ABSTRACT. This study used both quantitative and qualitative methodologies to assess the pediatric health-related quality of life (HRQOL) in siblings (n = 77) of cancer patients attending summer camp. On quantitative measures [Pediatric Quality of Life Inventory (PedsQL) parent and child versions], siblings reported statistically significant improvements in HRQOL from pre- to post-camp. The parent sample, as a whole, did not report a statistically significant improvement in the siblings' HRQOL; however, statistically significant improvements were found when the analysis controlled for the responses of bereaved parents.

On the qualitative measures (Sibling Qualitative Interview and Camp
Okizu Satisfaction Surveys), both children and parents described the positive impact of camp. Using grounded theory, we identified the major themes and found that the positive emotional and social experiences captured by the quotes were paralleled in the quantitative findings of improved HRQOL in psychosocial domains on the PedsQL. These findings suggest the beneficial effects of camp as a psychological intervention and illustrate the value of integrating quantitative and qualitative methodological approaches in research. 

**KEYWORDS.** Siblings, pediatrics, cancer, quality of life

**REVIEW OF LITERATURE**

**Siblings of Pediatric Cancer Patients**

When a child is diagnosed with cancer, the entire family system is confronted with severe distress (Houtzager, Grootenhuis, & Last, 1999; Kazak et al., 1999). Several studies have documented increased psychological risk among healthy siblings of pediatric cancer patients (Sahler et al., 1994; Sahler & Carpenter, 1989). In a study of children with cancer, investigators found that siblings’ emotional needs were met at a significantly lower level than those of other family members (Spinetta & Deasy-Spinetta, 1981).

Cancer in a child upsets the normal family patterns and activities in major ways, and siblings are significantly impacted. They are often asked to assume greater family responsibility, but get less attention and reward from their parents (Powell & Ogle, 1985). Siblings often become jealous and angry about the extra attention lavished on the cancer patient, but then often feel guilty for having these negative feelings (Packman et al., 1997). These emotions and feelings are often internalized, and translate as lowered self-esteem for these children. This is expressed in a variety of ways, including discipline problems, poor school performance, and sometimes health-risk behaviors (Houtzager et al., 1999; Packman et al., 1997). In an examination of donor and non-donor siblings of pediatric bone marrow transplant patients, researchers found anxiety, social withdrawal, and moderate to severe levels of post-traumatic stress disorder in close to one third of the sibling sample (Packman et al., 1997). It has also been noted that siblings of cancer patients
could develop a range of emotional and somatic symptoms unless an intervention that focused on the siblings’ adjustment to the family crisis was implemented (Bearison & Mulhern, 1994).

A promising intervention for siblings of pediatric cancer patients is summer camp. An earlier study (Carpenter, Sahler, & Davis, 1990; Sahler & Carpenter, 1989) evaluating a camping program for siblings found that the camp experience improved siblings’ overall mood states. In a related vein, Heiney, Goon-Johnson, Ettinger, & Ettinger’s study (1990) of the effects of a support group for siblings of pediatric oncology patients reported siblings demonstrated ventilation of feelings in social interaction with peers, and expressing feelings and talking to others appeared to be an important coping strategy. A study by Cohen, Friedrich, Jaworski, Copeland, and Pendergrass (1994) determined variables related to good and poor adjustment of siblings, within a coping model. More social support was one of the factors for fewer adjustment problems. The social support received can be a significant intervening resource in the adjustment of siblings of children with cancer (Houtzager et al., 1999).

We recently completed a study that empirically examined whether participation in Camp Okizu’s SIBS Camp was associated with improvement in psychosocial functioning. The study design consisted of a pre- and 3-month post-camp intervention evaluation. Statistically significant differences emerged on all sibling objective self-report measures. Specifically, the total post-traumatic stress disorder severity scores and the total anxiety scores were significantly reduced; and, there was significant improvement in quality of life and self-esteem scores.

The present article represents an effort to advance our understanding of quality of life in siblings of pediatric cancer patients. We used quantitative and qualitative methodologies to evaluate quality of life. First, we report on the siblings’ quality of life as reported by siblings’ and parents’ responses to the quantitative PedsQL. Next, we present the siblings’ and parents’ views, concerns, and perceptions in their own words. The qualitative measures were included to give the participants the opportunity to express feelings and thoughts about the camp experience that were not captured by the quantitative measures. These data are organized according to the major themes that emerged from siblings’ and parents’ responses to open-ended questions.

