The Influence of a Peer Support Camp on Mitigating Emotional Distress in Siblings of Children With Cancer

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Abstract

Background: Siblings of children with cancer often experience anxiety and posttraumatic stress symptoms (PTSS), which negatively impact their self-esteem due to emotionally upsetting circumstances. The purpose of this longitudinal quantitative study was to investigate changes in anxiety, PTSS, and self-esteem of youth who participated in a peer support camp for siblings of children with cancer. **Methods:** A longitudinal study examined changes over time. Data were collected from 32 sibling surveys pre-, post-, and three months after camp. Siblings completed assessments to measure anxiety, PTSS, and self-esteem. A repeated measures ANOVA or Friedman Test was conducted to identify changes across the three data points for each outcome measured. Post hoc comparisons using paired sample t-tests or Wilcoxon Signed-Rank tests were conducted. **Results:** Significant improvements in anxiety; T1 and T2 (p < .000); T1 and T3 (p < .000). Significant decrease in PTSS; T1 and T2 (p = .001); T1 and T3 (p = .011). Significant improvement in self-esteem for younger participants (ages 7–9); T1 and T3 (p = .005). **Discussion:** The data generated in this study expand knowledge about the influence of peer support camps on reducing the emotional distress of siblings of children with cancer. The findings warrant further research on the long-term impact of such camps, the value of repeated participation, differences between bereaved and nonbereaved siblings, the phase of the cancer experience, and elements of the camp that have the most impact.

Introduction

In 2019, the American Cancer Society estimated that 11,060 children from birth to age 14 would be diagnosed with cancer in the United States (American Cancer Society, 2019). A cancer diagnosis brings significant stress to, and impacts all, members of the family. Routines are disrupted as family members worry and focus on the needs of the sick child. This can significantly impact a healthy sibling as the experience can lead to feelings of uncertainty and chaos (Ballard, 2004; Gerhardt et al., 2015; Packman et al., 2005; Zegaczewski et al., 2016), and the belief that their own needs are not important (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016; Vermaes et al., 2012; Wilkins & Woodgate, 2005). These experiences (disruption in routine, worry, feeling insignificant, and inability to voice their concerns) often lead to high levels of anxiety, posttraumatic stress symptoms (PTSS), and decreased self-esteem in siblings of children with cancer (Ballard, 2004; Gerhardt et al., 2015; Packman et al., 2005; Zegaczewski et al., 2016).

Siblings of children with cancer fall into clinical ranges of anxiety at rates greater than the general population (Alderfer et al., 2020; Barrera et al., 2002; Neville et al., 2016). Anxiety is characterized by feelings of worry, nervousness, tension related to uncertainty, and increased sensitivity to surroundings (American Psychological Association, 2018). Siblings of children with cancer are likely to experience a significant amount of anxiety due to a variety of factors, including fear of the unknown, worry about their sibling's reactions to treatment, and the visible physical effects of the disease (O'Brien et al., 2009; Sharpe & Rossiter, 2002). A study that examined the long-term effects of distress on siblings of children with cancer found that insufficient

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communication with parents, trusted adults, and siblings was associated with a risk of anxiety, especially in bereaved siblings (Wallin et al., 2016). In addition to anxiety, siblings of children with cancer were at risk of PTSS (Alderfer et al., 2003, 2020; Kaplan et al., 2013).

Posttraumatic stress is a mental health response to a terrifying experience, and symptoms may include intrusive thoughts, nightmares, avoidance, negative changes in temperament, ongoing distress, irritability, trouble concentrating, and self-destructive behavior (Kazak et al., 2004). A substantial number of siblings experience PTSS (Alderfer et al., 2010, 2020; Gerhardt et al., 2015; Hancock, 2011; Kaplan et al., 2013; Long et al., 2018; Tasker & Stonebridge, 2016; Yu & Bang, 2015). In one study examining family functioning and sibling distress, 62% (n = 209) of siblings reported moderate to severe PTSS, warranting a need for support services (Long et al., 2013). More than half of the participants reported feeling easily startled, irritable, and having difficulty sleeping. Another study specific to siblings of children with cancer described the most commonly reported cancer-related PTSS as avoidance and feeling upset when thinking about cancer (Kaplan et al., 2013). The cancer-related distress experienced by siblings of children with cancer, including anxiety and PTSS, may have a negative impact on self-esteem (Alderfer et al., 2010; Eilegård et al., 2013; Packman et al., 2004).

