations were conducted in order to determine if selected items from the CDI (e.g., Items 20, 22, and 25) and SA (e.g., Item 5) questionnaires were related. The scaling of CDI and SA items is different, with CDI items ranging from 0 to 2, with 0 representing no distress and 2 representing high distress, and SA items ranging from 1 to 3, with 1 representing maladjustment and 3 representing better adjustment. SA Item 5 was re-coded and scaled according to CDI item scaling and reverse scored. Next, a scale of perceived social support was created using the above selected items and analyzed for reliability. Finally, a
repeated measures MANOVA was selected to examine perceived social support across time for various demographic groups. $P = 0.05$ was utilized to indicate significance, as this is the most commonly used level for significant findings. Consistent with other similar studies, $P$ values between 0.05 and 0.10 were considered to be approaching significance or indicative of borderline significance (Wellisch et al., 2006).
Results

Distribution of gender, age, and ethnicity were generally evenly distributed between patient and sibling groups. A summary of these demographics can be viewed in Table B1.

Psychosocial Adjustment

Repeated measures MANOVAs were utilized to examine change in psychosocial adjustment scores between baseline, first follow-up, and second follow-up when considering various demographic groups. It was hypothesized that all groups (e.g., patients and siblings, males and females, children and adolescents) would experience improved levels of psychosocial adjustment following participation in a camp intervention, however this was not the case as there was not a significant main effect when looking at the entire sample, Wilks’ $\lambda = .980$ $F(2, 50) = .522, p > .05$, partial eta squared = .02.

There was no significant change found when broadly looking at change over time for patients vs. siblings, Wilks’ $\lambda = .990$ $F(2, 52) = .261, p > .05$. This means the effect of the camp intervention was the same across both groups of campers (e.g., patients and siblings) with no significant difference between them. When examining the effect of the intervention over time (e.g., baseline to second follow-up) considering age category and gender, there was no significant main effect, Wilks’ $\lambda = .980$ $F(2, 50) = .522, p > .05$. Despite this finding, there was a three-way interaction (e.g., age, gender, time) that approached significance, Wilks’ $\lambda = .889$ $F(2, 50) = 3.123, p = .053$, partial eta squared = .111. Refer to Table C1 for psychosocial adjustment means across time for age category and gender.

Follow-up main effects were non-significant for males across age groups, Wilks’ $\lambda = .983$ $F(2, 19) = .160, p > .05$, as well as females across age groups, Wilks’ $\lambda = .958$ $F(2, 30) = .665, p = > .05$. However, there was a significant interaction for females when considering different age
groups, Wilks’ $\lambda = .764$, $F(2, 30) = 4.645$, $p = .017$. Furthermore, follow-up analyses revealed a significant increase in psychosocial adjustment from baseline to second follow-up for adolescent females, Wilks’ $\lambda = .729$, $F(1, 13) = 4.828$, $p = .047$. Refer to Figure E1 for visual representation of psychosocial adjustment means for the interaction between time, gender, and age category.

**Perceived Social Support**

Repeated measures MANOVAs were conducted to investigate the change in perceived social support between the three time points when considering different demographic groups. It was hypothesized that all groups (e.g., patients and siblings, males and females, children and adolescents) would experience improved levels of perceived social support from baseline to second follow-up. It was also hypothesized that adolescents would experience a greater change in perceived social support following the intervention across time, and no other group differences were expected. Results indicated that there was no main effect of perceived social support over time when considering the whole sample, Wilks’ $\lambda = .963$, $F(2, 47) = .903$, $p > .05$. Refer to Table D1 for perceived social support means across time for age category and gender.

Closer examination of analyses indicated an interaction between time and age, that approached significance, Wilks’ $\lambda = .885$, $F(2, 47) = 3.043$, $p = .057$, partial eta squared $= .115$. There was a significant interaction when considering gender and perceived social support, Wilks’ $\lambda = .963$, $F(2, 47) = 3.787$, $p = .03$, partial eta squared $= .139$. Results revealed a significant three-way interaction when considering perceived social support as moderated by age and gender, Wilks’ $\lambda = .861$, $F(2, 47) = 3.804$, $p = .029$, partial eta squared $= .139$. Specifically, adolescent males were noted to have diminished levels of perceived social support and females were found to have increased perceived social support considering the change from baseline to second follow-up. Additionally, as predicted, when cancer status (e.g., patient vs. sibling) was
included in the interaction, all findings were non-significant. Refer to Figure F1 for visual representation of perceived social support adjustment means for the interaction between time, gender, and age category.
Discussion

The purpose of the present study was to investigate important constructs not initially reported upon in the original study conducted by Wellisch et al. (2006) in order to evaluate the impact of participation in an oncology camp experience for pediatric cancer patients and siblings. Psychosocial adjustment and perceived social support are two specific variables for study when considering domains where pediatric cancer patients and siblings may have difficulty, as well as areas where oncology camps may be able to fill those gaps. There are several questions for research that will be addressed below and will be grouped by variable.

Results revealed that psychosocial adjustment in adolescent females increased at a borderline significance level following a weeklong oncology camp intervention compared to child females and all males. Specifically, the dramatic difference in psychosocial adjustment between child females and adolescent females indicates adolescent females benefit significantly more than their child counterparts when considering psychosocial adjustment. Furthermore, female adolescents had higher levels of psychosocial adjustment at the 4-6 month follow-up, suggesting that the psychosocial effects of camp participation are long-lasting in nature. The mean at baseline for adolescent females was the lowest of all age group and gender combinations, but their psychosocial adjustment mean was the highest by the second follow-up.