**Description of Camp Okizu’s Sibs Program**

The SIBS (Special and Important Brothers and Sisters) Camp, run by the Okizu Foundation for the siblings of pediatric cancer patients, was
instituted in 1985. It is designed to help with the psychosocial and behavioral issues faced by the siblings of children with cancer. Camp Okizu is designed to provide siblings with peer support, to validate their feelings as normal in the context of serious illness in the family, and to bolster their self-confidence and esteem. On the second day of each session, the siblings meet for a facilitated discussion of their family situations, and to share tips on coping. This establishes a bond of understanding that continues to grow throughout the week. Additionally, the camp is structured to provide consistent positive feedback from caring adult counselors. There are opportunities to acquire new skills or improve performance of traditional camping skills such as archery, swimming, boating, sports, and arts and crafts. Counselors are specifically trained in techniques for recognition and reinforcement of positive behaviors and for ensuring that all campers have the experience of succeeding at something during the week. Older campers also participate in traditional trust activities, team initiatives, and high ropes course elements to allow them to experience success in the context of strong peer support and adult mentoring. Siblings also have the opportunity to attend a bereaved discussion group.

Assessment of Quality of Life

The terms “quality of life” and more specifically, “health related quality of life” (HRQOL) refer to the physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person’s experiences, beliefs, expectations, and perceptions (Testa & Simonson, 1996). HRQOL has received ever-increasing recognition as an important health outcome in clinical trials and health services research and evaluation (Varni, Seid, & Kurtin, 1999). Pediatric HRQOL, a relatively new assessment tool, has been a viable source of important information aiding clinicians in their understanding of the impact of childhood chronic illness on overall life experience (Landgraf & Abetz, 1998). HRQOL issues often relate to the everyday functioning of children including their physical functioning, emotional and social well-being, behavior, school performance, self-esteem, and family life (Landgraf & Abetz, 1998).

Although some research has been conducted concerning the HRQOL of pediatric cancer patients (Barrera et al., 2003; Goodwin, Boggs, & Graham-Pole, 1994), few studies have examined the HRQOL of siblings of pediatric cancer patients. Nonetheless, the domains that com-
prise the HRQOL construct (physical functioning, emotional, social, and school) have been examined in siblings. For example, studies have suggested that siblings of cancer patients present with somatic complaints (Walker, 1990; Zeltzer et al., 1996), school problems (Fife, Norton, & Groom, 1987; Packman et al., 1997), social problems (Cohen et al., 1994; Sahler et al., 1994) and emotional reactions (Packman et al., 1997; Spinetta & Deasy-Spinetta, 1981).

Pediatric HRQOL instruments must be multidimensional, sensitive to cognitive development, and integrate both child self-report and parent proxy-report to reflect their potentially unique perspectives. Wallander and Thompson (1995) suggest that child adjustment needs to be assessed through both the child and the parents in order to differentiate child adjustment from parent adjustment and parent perception of the child’s behavior. Thus, the impact of family functioning is a crucial aspect in understanding a child’s HRQOL. According to Varni, Burwinkle, Katz, Meeske, & Dickinson (2002), imperfect concordance between child and parent proxy report has been documented in the HRQOL assessment of healthy children (Achenbach, McConaughy & Howell, 1987) and children with chronic health conditions (Czyzewski, Mariotto, Bartholomew, LeCompte, & Sockrider, 1994; Guyatt, Juniper, Griffith, Feeny, & Ferry, 1997).

The PedsQL 4.0 Generic Core Scales were designed to measure the physical, mental, and social health dimensions delineated by the World Health Organization, (WHO, 1948) as well as school functioning. The PedsQL is a modular approach to measuring pediatric HRQOL, integrating the merits of generic and disease-specific approaches (Sprangers, Cull, Bjordal, Groenvold, & Aaronson, 1993; Varni, Seid, & Rode, 1999). In Varni et al.’s view (2002), disease-specific modules may enhance measurement sensitivity for health domains germane to a particular chronic health condition. A generic HRQOL measurement instrument enables comparisons across pediatric populations and with healthy population norms (Varni et al., 2002).