Siblings of children with cancer also experience low self-esteem (Alderfer et al., 2010). Self-esteem is the degree of satisfaction with one's feeling of perceived worth (Davis-Kean & Sandler, 2001). Studies indicated that adolescents in particular can experience lower self-esteem after a sibling's cancer diagnosis and the subsequent disruption in family and social life (Hancock, 2011; Prchal & Landolt, 2009).

During the past decade, research has expanded to explore interventions that seek to mitigate the emotional distress of siblings of children with cancer (Long et al., 2018). Emotional distress is defined in this paper as a range of feelings and emotions from temporary sadness and fear to more severe and persistent reactions such as anxiety, PTSS, and decreased self-esteem. As described above, siblings of children with cancer frequently experience anxiety, PTSS, and decreased self-esteem, especially at the time of diagnosis and in the early stages of cancer treatment. Several publications reported the need to develop and implement interventions and programs that increase siblings' support, facilitate communication about the cancer experience, increase cancer-related knowledge, and evaluate the impact on sibling emotional distress (Koumarianou et al., 2020; Gerhardt et al., 2015; Prchal & Landolt, 2009; Wiener et al., 2015; Yu & Bang, 2015).

One potential approach to reduce the emotional distress of siblings of children with cancer is a camp experience that draws on Positive Youth Development (PYD). PYD is a strengths-based approach intended to help youth grow and thrive by focusing on individual strengths instead of defining and treating deficits (Benson et al., 2004; Damon, 2004; Hamilton et al., 2004; Lerner, et al., 2005; Roth & Brooks-Gunn, 2016). It has served as a framework for many camp programs interested in facilitating healthy development and positive outcomes (American Camp Association, 2006; Arnold & Silliman, 2017; Bialeschki et al., 2007; Browne et al., 2011; Garst et al., 2016; Lerner et al., 2005; Povilaitis & Tamminen, 2017; Thurber et al., 2007).

An extensively studied PYD model that is widely used in traditional camp programs is the Community Action Framework for Youth Development (American Camp Association, 2006; Browne et al., 2011; Gambone & Connell, 2004; Walker et al., 2011). It identifies that supportive relationships with peers and adult mentors, skill building, leadership development, and safety are essential for healthy youth development (American Camp Association, 2006; Browne et al., 2011; Gambone & Connell, 2004; Walker et al., 2011). Camp programs and activities grounded in PYD (including the Community Action Framework) are considered standard practice and have been shown to contribute to decreased anxiety and stress (Bialeschki & Sibthorp, 2011; Hayhurst et al., 2015) and enhanced self-esteem (Benson et al., 2006; Bialeschki & Sibthorp, 2011; Garst et al., 2011a, b).

Although the existing research on peer support camps for siblings of children with cancer does not explicitly include PYD, it describes combining traditional camp activities and leadership development with peer support programmatic elements such as volunteer staff who have had similar life experiences, staff training focused on nonjudgmental support, and facilitated peer support sessions to address the unmet psychosocial needs of this unique population (Hancock, 2011; Packman et al., 2004, 2005; Sidhu et al., 2006). These camps include activities related to stress and coping, as well as facilitated discussions about childhood cancer and family situations (Hancock, 2011; Packman et al., 2004, 2005; Sidhu et al., 2006). However, research is limited on such peer support camps.

Specifically, three studies have assessed the impact of peer support camps on the distress of siblings of children with cancer (Packman et al., 2004, 2005; Sidhu et al., 2006). Two of the three studies were conducted at the same camp; pretest and three-month posttest measures demonstrated positive outcomes in anxiety, PTSS, self-esteem, and health-related quality of life (Packman et al., 2004, 2005). These studies only included baseline and three-month follow-up and did not assess the immediate impact of camp as measures were not administered when camp ended. As a result, it is hard to determine if the changes that occurred were due to camp or subsequent factors.

The third study was conducted at a peer support camp in Australia (Sidhu et al., 2006). It investigated the influence of a peer support camp for siblings of children with cancer on personality anxiety, social stress, somatization, and locus of control over three-time points, pretest, posttest, and three months after the camp experience. It, too, demonstrated positive mental health outcomes. However, the Australian study did not investigate the impact of camp on PTSS or self-esteem. The current study was designed to expand the existing literature by examining the immediate and long-term impact of a peer support camp for siblings of children with cancer on mitigating emotional distress.

Methods

This longitudinal quantitative study was part of a larger multimethod study designed to understand the influence of a peer support camp for siblings of children with cancer (Gregory, 2021). Specifically, the aim of this study was to determine whether there were changes in anxiety, PTSS, and self-esteem of participants after a weeklong peer support camp for siblings of children with cancer over three-time points: baseline (T1), posttest (T2), and three-month follow-up (T3).