While the original hypothesis is partially supported by these findings (e.g., adolescent females will have lower levels of psychosocial adjustment compared to other groups), it is also in contrast with the second half of that hypothesis (e.g., adolescent females will have lower levels of psychosocial adjustment compared to other groups after the intervention), as adolescent females were shown to have the highest average psychosocial adjustment by the second follow-up. Similar trends were not seen across other demographic groups, despite the original
hypothesis that all groups would experience increased psychosocial adjustment after camp participation. This is likely attributed to ceiling and floor effects that make it difficult to identify additional marked changes in psychosocial adjustment. Because pediatric cancer patients and siblings are not necessarily considered a clinical population, it is possible that the clinical measures used were not sensitive to smaller, less clinical changes in other demographic groups (e.g., patients vs. siblings).

The present study attempted to create a new construct (e.g., perceived social support) from measures that did not explicitly measure social support. Results indicated that when using a three-item scale (e.g., CDI Items 20 and 22 and SA Item 5), there was adequate reliability. Analysis showed that when considering the sample as a whole, perceived social support did not increase significantly from baseline to second follow-up, which rejects the original hypothesis that all groups would experience improved perceived social support over time. This null finding is likely attributed to floor effects and low levels of sensitivity to change across time in a non-clinical population. It is also possible that the scale created to measure perceived social support was not large enough or that there could have been items used that were ultimately more reflective of the overall construct.

With that said, there were other findings that are interesting for further discussion. Although gender was not initially hypothesized as a variable that would moderate levels of perceived social support, the borderline significant interaction (e.g., gender and perceived social support over time) suggests these groups do, in fact, endorse perceived social support differently. It appears that males have a slight decrease in overall sense of perceived social support, whereas females have a larger increase in perceived social support following camp participation. Gender
differences have not been found in the broader literature base, however this may be a continued area of study, given these findings.

The hypothesis regarding adolescents experiencing a greater increase in perceived social support is only partially supported by the current findings. At first glance, it appears that adolescents (males and females combined) did not endorse changed levels in perceived social support from baseline to second follow-up. There appears to be a slight increase in perceived social support levels at the first follow-up measurement, suggesting that participation in a weeklong oncology camp program helps adolescents feel more supported by the end of the camp session but not necessarily in the weeks to months afterwards. In contrast, child participants demonstrated a small increase in endorsement of perceived social support levels from baseline to second follow-up, which does not support the original hypothesis. With this in mind, the mean of the perceived social support scale indicated an increase in perceived social support levels from baseline to second follow-up for adolescent females, however adolescent males seemed to endorse lessened levels of perceived social support from baseline to second follow-up.

Ultimately, both groups ended with similar levels of perceived social support at the second follow-up, despite the original discrepancy in their average levels of perceived social support at baseline. This is not likely attributed to gender alone, as male children experienced virtually no change across time and female children endorsed minimal improvements in perceived social support comparing baseline to second follow-up. The role of gender in levels of perceived social support is inconsistently reported in the available literature, with some noting no differences and some reporting that females endorse higher levels than males.

It is important to consider the potential contributions of the differences in socialization between males and females and how this may influence results (Kazak et al., 1994). While this
phenomenon has not been explicitly investigated in the context of disease-specific camping as it relates to perceived social support, there is available research that begins to highlight this issue. It suggests that female campers may focus their energies more intentionally on fostering social connections while male campers may be more invested in participation in the structured activities provided within programs (Conrad & Altmaier, 2009). It is possible that females may be more aware of their social supports while in the camp environment and take steps to continue to foster these relationships upon returning home. Males are traditionally found to be more socially isolated, so integration into a camp environment, where collaboration, connectedness, and constant socialization is expected may acutely influence results immediately following camp participation; when males return home, it may be that they have the insight to recognize that they are returning to more isolated environments and socialization patterns, which is starkly contrasted with the camp experience and subsequently reflected in lowered perceived social support levels.

In summary, it appears that the combination of age and gender (e.g., adolescent females) moderate endorsement of perceived social support levels and although adolescents as a whole did not experience higher levels of perceived social support, adolescent females did. Possible reasons for lessened perceived social support levels in adolescent males may be the low number of adolescent male participants (n = 10) or individual characteristics of the sample (e.g., did not keep in contact with camp friends over time, etc.). This is an area for future study, as it would be important to better measure why adolescent male campers report less perceived social support 4-6 months following camp participation.

Overall, results from both dependent variables under consideration (e.g., psychosocial adjustment and perceived social support) suggest that patient or sibling status does not affect the
outcome, however age (e.g., child vs. adolescent) and gender appear to be moderators. Adolescent females seem to consistently endorse improved psychosocial adjustment and perceived social support, and aside from adolescent males reporting diminished perceived social support following camp participation, all other groups either experienced marginal change or no change at all. This is an interesting and important finding, as adolescent females appear to have unique benefits from participation in camp programming, especially when compared to other demographic groups. As discussed above regarding socialization of males, it is possible that camp programs implicitly and explicitly support existing socialization patterns of females. It is also considered that male and female patients/siblings of pediatric cancer may be treated differently in their home environments, which contributes to some of the presently unidentified benefits of camp participation for adolescent females (Kazak et al., 1994). Ultimately, this study contributes knowledge to the existing literature bases that adolescent females appears to benefit more than their male and younger female counterparts and highlights the need for future research in this area. There are many strengths and limitations of the present study that have been highlighted throughout and will be discussed thoroughly below.