In order to capture the complete range of ways siblings’ HRQOL may be affected by their brother or sister’s cancer, we integrated quantitative (PedsQL) and qualitative methodologies (Steckler, McLeroy, Goodman, Bird, & McCormick, 1992). The objective of this approach to research is to utilize methods that will complement each other and enhance the relevance of findings (Murray, 1999). In our view, psychosocial interventions such as camp for siblings of cancer, are complex
phenomena that require “the application of multiple methodologies in order to properly understand or evaluate them” (Steckler et al., 1992, p. 4).

METHODS

Participants and Procedure

Participants included siblings ages 6-17 about to attend Camp Okizu for one of the 2001 summer sessions. Seventy-seven participants completed both pre- and post-camp measures. Because this was a convenience sample, there was no available comparison group and a randomized control design was not feasible. The 23 participants with missing post-camp data can be grouped into five categories: lost to follow-up ($n = 3$); could not be interviewed due to weather conditions or geographic logistical problems ($n = 6$); siblings did not attend camp ($n = 3$); scheduling difficulties or multiple cancellations by family ($n = 10$); and sibling or parent declined to participate ($n = 1$).

As shown in Table 1, the average camper was 11.7 years old (range 6-17 years) and in the sixth grade (range 1 to 11). There were 42 females (54.5%) and 35 males (45.5%). The sample was 75.3% Caucasian ($n = 58$), 14.3% Latino ($n = 11$), 3.9% African American ($n = 3$), 1.3% Asian ($n = 1$), and 5.2% other ($n = 4$). Socio-economic indicators, family income, and both maternal and paternal education, are also detailed, indicating a middle income majority. In 18 of the 77 families, the child with cancer had died by the end of the second data collection.

Families with siblings were recruited from the Camp Okizu Registry according to inclusion criteria: currently enrolled in camp for one of the 2001 one-week sessions; between the ages of 6-17 years; English-speaking; and, ability to understand and respond to the study instruments. If there were more than one sibling per family eligible to participate, we interviewed the sibling closest in age to the patient to minimize developmental differences.

Recruitment was conducted through procedures approved by the Administrative Panel on Human Subjects in non-Medical Research (Stanford University). A member of the research team phoned and explained the purpose of the study to parents. Approximately 280 eligible registered campers were contacted, 180 declined to participate or were non-responsive. There were no data available to allow us to differentiate the participants from non-participants. If parents agreed to
participate, informed written consent was obtained along with informed written assent from children at the time of data collection. The research team administered the study instruments to families in their homes, starting 4-8 weeks before camp for the pre-camp phase, and 12-16 weeks after camp. The Sibling Qualitative Interview was used in the post-camp phase with the children. The Camp Okizu Satisfaction Surveys (children and parents) were mailed to families following camp and were returned to the researchers.

<table>
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<th>Variable</th>
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<th>Range/n</th>
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</thead>
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<td>6-17</td>
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<tr>
<td>Grade:</td>
<td>6th</td>
<td>n/a</td>
<td>1-11</td>
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<td></td>
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<tr>
<td>Male:</td>
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</tr>
<tr>
<td>Female:</td>
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<td>n = 42</td>
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</tr>
<tr>
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</tr>
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<td></td>
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</tr>
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<td>11</td>
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<td>3</td>
</tr>
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<td>1</td>
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<td>Mother’s Education:</td>
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<td></td>
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<td>1</td>
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<td>13</td>
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<td>4 or more yrs of graduate school:</td>
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<td>1</td>
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<tr>
<td>Father’s Education:</td>
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Quantitative Outcome Measures

Pediatric Quality of Life Inventory (PedsQL). The PedsQL consists of brief, generic core scales suitable for use with pediatric populations with acute and chronic illness (Varni, Seid, & Kurtin, 1999). The PedsQL consists of developmentally appropriate forms for children ages 2-18, and the parent proxy-report is also used for children ages 2-18 (Table 2). The PedsQL is a paper and pencil form which consists of 23 items, 4 scales, and 3 summary scores. The four scales are physical, emotional, social, and school functioning. The summary scores include total scale score, physical health, and psychosocial health. The PedsQL generic scales are designed to enable comparisons across patient populations (Varni, Seid, & Kurtin, 1999).