Participants

This study was approved by the Clemson University Institutional Review Board prior to enrolling participants. The criteria for inclusion in this study required that the individuals were a sibling of a child with cancer, and between the ages of 7 and 16 years. Individuals were also required to meet camp eligibility requirements, which included being a sibling of a pediatric cancer patient on treatment or within 3 years of treatment or bereaved, and living in the same household at the time of diagnosis and treatment for cancer. The exclusion criterion for this study was an inability to speak and understand English. This study was open to all siblings who attended camp in its entirety, applying a convenience sampling approach. All parents of potential participants received a research study recruitment letter from the nonprofit organization sponsor as part of their 2019 electronic camp registration packet. They were asked to click on a hyperlink, indicating interest in enrolling their child(ren) in the research study, if they were interested in enrolling. The nonprofit organization provided the Principal Investigator's (PI) contact information for families who expressed interest in participating in the study. Parents/guardians were contacted by the PI via email prior to camp with a link to a Qualtrics survey containing additional information about the study, permission forms for their child(ren) to participate, and a brief demographic questionnaire. Parents/

guardians provided written documentation of informed consent; children 7 to 16 years provided verbal assent prior to participation.

Setting

The peer support camp is an annual seven-day residential program serving approximately 110 siblings of children with cancer, ages 7 to 16 years. It is located in the Mid-Atlantic region of the United States. The camp was established in 1992 based on an expressed need by affected families to support the unmet needs of siblings impacted by childhood cancer. It was created as a partnership between a nonprofit organization serving families impacted by childhood cancer and a regional 4-H camp accredited by the American Camp Association. 4-H is America's largest youth development organization and has an extensive research base associated with program delivery and positive outcomes (Garst et al., 2011a, 2011b; Wahle et al., 2019).

Leadership

The leadership team encompasses adults with a variety of skills and backgrounds including a pediatric nurse practitioner, recreational therapist, social worker, and primary school educator. Some of the counselors and members of the leadership team were former 4-H camp program staff and were instrumental in establishing the youth development camp model. The majority (approximately 90%) of the counselors and adult leaders are siblings of a child with cancer and former campers. The peer support camp intentionally matches campers and counselors (former campers who successfully completed relevant training) based on age, gender, and phase of the cancer journey. Counselors are assigned to cabin groups based on knowledge of the current status of the child with cancer and the counselor's own cancer experience. For example, bereaved campers will have at least one bereaved counselor assigned to their cabin. The counselor to camper ratio is approximately 1:3. This purposeful approach is consistent with the Community Action Framework, which recognizes supportive relationships with peers and adult mentors as instrumental in contributing to healthy development.

A structured Counselor in Training (CIT) leadership development program for 15- and 16-year-old siblings of children with cancer is incorporated into the camp organization. It is designed to promote leadership skills and collaborative experiences for helping others (Gillard et al., 2011; Richardson et al., 2017). It provides elements of PYD focused on skill building and leadership. It consists of a structured daily block class focused on decisionmaking, problem-solving skills, communication, and program development. CITs are assigned a "buddy cabin" where they work with counselor mentors, build relationships with younger campers, and have opportunities to lead activities. CITs also engage in a CIT-only after hours program consisting of social engagement, team building activities, and discussions related to their buddy cabin experiences.

Camp Daily Program

A typical day involves traditional camp activities (canoeing, swimming, arts and crafts, sports etc.). Each afternoon includes a structured facilitated chat time (FCT) for both bereaved and nonbereaved siblings by cabin group. FCT consists of age-appropriate team building activities and discussions grounded in peer support. FCTs provide the opportunity for siblings of children with cancer to safely talk about their experiences and feelings of sadness, anger, guilt, and fear (Franklin et al., 2018; Long et al., 2013, 2018; Samson et al., 2016). FCTs are led by cabin counselors and adult leaders who have shared life experiences and received additional training and support in techniques for recognizing and promoting positive experiences, validation of feelings, group facilitation, team building, and active listening skills.

FCTs for siblings and counselors who are bereaved (called B chat) are offered twice during the week. Attendance and participation in B chat are voluntary. Team building and discussions in B chat are led by counselors who are bereaved. The intent of FCTs and B chats is to offer a safe environment to share feelings and challenges related to the unique experiences associated with being a sibling or losing a sibling to cancer, to promote a sense of belonging, and foster healthy coping skills.