Limitations

There are limitations of the current study that must be taken into account when interpreting findings. The limitations of this study are comparable to much of the available literature focusing on pediatric oncology camp interventions and their impact on psychosocial adjustment and perceived social support. First, the final sample is relatively small in size ($N = 64$) and all data was collected throughout the summer at one pediatric oncology camp in Southern California. Participants were fairly homogenous and not representative of the population of Southern California with regard to ethnic background, with 63% of participants
identifying as Caucasian and 23% identifying as Hispanic/Latino. Given these limitations, it is important to consider that the findings of this study (e.g., adolescent females reporting increased psychosocial adjustment and perceived social support, null findings regarding psychosocial adjustment and perceived social support for the entire sample) may not meaningfully generalize across all pediatric oncology camps, geographic locations, or individuals of diverse ethnic backgrounds.

Additionally, it should be noted that data collection occurred in the early 2000s, and results may not be fully representative of pediatric cancer patients and siblings who attend pediatric oncology camps currently. When considering the medical advancements of the past 15 years, it is possible that increased survivorship and efforts to reduce highly neurotoxic treatment methods may impact overall adjustment or perceived levels of social support, and results from the current study may not be as relevant to current patients and siblings. Similar to most studies examining the effects of pediatric oncology camps, the present study lacks a control group and the longitudinal design only captures information up to 6-months post-camp. Furthermore, many of the participants in the current study were returning campers, therefore the combined effects of their repeated exposure to a camp experience on these findings is unknown and represent a potential confounding variable.

Although the SA Youth Self Report questionnaire is designed for use with children ages 11 to 18 years, it was administered to children as young as 7 in the original study, and therefore part of the sample for the present study. The information gathered from children younger than the intended age of 11 should be interpreted with caution, as it was not designed for use with children under that age. The sole reliance on self-report measures from young children or youth with possible cognitive deficits (e.g., patients with late effects as a result of their treatment, etc.)
is a limitation of this sample. This study could have been strengthened by the addition of collateral report (e.g., parent, physician, camp counselor, teacher, etc.). There is also a lack of information about the possible medical treatments (e.g., chemotherapy, radiation, pain medication, steroids, etc.) that patients may have been receiving at or around the time of data collection that could potentially impact their psychosocial adjustment, perceived social support, or ability to effectively complete measures.

Perhaps most significantly, this study sought to examine a non-clinical population and variables through use of an existing database that utilized clinical measures (e.g., CDI, SA). As discussed later, it will be important for researchers to employ an approach grounded in strengths-based and positive psychology measures in order to fully capture this information in the future.

**Strengths**

This study features several strengths that should be recognized. First, it contributes empirical knowledge to the relatively small base of literature on the effectiveness of pediatric oncology camps. Although Wellisch et al. (2006) previously published results from this data set regarding affective changes and suicidality, the present study contributes information regarding variables not initially examined in this particular sample (e.g., psychosocial adjustment and perceived social support). Consistent with contemporary research being conducted with pediatric cancer patients and siblings, the present study focused more towards a positive, strengths-based approach; variables being considered (e.g., psychosocial adjustment and perceived social support) are viewed as outcomes that are targeted for increase following camp participation rather than those being targeted to be decreased (e.g., negative affect, etc.). This study also utilized innovative ways of identifying a single, reliable construct (e.g., perceived social support)
across two different measures (e.g., CDI, SA) in order to more deeply examine potential benefits of oncology camp participation for patients and siblings.

This study underscores the value of obtaining data points at baseline and multiple times thereafter. Several studies have found that improvements in functioning are not necessarily seen immediately following a camp intervention owing to the emotional nature of the end of a camp session (Martiniuk et al., 2014b; Wellisch et al., 2006), and these findings are reflected in the current results. Another strength of the present study is inclusion of a follow-up at 4 to 6 months post-intervention. This allowed for exploration of potential gains that may have been masked or adversely impacted by the emotionality (e.g., sadness, anticipation of loneliness, etc.) of the end of a camp session (Martiniuk et al., 2014b; Wellisch et al., 2006).

This study included patient participants with a wide range of pediatric cancers. Available literature often excludes children with certain types of cancers (e.g., brain tumors), owing to their particularly high potential for late effects, especially cognitive deficits. A particular strength of this study is the inclusion of these children, as they represent a major demographic group who regularly participate in pediatric oncology camps. It is important to understand the impact of these specialized camps on all campers who attend. Similarly, the present study allows for investigation of psychosocial adjustment and perceived social support in both patients and siblings. Several similar studies in the literature base only contribute information about one of these groups, however there is evidence to support the importance of camp participation for all children affected by pediatric cancer.

Ultimately, the findings from the present study contribute valuable empirical information to existing literature on the many benefits of patient and sibling participation in an oncology camp intervention.
Implications for Future Research

Despite several existing studies indicating pediatric oncology camps are effective in increasing psychosocial adjustment, the effects of camp on perceived social support are minimally documented. There is very limited information in the existing literature base regarding perceived social support and most of the published research is exploratory or qualitative, with an emphasis on individual experiences rather than drawing more generalized conclusions (Conrad & Altmaier, 2009; Decker, 2007); additionally, findings in the literature base regarding differences between demographic groups (e.g., male vs. female) are mixed or inconclusive. It is clear that additional research is required in this area to help further explore the potential benefits of oncology camps on perceived social support. Conrad and Altmaier (2009) further explain how there are few measures of social support and none specifically targeted for use in a camp setting. Although the present study created a scale that reliably measured the same construct, it would be ideal to have a measure specifically designed to quantify perceived social support levels.

Methodology is an area to consider for future research on this topic; use of a mixed methods design that integrates appropriate quantitative and qualitative data would not only allow researchers to understand more about the implications of camp on perceived social support, but also hone in on the exact types of support felt by participants (Epstein et al., 2005; Laing & Moules, 2014).