Internal consistency reliability was established, with alphas for both child and parent proxy-reports approaching .90. Validity was demonstrated through known group comparisons, and correlations with other measures of disease burden (Varni, Seid, & Kurtin, 1999). The PedsQL has high internal consistency with alphas for the full 23-item scale.

TABLE 2. Child and Parent Means and Standard Deviations on the PedsQL Inventory

<table>
<thead>
<tr>
<th>PedsQL–Child Report (N = 77)</th>
<th>Pre-camp Mean</th>
<th>SD</th>
<th>Post-camp Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life Total</td>
<td>77.18</td>
<td>11.98</td>
<td>80.98</td>
<td>11.39</td>
</tr>
<tr>
<td>Physical Health</td>
<td>83.64</td>
<td>11.33</td>
<td>86.04</td>
<td>10.62</td>
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<tr>
<td>Emotional Functioning</td>
<td>71.49</td>
<td>17.64</td>
<td>76.17</td>
<td>16.93</td>
</tr>
<tr>
<td>Social Functioning</td>
<td>80.45</td>
<td>18.09</td>
<td>84.29</td>
<td>15.53</td>
</tr>
<tr>
<td>School Functioning</td>
<td>73.12</td>
<td>16.62</td>
<td>76.75</td>
<td>15.60</td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>75.02</td>
<td>13.46</td>
<td>79.31</td>
<td>12.66</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PedsQL–Parent Proxy Report (N = 74)</th>
<th>Pre-camp Mean</th>
<th>SD</th>
<th>Post-camp Mean</th>
<th>SD</th>
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</thead>
<tbody>
<tr>
<td>Quality of Life Total</td>
<td>78.93</td>
<td>12.41</td>
<td>80.33</td>
<td>11.74</td>
</tr>
<tr>
<td>Physical Health</td>
<td>84.73</td>
<td>14.69</td>
<td>87.84</td>
<td>12.81</td>
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<tr>
<td>Emotional Functioning</td>
<td>72.67</td>
<td>15.03</td>
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<td>15.02</td>
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<td>82.43</td>
<td>18.60</td>
<td>82.63</td>
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<td>77.03</td>
<td>18.13</td>
<td>76.15</td>
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<td>Psychosocial Health</td>
<td>77.21</td>
<td>13.35</td>
<td>78.11</td>
<td>13.72</td>
</tr>
</tbody>
</table>
approaching 90 (Varni, Seid, Knight, Uzark, & Azer, 2001). Items are reverse scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) so that higher scores indicate better HRQOL (Varni et al. 2002).

**Qualitative Outcome Measures**

The qualitative measures included the Sibling Qualitative Interview, and the Camp Okizu Satisfaction Surveys (children and parents). The interview included 15 forced-choice and open-ended questions and were used to quantify and explore siblings’ subjective responses to camp. The questions were developed based on a review of the literature on siblings of children with cancer as well as the literature on summer camps for pediatric populations (Briery & Rabian, 1999; Murray, 1999). The Satisfaction Surveys consisted of open-ended questions to siblings and parents including questions about the siblings’ experience at camp and any changes in the siblings’ behavior or attitude following camp.

**RESULTS**

**Quantitative Analyses: PedsQL**

*The PedsQL–Child Report.* For the PedsQL total score, the mean pretest sum score was 77.18 (SD = 11.98), and the mean posttest score was 80.98 (SD = 11.39). The PedsQL total score decreased significantly pre- to post-camp (t(76) = 3.454, p = .001), indicating an improvement in HRQOL. In addition, the 5 domain scores were analyzed. The mean score for the physical health domain at pre-camp was 83.64 (SD = 11.33); and at post-camp was 86.04 (SD = 10.62). The mean score for the emotional health domain at pre-camp was 71.49 (SD = 17.64); and at post-camp was 76.17 (SD = 16.93). The mean score for the social functioning domain at pre-camp was 80.45 (SD = 18.09); and at post-camp was 84.29 (SD = 15.53). The mean score for the school functioning domain at pre-camp was 76.17 (SD = 16.93). The mean score for the psychosocial health domain (emotional health, social and school functioning) at pre-camp was 75.02 (SD = 13.46); and at post-camp was 79.31 (SD = 12.66). The t test results indicate that four of the domains—emotional, social, school, and psychosocial—contained statistically significant differences at pre- to post-camp.
It is noteworthy that in our sample there was marked improvement in the siblings’ HRQOL following camp. When compared to both the healthy and oncology sample means in Varni et al. (2002), the pre-camp mean total PedsQL scores of siblings (77.18) were approximately half-way between the healthy (83.00) and oncology (72.20) sample means. The post-camp mean total PedsQL scores of siblings (80.98) were closer to the healthy sample mean (83.00) than the oncology sample mean (72.20).