In addition, the daily schedule includes four larger heterogeneous team meetings and activities. Teams meet after lunch to create something to share at campfire each evening (e.g., communal art project, skit or team song based on the daily theme). Camp-wide evening programs include scavenger hunts, outdoor movies, relays, talent show, and dance. A nightly campfire incorporates a variety of traditions and routines including camp songs, rules of the campfire circle, skits, stories, and camper recognition. The week ends with a structured campfire and dock ceremony, which encompasses sharing favorite memories from the week and opportunities to recognize the unique bond siblings of children with cancer experience. The program includes sharing honors (recognizing peers and counselors who had a positive impact), reminding siblings that they are not alone and encouraging campers to take their experiences from camp home with them.

Data Collection Procedures

The PI and four Research Assistants (RAs) collected the data. The PI and two of the RAs were members of the

camp leadership team. The other two RAs were postgraduate adults interested in supporting the research project. They were not affiliated with the camp and only participated in data collection. Prior to the start of camp in July 2019, the PI identified study instruments, developed a standardized protocol for administering the measures in a camp setting on an iPad, and provided training to the RAs. Training included a detailed review of the instruments and web-based and live rehearsals of procedures for conducting the surveys. To mitigate the potential for bias, the PI and RAs instituted control measures, including a process of mind map bracketing and reflexive journaling in an effort to optimize the rigor of the study (Tufford & Newman, 2012).

On the first day of camp, participants were assigned to cabins. Each cabin group was invited to one of three designated locations to complete the baseline (T1) measures. All study-related instruments were completed via an electronic Qualtrics platform following the consent/assent process. Older participants (between the ages of 10 and 16 years) completed the measures independently. Instructions and questions were read to all participants between the ages of 7 and 9 years by a member of the research team. This method of administering research measures to young children is standard practice to enhance age-appropriate understanding (Fargas-Malet et al., 2010). Participants completed the same measures using the same process on the last day of camp (T2).

Follow-up (T3) surveys were completed three months later at an in-person October family weekend, via phone or email. Parents were asked to share the link with older siblings to complete the T3 survey independently. Most of the younger siblings completed the survey in person with the PI who, as a camp leader had an established rapport with the sibling, read the instructions and questions at the October family weekend. One younger sibling completed the follow-up survey via phone by responding to the questions read and entered by the PI. In an effort to minimize social desirability, the PI encouraged siblings to answer honestly and indicated that their answers would not influence their camp experience. In general, for all three-time points, older participants finished within 15 and 30 min and younger participants finished within 45 to 60 min.

Measures

Demographic Questionnaire. The demographic questionnaire was completed by a parent or guardian prior to the week of camp or onsite on the day of arrival. It provided supplemental information to the camp application and included: participant's current age and gender, the status of the sibling with cancer (i.e., on treatment, off treatment, deceased), and how many times the participant(s) had attended the peer support camp. Anxiety. The Revised Children's Manifest Anxiety Scale second edition short form (RCMAS-2) measures changes in anxiety (Reynolds & Richmond, 2008). The RCMAS-2 has been utilized extensively for assessing anxiety among children ages 6 to 19 years with different cultural and ethnic backgrounds (Wu et al., 2014). Results from prior studies indicate that it can serve as a way to track changes in anxiety over time or measure changes associated with an intervention (Reynolds & Richmond, 2008). The 10 item scale takes less than five minutes to complete. Responses are indicated with (0 =*no* or 1 = yes). Questions are designed to be understood easily by children with a second-grade reading level. The RCMAS-2 has strong internal consistency with a Cronbach's alpha of 0.90 (Wu et al., 2014). The raw scores were recoded using the RCMAS-2 Profile Form. Each raw score value was translated to a normalized T-score based on age. RCMAS-2 scores are normalized T-scores with a mean of 50 and a standard deviation of 10. Scores of 39 and lower indicate less problematic than most students, 40-60 = no more problematic than most students, 61-70 = moderately problematic, and 71 and higher = extremely problematic (Reynolds & Richmond, 2008).

PTS. The Child PTSD Symptoms Scale (CPSS-V) was used to assess PTSS in siblings based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) diagnostic criteria for PTS Disorder (Kazak et al., 2004). The scale has been used with children ages 8-18 years. There are two parts to the 27-item scale, and it takes approximately fifteen minutes to complete both parts. The first part consists of 20 items and evaluates the frequency and severity of symptoms that children and adolescents exposed to trauma or distressing events may have experienced over the past month using a five-point Likert scale (0 = not at all, 1 =a little, 2 = somewhat, 3 = a lot, and 4 = almostalways). The second part of the CPSS-V contains seven items and determines whether any of the PTSS have impacted function over the past month. Responses are indicated with (0 = no or 1 = ves). Although this measure was validated with children as young as eight and has an excellent internal consistency ($\alpha = .92$) (Foa et al., 2001), it is important to note that younger participants in this study may have difficulty recalling information over the past month. Scores for the first part of the CPSS-V range from 0–80 with higher scores indicating greater symptom severity. The second part of the scale ranges from zero to seven and higher scores indicate greater functional impairment (Kazak et al., 2004).