Additionally, the effects of repeated exposure to a camp intervention are minimally documented. While some studies found no difference between new and returning campers, considering patients and siblings, others documented that returning campers benefited more or less than new campers (Epstein et al., 2005; Prchal & Landolt, 2009; Wellisch et al., 2006). Given the limited and inconclusive literature available on potential dose effects, this may be
another area of continued research. Furthermore, year-round programming, compared to once-per year programs, may also moderate outcomes and should be explored further.

This may also be impacted by use of social media, as camp friendships and memories may remain across time. The role of social media as a way to purposefully target social interactions in children and adolescents is interesting to consider in the context of a camp setting. Today’s youth has more access to social media than generations previously and is used as a platform for a variety of issues, including maintaining friendships with individuals whom one may not be able to see in person frequently. Preliminary meta-analyses of the impact of technology on social outcomes in youth with chronic illnesses is promising, as results indicate these youth are able to successfully connect with peers who have similar life experiences and feel supported by this online community (Maor & Mitchem, 2015). Future research may focus on identifying the role of connectedness via social media for campers between sessions and if this enhances campers’ sense of social support. This also should be investigated in the context of understanding any differences between adolescent males and females, given the discrepant findings between perceived social support for males and females in the present study.

Children with cancer and their siblings are not traditionally a clinical population, therefore contemporary studies are moving towards a positive psychology and strengths-based approach when attempting to understand the experiences of these children. The shift from a traditionally deficit-centered model to a more holistic perspective of psychosocial adjustment and perceived social support allows for more in-depth consideration and understanding of resilience factors (Fearnow-Kenney & Kliewer, 2000; Kim & Yoo, 2010). This is also oftentimes consistent with the approaches taken by many camp programs, which strive to enhance strengths and use those strengths to one’s advantage both on the individual and community levels (Balen
et al., 1996; B. Crater, personal communication July 29, 2014). When considering the direction for future research in the areas of psychosocial adjustment and perceived social support in oncology camp settings, it is likely that the most successful and ultimately useful investigations will be oriented towards positive psychology frameworks.

There is a recently renewed focus on the importance of providing psychosocial interventions for children with cancer and their families throughout the disease process (Gerhardt et al., 2015; Steele et al., 2015; Wiener et al., 2015). As efforts focus in on specified standards of care for pediatric cancer patients and siblings, it will be important to demonstrate the ways in which oncology camp programs can positively contribute to the overall wellbeing and psychosocial health of these children. Ultimately, there are many rich and salient areas for exploration within this population and furthered understanding will contribute to the ways in which pediatric oncology patients and siblings are approached, as well as how pediatric oncology camps structure their outcomes and programs.
REFERENCES