The PedsQL—Parent Proxy Report

Entire Parent Sample (Bereaved and Nonbereaved). For the entire parent sample (n = 77), the mean pretest sum score was 78.93.18 (SD = 12.41), and the mean posttest score was 80.33 (SD = 11.74). There were no statistically significant differences on the PedsQL total score pre- to post-camp. As reported by all of the parents, there was no significant improvement in the siblings’ HRQOL following camp (PedsQL). However, when compared to both the healthy and oncology sample means in Varni et al. (2002), the pre-camp mean total PedsQL parent proxy scores (79.83) and the post-camp mean total PedsQL parent proxy scores (80.33) were both closer to the healthy sample mean (87.61) than the oncology sample mean (69.70).

Bereaved Parent Subsample Compared with Nonbereaved Parent Subsample

Since we found a significant improvement in HRQOL from the child reports and not from the parents, we decided to look at whether bereaved status was playing a role in the difference between the child and parent reporting. We found that bereaved status did not affect the child reports, however, there was a consistent pattern of the bereaved parents reporting the child’s HRQOL as less positively impacted by camp than the nonbereaved parents. Thus, we conducted additional analyses comparing the bereaved with the nonbereaved parents to further explore these findings.

For the bereaved parents (n = 18) the mean pretest total score was 80.12 (SD = 13.14), and the mean posttest score was 77.64 (SD = 13.06). This was not statistically significant and was actually a change in the negative or worsening direction, albeit not very large and not clinically significant. Also, none of the subscales showed statistically or clinically significant differences pre-to post camp. For the nonbereaved
parents \((n = 59)\), the mean pretest total score was 78.38 \((SD = 12.30)\), and the mean posttest score was 81.16 \((SD = 11.44)\). While this difference was also not statistically significant, three of the subscales did show both statistically and clinically significant differences pre- to post-camp. The mean score for the physical health domain at pre-camp was 84.00 \((SD = 14.68)\); and at post-camp was 89.62 \((SD = 12.55)\). This was statistically and clinically significant \(t(54) = -2.55, p = .01\). The mean score for the emotional health domain at pre-camp was 72.04 \((SD = 13.62)\); and at post-camp was 76.67 \((SD = 14.27)\). This was statistically and clinically significant \(t(53) = -2.27, p = .03\). The mean score for the social functioning domain at pre-camp was 76.91 \((SD = 26.39)\); and at post-camp was 84.07 \((SD = 19.81)\). This trended towards statistical significance and was clinically significant \(t(53) = -1.79, p = .08\).

When the analysis controlled for the responses of the bereaved parents, there were statistically significant differences on the physical and emotional domains and a trend towards significance on the social domain. We compared our sample means to both the healthy and oncology sample means in Varni et al. (2002). The physical health pre-camp mean of nonbereaved parents (84.00) was closer to the healthy sample mean (89.32) than the oncology sample mean (68.75), and moved into the healthy range post-camp (89.26). The emotional health pre-camp (72.04) was approximately halfway between the healthy (82.64) and oncology (67.53) sample means and post-camp was closer to the healthy sample (76.67). The social functioning (76.91) was almost at the oncology group level pre-camp (75.64) but moved to halfway between the oncology (75.64) and healthy samples post-camp (84.07). Thus, the nonbereaved parents reported significant improvement in three domains of the siblings’ HRQOL following camp.

**Qualitative Analyses: Core Themes**

To complement the quantitative PedsQL results and provide a more in-depth meaning of the effects of camp on HRQOL, we conducted a qualitative analysis of siblings’ and parents’ comments. Following the guidelines of grounded theory (Glaser & Strauss, 1967; Patton, 1990), we proceeded in an inductive fashion from the data to discover major themes that were common to the siblings’ and parents’ experiences. The second author entered all of the comments verbatim into the computer, read the comments and subdivided them into themes. The fourth author independently read the comments. The two raters discussed the differ-
ences until they reached agreement, refined the classification of themes and reduced the data based on the frequency and content of statements. As a reliability check, the first and third authors reviewed the interviews and surveys independently to identify common themes.