Self-Esteem. The Rosenberg Self-Esteem Scale (RSE) was implemented to assess global feelings of self-esteem (Rosenberg, 1965). The scale is validated for children older than 9 and consists of 10 items. The scale is

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constructed with a mix of positively and negatively phrased items. Children respond using a four point Likert scale (1 = *strongly agree*, 2 = *agree*, 3 = *disagree*, and 4 = *strongly disagree*) (Supple et al., 2013). It is a widely used measure and has excellent internal consistency ($\alpha = .92$) (Sinclair et al., 2010). The scale ranges from 0 to 30 and scores below fifteen suggest low self-esteem.

In order to evaluate self-esteem in younger children, the Children's Self-Image Scale (CSI) was developed with items from the RSE that were rephrased to be age appropriate for children ages 6 to 9 years (Weisman, 1974). Children respond to six questions with predefined options. Question 1 options include (0 = bad, 1 = both bad and good at the same time, 3 = good). The second, third, fourth, and fifth response options are (0 = a lot, 1 = a little, 2 = no). The final question responses are (0 = not happy at all, 1 = a little happy, 2 = pretty happy, and 3 = very happy). Psychometric information is not available for this scale, however; the Cronbach's alpha (α) for the scale in this study was 0.632. The scale ranges from 0 to 14 with higher scores indicating higher self-esteem.

Data Analysis

Quantitative data were analyzed using IBM Statistical Package for Social Sciences (SPSS) for windows, version 26 (IBM Corp., Armonk, N.Y., USA). Descriptive statistics were used to calculate the mean and standard deviation (parametric data) or median (for nonparametric data) as well as the frequency of the demographic variables. Siblings were clustered into two age groups, 7–9 years and 10–16 years. Preliminary assumption testing was conducted to check for normality, linearity, homogeneity of variance-covariance matrices, and multicollinearity with no serious violations noted for the RCMAS-2, RSE, and CSI.

A one-way repeated measure analysis of variance (RM ANOVA) was conducted for these measures to determine differences in scores over time. A partial eta squared effect size statistic was used to indicate the magnitude of the difference between means (Tabachnick & Fidell, 2012). The acceptable thresholds for effect size shown by partial eta squared values are small ($\eta^2 = 0.01$), medium ($\eta^2 = 0.06$), and large ($\eta^2 = 0.14$) effects (Tabachnick & Fidell, 2012). If the test indicated significant differences between time points, post hoc analysis with pairwise comparisons and paired-samples t-tests were conducted to determine which time points difference.

The CPSS-V part 1 and part 2 had nonnormally distributed data; therefore, the nonparametric Friedman test was used for these measures to compare the means across the three time points (T1, T2, T3). If Friedman's test indicated significant differences between time points, Wilcoxon Signed-Rank tests were conducted to determine which time points differed. The nonparametric Wilcoxon Signed-Rank Test Z scores were used from the comparison of each time point (T1:T2, T1:T3, and T2:T3) to establish effect size for PTSS. The Z score was divided by the square root of n to compute an effect size *r* statistic (Field, 2013). Only T1:T2 was used to calculate r and reported effects size for PTSS because it was statistically significant. The acceptable thresholds for effect size shown by *r* values are small (r = 0.10), medium (r = 0.30), and large (r = 0.50) effects (Tabachnick & Fidell, 2012). A Bonferroni correction was applied based on the number of measures included in the post hoc analysis (p = .05/3) resulting in a significance level set at p < .017.

Results

A total of 81 siblings of children with cancer participated in the study, representing 76% of the 107 siblings who attended the July 2019 peer support camp. Thirty-two of the original 81 siblings participated in the three-month follow-up, thus, only these data are presented here. Participants in the study ranged in age from 7 to 16 years, with an average age of 11.7. Over half of the campers were female (59%). Thirty-two percent of the participants attended other childhood cancer camps, including family camps and a sibling weekend camp. Most of the participants had previously attended this sibling camp at least once (see Table 1 for participant demographic information).