APPENDIX A

Review of the Literature
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<thead>
<tr>
<th>Study</th>
<th>Sample/Setting</th>
<th>Type</th>
<th>Purpose</th>
<th>Data Collection Method</th>
<th>Major Findings</th>
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<tbody>
<tr>
<td>Alderfer, M.A., Long, K.A., Lown, E.A., Marsland, A.L., Ostrowski, N.L., Hock, J.M., &amp; Ewing, L.J. (2009). Psychosocial adjustment of siblings of children with cancer: a systematic review. Psycho-Oncology, 19(8), 789–805.</td>
<td>65 relevant qualitative, quantitative, or mixed methods' papers published between 1997 and 2008</td>
<td>Systematic review</td>
<td>To promote a broader understanding of the psychosocial impact of childhood cancer on siblings, a systematic review was undertaken.</td>
<td>Review of available literature</td>
<td>Three of 8 studies found female siblings reported greater levels of post-traumatic stress, anxiety, and social problems than males. Two found no differences between female and male siblings on anxiety or loneliness. The remaining three studies examined gender as a predictor of outcomes across siblings and cancer survivors and found female gender to be a significant predictor of poorer adjustment. Also, generally, siblings exhibit higher levels of distress close to the time of diagnosis, with less distress shown over time. Adolescent siblings seem to show the poorest adjustment compared to adults, school age, and preschool children.</td>
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<tr>
<td>Beckwitt, A. E. (2014). Childhood cancer camps: Their role in adults surviving childhood cancers lives. Journal of Pediatric Oncology Nursing, 31(1), 1-7. doi:10.1177/1043454213515335</td>
<td>23 adult survivors of childhood cancer (ASCC); all 18 and older; recruited from nine camps serving children with cancer.</td>
<td>Narrative</td>
<td>Understand how pediatric oncology camps continue to positively affect the lives of campers as they survive into adulthood. Identify themes across their experiences.</td>
<td>Phone interviews (n=22), in-person interview (n=1), demographic surveys</td>
<td>Three main themes identified include the following: normalcy, meaningful camp experiences, and access to information. ASCCs were provided with opportunities to engage with peers while attending camp as children, feel less isolated, and learn about latent effects caused by cancer and treatment. This was considered an integral part of the &quot;normalizing&quot; process and that relationships formed in the camp environment were valued even later in adult life.</td>
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<td>Chao, C. C., Chen, S. H., Wang, C. Y., Wu, Y. C., &amp; Yeh, C. H.</td>
<td>24 patients (ages 8-17; 14 male, 10 female) and 18 parents; Pediatric Hem/One Department at Children's Hospital in Taiwan</td>
<td>Quantitative</td>
<td>To study the psychosocial difficulties faced by children with cancer and their families, including child depressive symptoms</td>
<td>Self-report measures</td>
<td>Children and parents have a better relationship post-diagnosis, with no more depressive symptoms than a normative group.</td>
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<tr>
<td>Conrad, A. L., &amp; 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</td>
<td>25 children; week long summer oncology camp (patients)</td>
<td>Quantitative</td>
<td>Exploration of types of social support received while attending a specialized summer camp</td>
<td>Self-report measures</td>
<td>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.</td>
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<tr>
<td>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</td>
<td>Reviewed 17 research studies.</td>
<td>Literature Review</td>
<td>Review of literature related to social support in adolescent cancer survivors.</td>
<td>CINAHL, Medline, PsychINFO, SSCI, CANCERLIT.</td>
<td>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. Both age groups valued family support.</td>
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<tr>
<td>Epstein, I., Stinson, J., &amp; Stevens, B. (2005). The effects of camp</td>
<td>18 studies identified through review of literature. Number of participants in</td>
<td>Systematic review</td>
<td>Review literature to determine the effects of specific chronic-</td>
<td>Online search of MEDLINE, CINAHL, and PsycINFO using the following terms: camping,</td>
<td>Following camp participation, some increase in HRQoL. Inconsistent findings.</td>
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<td>on health-related quality of life in children with chronic illnesses:</td>
<td>studies ranged from 13-256 participants; age range from 6-25 years. Total of</td>
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<td>illness camps on the health-related quality of life in children with</td>
<td>chronic diseases, quality of life, children, adolescent, and pediatric.</td>
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<td>A review of the literature. Journal of Pediatric Oncology Nursing,</td>
<td>1270 children included in 18 studies examined.</td>
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<td>chronic illness.</td>
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<td>22(2), 89-103. doi:10.1177/1043454204273881</td>
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<td>Supporting siblings as a standard of care in pediatric oncology.</td>
<td>patients to receive psychosocial intervention, as well as provide information</td>
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<td>receive psychosocial intervention, as well as provide information to</td>
<td>included the following terms: siblings, childhood, cancer, psychosocial outcomes.</td>
<td>and researchers found they would benefit from being identified to receive</td>
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<td>Pediatric Blood and Cancer, 62, S750-S804. doi:10.1002/pbc.25821</td>
<td>to parents/providers regarding the needs of siblings.</td>
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<td>parents/providers regarding the needs of siblings.</td>
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<td>psychosocial intervention. Ultimately, found moderate support to support strong</td>
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<td>recommendation of easy access to intervention for these children.</td>
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<td>Houtzager, B. A., Grootenhuis, M. A., Hoekstra-Weebers, J. E. H. M., Caron, H. N., &amp; 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</td>
<td>66 siblings (61% female, age range from 7-18, from 49 different families). Two children's hospitals in Netherlands.</td>
<td>Quantitative</td>
<td>Study the extent of psychosocial risk factors in siblings of pediatric oncology patients over time.</td>
<td>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).</td>
<td>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.</td>
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<tr>
<td>Houtzager, B.A., Grootenhuis, M.A., Caron, H.N., &amp; Last, B. F. (2004). Quality of life and psychological adaptation in siblings of pediatric cancer patients, 2 years after diagnosis. Psycho-Oncology, 499–511.</td>
<td>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.</td>
<td>Quantitative (prospective)</td>
<td>To investigate the prevalence of psychosocial problems in siblings of pediatric cancer patients 2-years after the diagnosis of the illness.</td>
<td>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).</td>
<td>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.</td>
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<tr>
<td>Study</td>
<td>Sample/Setting</td>
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<td>Purpose</td>
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<tr>