As noted above, the literature on siblings of pediatric cancer patients suggests that support groups that promote openness and emotional expression, such as camp, may be helpful coping resources for siblings and improve psychosocial adjustment and HRQOL (Cohen, 1994; Heiney et al., 1990; Houtzager et al., 1999). As we reviewed the responses of siblings and parents to questions about the camp experience, we noted that their descriptions resembled Yalom’s (1995) therapeutic factors in group therapy. According to Yalom, interactional group therapy exerts its primary therapeutic power through 11 therapeutic factors. These therapeutic factors, considered to be prerequisite to growth and change are: (1) Instillation of Hope; (2) Universality; (3) Imparting information; (4) Altruism; (5) The corrective recapitulation of the primary family group (6) Development of socializing techniques; (7) Imitative behavior; (8); Interpersonal learning; (9) Group cohesiveness; (10) Catharsis; and (11) Existential factors.

Using Yalom’s framework, we describe the six core psychosocial themes that emerged from the qualitative questionnaires. It is noteworthy that the salient qualitative themes reflect especially the siblings’ positive emotional and social experiences at camp and parallel our findings on the quantitative PedsQL (Varni, Seid, & Kurtin, 1999) for children and nonbereaved parents.

**Theme 1: Group cohesiveness** refers to a sense of trust and belonging as well as the sense of being supported by the group. The quotes that illustrate this theme closely parallel the quality of life domain of social functioning; **Theme 2: Development of socializing techniques** refers to social learning, increase in social skills, increased peer relationships and meeting new people. The illustrative child and parent quotes parallel the quality of life domain of social functioning; **Theme 3: Universality** refers to shared personal experiences and the sense that “others understand me” and “I am not unique.” The illustrative quotes supporting this theme closely parallel the quality of life domains of social and emotional functioning; **Theme 4: Instillation of hope** refers to a sense of optimism often resulting from seeing improvement in others as well as growth, support, and confidence. These quotes closely parallel the quality of life domain of emotional functioning; **Theme 5: Interpersonal
learning involves receiving feedback from others and learning successful ways of relating. These quotes closely parallel the quality of life domains of psychosocial functioning (social, emotional, school); Theme 6: Catharsis refers to emotional expression, that is, the relieving of emotions by expressing one’s feelings. The quotes illustrating this theme closely parallel the quality of life domain emotional functioning (see Figure 1).

**CORE THEMES: SIBLING INTERVIEW AND SURVEYS**

**Theme 1: Group Cohesiveness**

The children poignantly expressed feeling a sense of trust and belonging as well as the sense of being supported by the group. When asked “what was the thing you liked best about siblings camp,” four of the siblings’ remarked:

Overwhelming love, acceptance, and understanding. [age 16]

The thing best about sibling camp was the dance and getting to tell people about my brother and they know how I feel. [age 12]

It just makes me feel more open and like everyone understands. [age 13]

The fact that you can be anyone you want to be. Feel Free [age 15]
Theme 2: Development of Socializing Techniques

Three siblings commented on how they especially enjoyed meeting new people and peers.

Meeting people that knew exactly what you went through . . . talking to friends, great counselors, activities (games, sports). [age 15]

Each year it helps a little more and I meet different people who have different stories. It makes me feel better to hear their stories. [age 10]

What I liked best was getting to know others in the similar situation. Talking about my feelings with someone who understands. [age 15]

Theme 3: Universality

When asked “Did Camp Okizu help you feel better about the experience of cancer in your family,” many siblings expressed the idea that they realized they were not alone, and that others are going through similar experiences. As noted in the quotes below, there was a sense that “they are not unique” or “others understand the experience:

It made me realize I wasn’t the only one feeling the way I did. It helps me be able to face and understand the experience along with helping me get past my negative feelings towards my brother and the experience. [age 15]

I know there’s a lot of other people who have gone through it so I’m not alone. [age 11]

Yes, being able to talk with others who had the same experience as opposed to talking to others who pretend they understand. [age 14]

Theme 4: Instillation of Hope

A sense of optimism resulting from seeing improvement in others as well as growth, support, and confidence are reflected in the following comments:
It just shows that good things always come from bad things. [age 11]