Comparison of Change Across Time

Scores from all three-time points were compared to examine change over time. In this study all measures demonstrated differences across the three-time points.

Table I. Participant Demographic Information.

Characteristics	(n = 32)
Age	M 11.7 (SD 2.93)
7–9	12
10+	20
Gender	n (%)
Male	13 (41%)
Female	19 (59%)
Sibling camps attended	n (%)
lst time attending camp	10 (31%)
2nd time attending camp	6 (19%)
3rd – 4th time attending camp	7 (22%)
5+ or more times attending camp	9 (28%)
Sibling's phase of cancer experience	
Newly diagnosed (within 6 months)	2 (6%)
Actively on treatment	6 (19%)
Posttreatment	20 (62.5%)
Bereaved	4 (12.5%)

Anxiety scores on the RCMAS-2 differed across the three-time points (p < .000) and the effect size was large ($\eta^2 = 0.42$). PTSS scores and PTSS impact on function scores on the CPSS-V differed across the three-time points. The PTSS score (p < .000) had a large effect size (r = 0.58) and the PTSS impact on function score (p = .014) demonstrated a large effect size (r = .50). Self-esteem scores for older children as measured by the RSE differed across time points (p < .000) and demonstrated a large effect size (r = .50). Self-esteem scores for older children as measured by the RSE differed across time points (p < .000) and demonstrated a large effect size ($\eta^2 = 0.67$). The analysis for self-esteem scores for younger children on the CSE changed across the three-time points (p = .006) and also revealed a large effect size ($\eta^2 = 0.64$). The repeated measures statistics are displayed in Table 2.

Post Hoc Comparison

Post hoc paired-samples t-tests using a Bonferroni correction showed a significant decrease in anxiety score between T1 and T2 (p < .000) and between T1 and T3 (p < .000) as measured by the RCMAS-2. A post hoc analysis using the Wilcoxon Signed-Rank test revealed a significant decrease in PTSS between T1 and T2 (p =.001) and between T1 and T3 (p = .011) as measured by the CPSS-V part 1. It also showed a significant decrease in PTSS impact on function between T1 and T2 (p =.005) and between T1 and T3 (p = .011) as measured by

 Table 2.
 Changes in Anxiety, PTSS, and Self-Esteem Across

 Three Time Points.
 Prints.

Measure	T I Mean ± SD or Median	T2 Mean± SD or Median	T3 Mean± SD or Median	þ value	Effect size (η ² or r)
Anxiety	51.69 <u>+</u> 9.19	45.34± 10.18	45.41 <u>+</u> 10.74	*<.000	0.42
^PTSS	15	11	14	*<.000	0.58
^PTSS Impact on Function	1.00	0.00	0.00	*.014	0.50
Self-Esteem (older, <i>n</i> = 20)	19.00 ± 5.88	23.16± 4.89	20.58 ± 4.93	*<.000	0.67
Self-Esteem (younger, <i>n</i> = 12)	11.00 ± 1.54	.67 <u>+</u> .23	12.33 <u>+</u> 0.89	*.006	0.64

Note: Mean \pm standard deviation is reported for parametric analysis while median is reported for nonparametric analysis. *Significant at the p < .017 value using a RM ANOVA.

Friedman's repeated measure test. TI = assessment at pretest, T2 = assessment at posttest, and T3 = assessment at three months after the camp experience. For nonparametric measures effect size is calculated at each time point but only the T1:T2 is reported in the table because it was statistically significant for PTSS and impact on function.

PostTraumatic Stress Symptoms (PTSS).

the CPSS-V part 2. Finally, post hoc paired samples t-tests revealed a significant increase in self-esteem scores for older participants (ages 10–16) between T1 and T2 (p < .000) as measured by the RSE as well as a significant increase between T1 and T3 (p = .005) as measured by the CSI (see Table 3 for the post hoc statistics).

Discussion

The purpose of this study was to determine changes in anxiety, PTSS, and self-esteem following a one-week peer support camp for siblings of children with cancer. Broadly, the improvements revealed in this study corroborate the findings of Sidhu et al. (2006), as the siblings who participated in a peer support camp demonstrated positive mental health outcomes. The large effect sizes revealed in the current study indicate that the peer support camp had a meaningful impact on anxiety, PTSS, and self-esteem. They also corroborated the findings of Packman et al. (2004) who reported significant improvements in the constructs of anxiety, self-esteem, and PTSS between precamp and three-month follow-up. However, results in this study indicate that PTSS and selfesteem in older siblings, although still above baseline, had trended down at the three-month follow-up. This finding suggests that the immediate benefits of the week-long camp experience for PTSS and self-esteem for older siblings in this sample may not be sustained over an extended period of time. This may indicate a need for additional peer support through camp weekends, social media connections, and/or special events throughout the year to reduce PTSS and improve self-esteem over time.