<td>Ishibashi, A., Ueda, R., Kawano, Y., Nakayama, H., Matsuzaki, A., &amp; Matsumura, T. (2010). How to improve resilience in adolescents with cancer in Japan. Journal of Pediatric Oncology Nursing, 27(2), 73-93. doi:10.1177/1043454209356786</td>
<td>7 adolescents with cancer (ages 11 to 18) and their mothers. 6 female, 1 male. 2 inpatient, 2 near discharge, and 3 outpatient.</td>
<td>Case Study</td>
<td>Examine development of resilience in adolescents undergoing cancer treatment, as well as presence of hope.</td>
<td>Semi-structured interviews, creation of social network map</td>
<td>Adolescents who were told about his/her diagnosis or relapse had higher levels of resilience compared to those who were indirectly told or not told about their relapse or diagnosis. Additionally, adolescents who felt supported by their network of family, friends, and others had similarly resilient outcomes. Finally, adolescents identified their mothers as most important in the social support system and family was particularly important. Most support was garnered from immediate/extended family and friends.</td>
</tr>
<tr>
<td>Kazak, A. E., Christakis, D., Alderfer, M., &amp; Coiro, M. J. (1994). Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. Journal of Family Psychology, 8(1), 74-84.</td>
<td>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.</td>
<td>Quantitative (short-term longitudinal)</td>
<td>To examine adjustment, including behavior problems, psychological distress, social issues, and family dynamics/functioning.</td>
<td>Self-report measures and parent-report measures</td>
<td>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.</td>
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<th>Study</th>
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<th>Data Collection Method</th>
<th>Major Findings</th>
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<tr>
<td>Kim, D. H., &amp; Yoo, I. Y. (2010). Factors associated with resilience of school age children with cancer. Journal of Pediatrics and Child Health, 46, 431-436. doi:10.1111/j.1440-1754.2010.01749.x</td>
<td>74 participants recruited from a pediatric oncology clinic in South Korea. Ages ranged 10 and 15, with the mean age of 13.11 years. Male and female participants were equally represented. The individuals in the sample had been diagnosed with cancer for more than 6 months prior to data collection, actively undergoing treatment, and did not suffer from cancer affecting the central nervous system.</td>
<td>Quantitative</td>
<td>To investigate adjustment and resilience in children diagnosed with cancer in South Korea.</td>
<td>Self-report</td>
<td>Results indicated that children with more positive family, peer, and teacher interactions were more resilient. Additionally, perceived family functioning was a predictor of a child’s adjustment level, specifically psychological status, self-esteem, and competence.</td>
</tr>
<tr>
<td>Laing, C. M., &amp; Moules, N. J. (2014). Children’s cancer camps: A sense of community, a sense of family. Journal of Family Nursing, 20(2), 185-203. doi:10.1177/107484071452071</td>
<td>19 individuals from 6 different families recruited from pediatric oncology camp</td>
<td>Hermeneutic</td>
<td>Understand the impact of pediatric oncology camps on families who have attended. Specifically, they looked at the meaning that these camps hold with the children and his/her family.</td>
<td>Semi-structured interviews, ethnographic (author attended as an observer at camp session)</td>
<td>Found that families were able to find a network of others with a commonality. Camps are welcoming and socially supportive for children with cancer and their family members.</td>
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<th>Study</th>
<th>Sample/Setting</th>
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<th>Purpose</th>
<th>Data Collection Method</th>
<th>Major Findings</th>
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<tbody>
<tr>
<td>Manne, S., &amp; Miller, D. (1998). Social support, social conflict, and adjustment among adolescents with cancer. Journal of Pediatric Psychology, 23(2), 121-130.</td>
<td>50 adolescent cancer patients (ages 12-20), currently undergoing cancer treatment. 58% males and average age = 16 years. Recruited from pediatric outpatient oncology clinic.</td>
<td>Quantitative</td>
<td>To understand close relationships and adjustment in adolescent cancer patients.</td>
<td>Self-report measures</td>
<td>Adolescents with cancer had more discord with their mothers when compared to their healthy peers and more prone to psychological adjustment problems and distress.</td>
</tr>
<tr>
<td>Martiniuk, A. L. C., Amylon, M. D., Briery, B. G., Shea-Perry, M., Kelsey, K. P., Lam, G. W., &amp; Körver, S. (2014). Camper learning and friendship at pediatric oncology camps in North America. Journal of Psychosocial Oncology, 32, 234-244. doi:10.1080/07347332.2013.874001</td>
<td>518 campers: 120 (age 6-9 years) and 398 (age 10 and older).</td>
<td>Cross-sectional</td>
<td>To better understand the changes in pediatric oncology campers after having attended a summer camp session. Specific factors investigated were independence, friendship, sense of community, teamwork, and responsibility.</td>
<td>Child self-report measures; 2 separate batteries of tests given, determined by age.</td>
<td>Found most younger campers learned about social skills and had increased competence, self-reliance, teamwork, and responsibility. Older children stated they felt their social skills and ability to befriend others also increased significantly. Improvements in areas related to social reintegration and acceptance also seen.</td>
</tr>
<tr>
<td>Martiniuk, A., Silva, M., Amylon, M., &amp; Barr, R. (2014). Camp programs for children with cancer and their families: Review of research progress over the past decade. Pediatric Blood &amp; Cancer, 61, 778-787.</td>
<td>Children with cancer and their families in oncology camp settings. Twenty articles, participants ranging in age from 5 to 18, mixed sample sizes.</td>
<td>Systematic literature review (some articles quantitative, some qualitative).</td>
<td>Investigate the outcome variables following participation in an oncology camp experience, including psychosocial adjustment.</td>
<td>Systematic literature review</td>
<td>Quality of life, emotional well-being, and mood increased following a camp experience, however the period right at the end of camp may reflect sadness and anticipation of loneliness which can skew data.</td>
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<tr>
<th>Study</th>
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<th>Type</th>
<th>Purpose</th>
<th>Data Collection Method</th>
<th>Major Findings</th>
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<tr>
<td>Meltzer, L. J., &amp; Rourke, M. T. (2005). Oncology summer camp: Benefits of social comparison. Children’s Health Care, 34(4), 305-314.</td>
<td>34 adolescents with cancer; week long summer oncology camp</td>
<td>Quantitative</td>
<td>To examine social comparisons made amongst adolescents with cancer who attend an oncology summer camp and the benefits of those comparisons.</td>
<td>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, Hyemel, &amp; Renshaw, 1984).</td>
<td>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.</td>
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<td>Packman, W., Mazaheri, M., Sporri, L., Long, J. K., Chesterman, B., Fine, J, &amp; 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. doi:10.1177/104345207311915</td>
<td>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.</td>
<td>Quantitative</td>
<td>To assess levels of emotional distress and adjustment following participation in an oncology camp session for siblings of pediatric cancer.</td>
<td>Projective drawings</td>