Each year it helps a little more and I meet different people who have different stories. It makes me feel better to hear their stories. [age 10]

Yes, [Camp] cheers you up–makes you feel a happier person because all the kids have the same problems. [age 13]

**Theme 5: Interpersonal Learning**

This involves receiving feedback from others and learning successful ways of relating. Some of the siblings who participated in the bereaved discussion group had the following remarks:

- It was pretty difficult, but in the end it was good. I’m happy to know I have friends to talk to. [age 15]

- Camp Okizu made me realize I wasn’t the only one feeling the way I did. It helps me be able to face and understand the experience along with helping me get past my negative feelings towards my brother and the experience. [age 15]

**Theme 6: Catharsis**

Catharsis refers to the relieving of emotions by expressing one’s feelings. This experience was mentioned by many siblings:

- My overall experience at camp was so enlightening. It feels like a lot of sadness and anger that builds up through the school year about what I went through with my sister I can let out at camp. [age 15]

- I liked [Camp] because I get to be around kids who have had a sibling die and express my feelings. [age 12]

- My overall experience at Camp was wonderful! Everyone was so kind and my cabin group became my family. I was able to face many of my fears this year, this was one of my best years ever! [age 15]
You are with other kids who can relate and talk with you. Gets the heavy feeling off your chest. [age 14]

When all of us had a discussion, I got to know what happened to everyone and everyone was able to relieve their stress. [age 12]

**CORE THEMES: PARENT INTERVIEW**

Similar to the siblings, parents commented on the positive impact of camp on siblings, especially group cohesiveness and universality, i.e., that the siblings could relate to others who had similar experiences. Parents also noted improvements in self-esteem, confidence, peer relationships and altruism. The theme of improved self-esteem is consistent with results reported in an earlier article where we reported statistically significant and clinically significant improvement in sibling self-esteem on the Rosenberg Self Esteem Scales (Rosenberg, 1965) from pre- to post camp (Packman et al. 2004).

When parents were asked “do you see any changes in your child’s attitude or behavior that you feel are related to having participated in SIBS camp,” several noted positive changes:

Every year she comes back with a better attitude toward her sisters. It seems to make her realize that others experience what she does and makes her feel not so isolated. [nonbereaved parent of 10-year old]

Our daughter has surprising strength in dealing with difficult issues. She also is very comforting to others who are sad or grieving. I feel many of these skills came from her interactions and conservations at camp. She was more sensitive to her sister’s emotional needs. [nonbereaved parent of 13-year old]

Our daughter seems more mature and more integrated into our family. I see her being a lot more self-assured–it’s great. I feel the week did wonders for her. [nonbereaved parent of 10-year old]

Our son couldn’t stop singing after camp. He sang camp songs and told us about the counselors and the fishing. This year, his second camp, he came home confident and without experiencing any homesickness. He also had an easier time getting along with his
peers. He usually doesn’t look for friendships with kids his own age. [bereaved parent of 12-year old]

Our son did not want to go to camp this year–His brother died in 2000 and he did not want to go last year. We did not force him to attend last summer. However, this year I insisted he go and prayed he’d have a great time. He did! He had lots of stories to tell and still he and his sister sit around and compare notes–weeks after camp ended! He has a ‘lightness’ about him that he seems more ready to show off. [bereaved parent of 12-year old]

When parents were asked to “share any comments about their child’s experience at SIBS camp,” the salient themes included universality, group cohesiveness and the development of socializing techniques:

She loves it. She has made many friends and role models. It has influenced her life and she is a stronger, kinder, better person because of her interactions. [nonbereaved parent of 13-year old]

I know that being around others who have lost a brother or sister has helped him feel like others do have to walk the same walk . . . and they still can have fun in life. Thanks Camp Okizu! [bereaved parent of 12-year old]

Camp is his best thing every year. We are getting on with our lives after losing our child but as a family we are too serious about everything. It’s good for our son to spend time with so many joyful people who know how to be silly. [bereaved parent of 12-year old]