Participants in this study demonstrated a significant decrease in anxiety from T1 to T2 and a sustained decrease at T3. Research has shown that siblings of children with cancer often fall into clinical ranges of anxiety (Alderfer

Table 3	. Post	: Hoc	Com	ıparison.
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Measure	TI:T2	TI:T3	T2:T3
Anxiety	*t = 4.433 (p	*t = 4.075 (p	t =048
	<.000)	<.000)	($p = .962$)
PTSS	$^{*}Z = -3.289$	X = -2.549	Z = 1.44 (p)
	(p = .001)	(p = .011)	= .150)
PTSS impact on	*Z = -2.837	*Z = -2.490	Z =607
function	(p = .005)	(p = .013)	(p = 544)
Self-esteem (older $n = 20$)	t = -4.824	t = -1.088	t = 1.947
	(p < .000)	($p = .290$)	($p = .066$)
Self-esteem (younger $n = 12$)	t = -1.232	t = -3.546	t = -2.00
	($p = .244$)	(p = .005)	($p = .071$)

Note: Post hoc analysis using paired-samples t-tests (t) and Wilcoxon's Signed-Rank test (Z) as appropriate. TI assessment at pretest, T2 assessment at posttest, and T3 assessment at three months after the camp experience.

*Significant at the p < .017 level using a post hoc Bonferroni correction.

et al., 2020; Barrera et al., 2002; Neville et al., 2016). An interesting and contradictory finding in this study with extant work was that at all three-time points sibling mean scores were within the 40-60 range, which has been described as no more problematic than for most students (Reynolds & Richmond, 2008). A possible explanation for these different results is that approximately 69% of the participants in this study had experienced the peer support camp more than once. In addition, 32% of the sample participated in other childhood cancer family programs and a sibling weekend camp. The repeated experience and support provided by counselors and peers who are also siblings of children with cancer may have a positive influence on anxiety over time. Another possible explanation is that 63% of participants have siblings in the posttreatment phase of the cancer journey, which may have contributed to lower anxiety levels overall and the scores plateauing at T3.

The PTSS and impact on function scores demonstrated that participants had a moderate level of PTSS before arriving at camp. This result is consistent with the existing literature indicating that a substantial number of siblings experience PTSS, especially at the time of diagnosis and in the early stages of cancer treatment (Alderfer et al., 2010; Gerhardt et al., 2015; Hancock, 2011; Kaplan et al., 2013; Long et al., 2018; Tasker & Stonebridge, 2016; Yu & Bang, 2015). Notable is the clinically significant decrease in PTSS and impacts on function from moderate to mild immediately following the camp experience. The data showed that PTSS increased between T2 and T3 indicating a trend back towards baseline. However, the PTSS impact on function score was sustained. This result suggests that siblings in this sample showed an increase in PTSS over time after the camp experience, although the increase in PTSS did not negatively impact their function. This finding suggests that siblings may benefit from ongoing peer support and continued reinforcement or development of coping skills following the week-long camp experience. These findings also support the Packman et al. (2004) findings that indicated that siblings of children with cancer are at risk of higher levels of PTSS and that the peer support camp had a positive impact on PTSS.

Similar to the results on anxiety in this study, participants demonstrated high self-esteem scores across all three-time points, indicating positive self-esteem at T1 and a notable increase for older participants at T2 and for younger participants at T3. The significant improvement in self-esteem in younger participants occurring between T1 and T3 may be related to developmental processing. Perhaps younger participants needed additional time to integrate positive self-esteem outcomes from the camp experience over time (Butler & Gasson, 2005; Mruk, 2013). Conversely, the significant increase in scores immediately following camp preceding a downward trend back to baseline for older participants at T3 suggests they were not able to sustain the statistically significant improvement in scores related to self-esteem over time. Similar to the results associated with PTSS revealing a downward trend at T3, this result suggests that older siblings may need additional peer support post-camp. It is important to note that the overall self-esteem scores for this sample were high at baseline demonstrating positive self-esteem at the start of camp. The possible explanations for anxiety may apply here; repeated experiences and support in this and other cancer-related support camps may have a positive influence on self-esteem over time.