<td>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.</td>
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<tr>
<td>Study</td>
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<tr>
<td>Prchal, A., &amp; Landolt, M. A. (2009). Psychological interventions with siblings of pediatric cancer patients: A systematic review. Psycho-Oncology, 18, 1241-1251.</td>
<td>Programs focusing on siblings of pediatric cancer patients, specifically excluding bereavement/grief programs. 14 studies selected, 10 published and 4 dissertations. Sample size ranging from 11 to 90 participants, age range from 6 to 20 years.</td>
<td>Quantitative</td>
<td>To evaluate the literature focusing on interventions targeting siblings of pediatric cancer patients and the resultant psychosocial issues they may face.</td>
<td>Systematic literature review</td>
<td>Participation in a camp experience led to lower symptoms of depression, increased knowledge of medical information, and higher health-related quality of life. Inconclusive findings included anxiety, behavior issues, social adjustment, self-esteem, and symptoms of trauma. Some support for camp intervention for siblings, as it allows them to relate to others with similar difficulties.</td>
</tr>
<tr>
<td>Sidhu, R., Passmore, A., &amp; Baker, D. (2006). The effectiveness of a peer support camp for siblings of children with cancer. Pediatric Blood Cancer, 47, 580-588.</td>
<td>26 siblings of pediatric cancer patients recruited from an Australian pediatric oncology unit. Ranged in age from 8-13 and 52% female.</td>
<td>Quantitative</td>
<td>Examined the effects of a sibling-specific oncology camp aimed at reducing 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.</td>
<td>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 &amp; Sahler, 1991).</td>
<td>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.</td>
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<td>Steele, A. C., Mullins, L. L., Mullins, A. J., &amp; Muriel, A. C. (2015). Psychosocial interventions and therapeutic support as a standard of care in pediatric oncology. Pediatric Blood and Cancer, 62, S585-S618. doi:10.1002/pbc.25701</td>
<td>Comprehensive literature review of studies looking at access to psychosocial support for patients and family members.</td>
<td>Literature Review</td>
<td>Provide empirical evidence for support of a psychosocial standard of care for children with cancer and their family members throughout the cancer experience.</td>
<td>Review of available literature through search of OVID, PsychInfo, and PubMed over the last 20 years.</td>
<td>Although it is often assumed that pediatric cancer patients and families have access to psychosocial services, there are a number of barriers. Researchers strongly recommended that pediatric oncology centers have accessible resources for these families throughout the disease process.</td>
</tr>
<tr>
<td>Thompson, A. L., Marsland, A. L., Marshal, M. P., &amp; Tersak, J. M. (2009). Romantic relationships of emerging adult survivors of childhood cancer, 774(December 2008), 767–774.</td>
<td>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</td>
<td>Quantitative (longitudinal)</td>
<td>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.</td>
<td>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.</td>
<td>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.</td>
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<tr>
<td>Study</td>
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<td>Wellisch, D. K., Crater, B., Wiley, F. M., Belin, T. B., &amp; Weinstein, K. (2006)</td>
<td>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.</td>
<td>Quantitative (prospective)</td>
<td>Researchers sought to examine the relationship between mood and the camp experience and children with cancer and their siblings</td>
<td>Self-report questionnaires</td>
<td>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.</td>
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<td>Study</td>
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<td>Williamson, H., Harcourt, D., Halliwell, E., Frith, H., &amp; Wallace, M. (2010). Adolescents’ and parents’ experiences of managing the psychosocial impact of appearance change during cancer treatment. <em>Journal of Pediatric Oncology Nursing</em>, 27(3), 168-175. doi:10.1177/104345454209357923</td>
<td>22 adolescent cancer patients, ages 18-18 in the United Kingdom. 6 parents additionally participated.</td>
<td>Qualitative: Case Study Interviews and also online survey</td>
<td>To better understand how changes in physical appearance affects adolescents.</td>
<td>Case study interviews, online survey</td>
<td>Positive relationship between resilience and support from friends and family. Three major themes emerged regarding how their family and friends supported them. They endorsed that peers &quot;shielded&quot; them from emotionally harsh or insensitive comments by others and that parents &quot;shielded&quot; them from distress related to physical appearance.</td>
</tr>
<tr>
<td>Woods, K., Mayes, S., Bartley, E., Fedele, D., &amp; Ryan, J. (2013). An Evaluation of Psychosocial Outcomes for Children and Adolescents Attending a Summer Camp for Youth With Chronic Illness. <em>Children’s Health Care</em>, 42(1), 85–98.</td>
<td>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.</td>
<td>Quantitative</td>
<td>To evaluate the psychosocial outcomes for children and adolescents attending a summer camp specifically designed for children with chronic illnesses.</td>
<td>Self-report measures, including a demographic questionnaire, the Pediatric Quality of Life Inventory (PedsQL), and the Children’s Hope Scale (CHS),</td>
<td>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.</td>
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<td>Study</td>
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<td>Wu, Y. P., Goldhof, G. J., Roberts, M. C., Parikshak, S., &amp; 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</td>
<td>65 cancer patients or survivors, 85 siblings, 19 of whom were bereaved; week long summer oncology camp</td>
<td>Quantitative</td>
<td>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</td>
<td>Self-report measures</td>
<td>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</td>
</tr>
<tr>
<td>Wu, Y. P., Prout, K., Roberts, M. C., Parikshak, S., &amp; 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</td>
<td>89 families w/ pediatric cancer (78 mothers, 9 fathers, 56 patients, 73 siblings, 8 of whom were bereaved); week long summer oncology camp</td>
<td>Program Evaluation; Qualitative and Quantitative</td>
<td>To determine what aspect of a summer oncology camp produces satisfaction in campers and parents, improving existing services for families</td>
<td>Self-report measures</td>
<td>Parents and campers were most highly satisfied with aspects related to the camp's mission, such as recreation, respite, and peer support.</td>
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<td>Study</td>
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<td>Zegaczweski, T., Chang, K., Coddington, J., &amp; 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:10.1177/10434545600426</td>
<td>Comprehensive literature review of studies related to psychosocial adjustment. 12 total studies were included and were obtained through search of Cumulative Index to Nursing &amp; Allied Health Literature and PubMed. Search terms included: siblings, pediatrics, children, neoplasms, and psychosocial adaptation.</td>
<td>Literature Review</td>
<td>Identify commonalities of healthy siblings of pediatric cancer patients with attention specifically paid to psychosocial adjustment.</td>
<td>Online search of CINAHL and PubMed.</td>
<td>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.</td>
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</table>
REFERENCES


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.


cancer and their families: Review of research progress over the past decade. *Pediatric


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. doi:10.1177/104345207311915

intervention for siblings of pediatric cancer patients: A randomized controlled pilot trial.
6-3


and therapeutic support as a standard of care in pediatric oncology. *Pediatric Blood and


APPENDIX B

Characteristics of Sample
Table B1.

*Characteristics of Sample*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Patients ($n = 30$) (47%)</th>
<th>Siblings ($n = 34$) (53%)</th>
<th>Total ($N = 64$) (100%)</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>Female</td>
<td>17 (55%)</td>
<td>20 (57%)</td>
<td>37 (56%)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (45%)</td>
<td>14 (43%)</td>
<td>27 (44%)</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<tr>
<td>Caucasian</td>
<td>17 (57%)</td>
<td>23 (68%)</td>
<td>40 (63%)</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>7 (23%)</td>
<td>8 (24%)</td>
<td>15 (23%)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (20%)</td>
<td>3 (8%)</td>
<td>9 (14%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
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<tr>
<td>Mean ($SD$)</td>
<td>11.57 (2.9)</td>
<td>12.09 (2.9)</td>
<td>11.84 (2.89)</td>
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<tr>
<td>Child (7-12)</td>
<td>18 (60%)</td>
<td>20 (59%)</td>
<td>38 (59%)</td>
</tr>
<tr>
<td>Adolescent (13-18)</td>
<td>12 (40%)</td>
<td>14 (42%)</td>
<td>26 (41%)</td>
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*Note.* Totals may not add to 100% due to rounding.
APPENDIX C

Psychosocial Adjustment Means
Table C1.

*Psychosocial Adjustment Means*

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<thead>
<tr>
<th>Variable</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
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<tr>
<td><strong>Children (7-12)</strong></td>
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<tr>
<td>Male ( (n = 16) )</td>
<td>55.06 (4.15)</td>
<td>55.21 (5.44)</td>
<td>55.56 (5.34)</td>
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<tr>
<td>Female ( (n = 22) )</td>
<td>55.86 (3.80)</td>
<td>55.81 (4.85)</td>
<td>54.73 (4.12)</td>
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<tr>
<td><strong>Adolescents (13-18)</strong></td>
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<tr>
<td>Male ( (n = 10) )</td>
<td>56.80 (2.97)</td>
<td>57.44 (1.94)</td>
<td>56.82 (5.64)</td>
</tr>
<tr>
<td>Female ( (n = 15) )</td>
<td>53.50 (5.52)</td>
<td>55.23 (5.70)</td>
<td>56.20 (4.20)</td>
</tr>
<tr>
<td><strong>Gender Totals</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male ( (n = 26) )</td>
<td>55.73 (3.78)</td>
<td>56.09 (4.48)</td>
<td>56.07 (5.39)</td>
</tr>
<tr>
<td>Female ( (n = 37) )</td>
<td>55.27 (4.27)</td>
<td>55.79 (4.34)</td>
<td>55.64 (4.69)</td>
</tr>
<tr>
<td><strong>Cancer Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient ( (n = 30) )</td>
<td>54.83 (3.42)</td>
<td>54.65 (4.29)</td>
<td>55.03 (5.10)</td>
</tr>
<tr>
<td>Sibling ( (n = 34) )</td>
<td>55.67 (4.92)</td>
<td>56.74 (5.12)</td>
<td>56.18 (4.31)</td>
</tr>
</tbody>
</table>
APPENDIX D

Perceived Social Support Means
Table D1.

*Perceived Social Support Means*

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (Standard Deviation)</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
</tr>
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<tbody>
<tr>
<td><strong>Children (7-12)</strong></td>
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<td></td>
</tr>
<tr>
<td>Male ((n = 16))</td>
<td>0.50 (1.03)</td>
<td>0.71 (1.20)</td>
<td>0.44 (0.89)</td>
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<tr>
<td>Female ((n = 22))</td>
<td>1.05 (1.32)</td>
<td>0.59 (0.96)</td>
<td>0.76 (1.0)</td>
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<tr>
<td><strong>Adolescents (13-18)</strong></td>
<td></td>
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</tr>
<tr>
<td>Male ((n = 10))</td>
<td>0.20 (0.42)</td>
<td>0.10 (0.32)</td>
<td>0.82 (1.25)</td>
<td></td>
</tr>
<tr>
<td>Female ((n = 15))</td>
<td>1.27 (1.22)</td>
<td>0.69 (1.03)</td>
<td>0.80 (1.08)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender Totals</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male ((n = 26))</td>
<td>0.38 (0.85)</td>
<td>0.45 (0.98)</td>
<td>0.59 (1.05)</td>
<td></td>
</tr>
<tr>
<td>Female ((n = 37))</td>
<td>1.14 (1.27)</td>
<td>0.62 (0.97)</td>
<td>0.78 (1.02)</td>
<td></td>
</tr>
<tr>
<td><strong>Cancer Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient ((n = 30))</td>
<td>0.72 (0.96)</td>
<td>0.48 (0.96)</td>
<td>0.63 (0.93)</td>
<td></td>
</tr>
<tr>
<td>Sibling ((n = 34))</td>
<td>0.91 (1.33)</td>
<td>0.62 (0.99)</td>
<td>0.76 (1.12)</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX E

Psychosocial Adjustment: Time by Gender by Age Interaction
Figure E1. Psychosocial adjustment: Time by gender by age interaction.
APPENDIX F

Perceived Social Support: Time by Gender by Age Interaction
Figure F1. Perceived social support: Time by gender by age interaction.
APPENDIX G

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 H

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 I

IRB Approval Notice
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,

[Signature]

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