The results of this study are consistent with the Sidhu et al. (2006) peer support camp study, which indicated that although positive changes occurred, the siblings' selfesteem scores were high prior to engaging in the peer support camp. In contrast, another study reported that siblings demonstrated poor self-esteem and attributed it to the focus of attention being on the sick child instead of the "well" sibling (Carr-Gregg & White, 1987). The discrepancy may indicate that siblings of children with cancer demonstrate higher levels of self-esteem if they participate in peer support programs.

The specific findings in this study indicate that participants demonstrated decreased anxiety and PTSS and increased self-esteem following involvement in a peer support camp for siblings of children with cancer. These findings are consistent with the current literature on peer support camps for siblings of children with cancer (Hancock, 2011; Packman et al., 2004, 2005; Sidhu et al., 2006). The current study extends the existing research by generating new data that contribute to understanding outcomes immediately following the camp experience in addition to three months after (Hancock, 2011; Packman et al., 2004; Sidhu et al., 2006), and adds to the limited research on appropriate support services for siblings of children with cancer to include outcomes associated with a peer support camp.

Limitations

As with all studies, there are limitations that should be noted. First, a major limitation of this study is the small sample size (n = 32). The results of the study cannot be generalized beyond the siblings who attended this camp. In addition, the sample included only four bereaved siblings, which prevented the opportunity to compare differences between bereaved and nonbereaved participants. A multiple camp study would increase the sample size and strengthen the ability to generalize results and explore differences between subgroups including bereaved and nonbereaved siblings. Sibling retention in follow-up measures may be improved in future studies by coordinating inperson data collection with sibling programs. A second limitation is the lack of a control group creating a potential threat to the internal validity of these findings. The absence of a control group limits the ability to conclude that outcomes were based on the camp experience and not influenced by other factors such as external supports, history and maturation. Although there are ethical considerations that confront the ability to establish a control group within a camp setting, it may be possible to create a control group by surveying siblings of newly diagnosed families prior to attending camp or siblings who choose not to attend camp.

Third, due to the established rapport with the PI and two of the RAs, it is possible that younger participants provided socially desirable responses during their 1:1 support to complete the measures. The PI and RAs attempted to mitigate this by encouraging participants to answer honestly and reminding them that their answers would not influence their camp experience. Fourth, there is a chance that a parent/guardian may have influenced siblings who completed their responses at home at T3 despite instructions to allow siblings to complete the measures independently. Fifth, it is also possible the T3 responses had a maturation effect based on the impact of participant experiences (e.g., 32% engaged in other cancer-related family camp programs) and developmental growth over time. Finally, participants completed the before and after camp measures in the camp setting upon arrival and on the last day. Although efforts were made to minimize the disruption to camp engagement, it is possible that some of the respondents were distracted by the activity around them resulting in decreased accuracy in their responses.

Implications for Practice and Future Research

Peer support camps for siblings of children with cancer present a promising approach to reduce anxiety and PTSS, and to enhance self-esteem. These findings suggest that incorporating traditional camp activities and PYD characteristics such as supportive relationships with peers and adult mentors, skill building, leadership development, and safety with facilitated peer support from others who have shared life experiences fosters decreased anxiety and PTSS and increased self-esteem. Specific facilitated peer support includes intentional cabin assignments including matching siblings with counselors who have shared life experiences, staff training (active listening, validation of feelings, group facilitation, team building and promoting coping skills, etc.), and structured peer support activities. Pediatric oncology professionals and oncology camp leaders should consider ways to strengthen such camps and increase their availability. These could include efforts to improve and standardize staff training, program design, program evaluation, and advocacy specific to peer support camps for siblings of children with cancer. Philanthropic and nonprofit organizations can use this and related studies to justify resource investments and fundraising efforts.

Although this study complemented two prior studies identifying positive outcomes related to peer support camps for siblings of children with cancer and contributed to the body of knowledge, there is more to be learned. In particular, future studies on the long-term impact of a peer support camp are needed. Research should explore the changes in scores over a longer period of time than the three months of this study. Additional research should explore potential differences in outcomes between bereaved and nonbereaved siblings as well as phase of the cancer journey (newly diagnosed, currently receiving treatment, posttreatment, bereaved), differences between first time and repeat campers, and differences based on age. It could demonstrate whether the positive outcomes would be sustained, plateau, or decrease over time. A larger multisite study would support a larger sample size and mitigate some of the limitations of this study. Future research should also investigate specific program components of peer support camps for siblings of children with cancer to better understand their relationship to positive outcomes and establish best practices. In addition, future studies should explore the long-term impact of childhood cancer on siblings who attended a peer support camp including how it has influenced their transition to adulthood.

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