**DISCUSSION**

This study represents one of the first attempts to use an empirically-based measure (PedsQL) to assess whether participation in summer camp for siblings of pediatric cancer patients leads to improvement in HRQOL. It is also one of the first attempts to integrate quantitative and qualitative methodologies. The need to understand the impact of pediatric chronic illness on a sibling’s HRQOL is an important progression of our understanding of the many psychological sequelae and social-emotional factors that are impacted by a child’s chronic illness.
The overall findings on the PedsQL–Child Report suggest that all siblings (bereaved and nonbereaved) reported marked improvements in HRQOL following camp, especially in the emotional and social domains. Nonbereaved parents also reported marked improvements in siblings HRQOL following camp. In our sample, the results noted a consistent pattern for the bereaved parents; they reported that the sibling’s quality of life was less positively impacted by camp than the non-bereaved parents. The reasoning behind this may include the bereaved parents’ multi-faceted issues. Moreover, they may be less able to objectively report on the positive improvement in siblings post-camp because of their continuing grief and possible post-traumatic stress reactions to the death of their child. It is important to note that part of the camp experience for children is peer support and discussion groups on bereavement. This affords children the opportunity to process the loss of a sibling whereas bereaved parents may not have the same opportunity. Of importance, the PedsQL results suggest that bereaved parents of cancer patients may be a particularly at-risk group in need of targeted mental health services.

The responses of our sibling sample on the emotional health subscales of the PedsQL accounted for the greatest change pre- to post-Camp. Next in magnitude was the improvement in social functioning on the PedsQL. In our view, the siblings’ opportunity to communicate and bond with a true peer group, as well as the positive feedback, reinforcement and recognition from supportive counselors may have accounted for the dramatic improvement in emotional and social functioning. The nonbereaved parents likewise noted marked improvement in the siblings’ emotional, social and physical functioning.

The PedsQL findings of improved emotional and social functioning mirror the themes that emerged from the qualitative measures. On these measures, all siblings and parents (bereaved and nonbereaved) described the positive impact of camp on siblings and the majority of responses emphasized the importance of group cohesiveness, universality, socializing, and catharsis. It is important to point out that the open-ended survey questions completed by parents were not part of the packet of quantitative measures completed in the pre- and post-camp interviews. They were mailed to parents after camp and filled out separately. It is possible that when parents, in particular bereaved parents, have the time and opportunity to reflect and observe their child’s behavior following camp, they are more able to accurately process and describe the effect of camp on the child’s HRQOL. Thus, the use of two different methodologies to capture HRQOL could account for the dif-
ferences we see on the PedsQL and the Camp Okizu Satisfaction Survey for bereaved parents, reinforcing the value of integrating qualitative and quantitative techniques.

The positive quality of life representation of a camp participant is poignantly reflected below:

Yo! I just got home about seven hours ago and felt the burning urge to write and describe my emotions at the moment. It’s odd being home but it’s different than any other year. It’s hard to explain. Usually after camp I go through this period of depression and longing for camp. Naturally one would think that I would be going through it again being that it was the best week ever, but I am not. Camp fulfilled me so much this year that’s it’s almost like it is still going on in my heart. Also, I am positive that I will keep in touch with all those who I grew to love at camp. I’ve never been so content in my life. Believe it or not, I am not that popular in school. The overwhelming love and acceptance I feel at camp will last a year and keep me sane when I need it the most. Camp enables me to feel the negative emotions that I tend to repress and let the tears flow freely, like at inspirations. I never knew the heart was capable of loving so many people in such an immense way. [age 16 years]

LIMITATIONS

The lack of a comparison or control group limits the internal validity of the results of the present study. Thus, we cannot rule out the effects of history and maturation. In addition, interpretation of the current findings must be made cautiously due to the absence of a second follow-up assessment phase. Finally, qualitative interpretations are affected by the perception, bias, and assumptions of the researcher, despite the rigorous requirements of grounded theory methodology. The potential benefit of these interpretations will outweigh the inherent risks associated with the use of qualitative data to support and illustrate the study’s findings.

CONCLUSION

Prior to this study, there had been no empirical investigations into the effects of summer camp for siblings of pediatric cancer patients on the construct of HRQOL. Our overall findings on the positive impact of Camp Okizu on siblings’ HRQOL are encouraging and suggest the ben-
eficial effects of camp as a psychological intervention for siblings. Further, our findings illustrate the value of integrating quantitative and qualitative methodologies in research to capture the complete range of ways siblings’ HRQOL may be affected by their brother or sister’s cancer. Our objective was to utilize methods that complement each other and enhance the relevance of findings (Murray, 1999). In our view, psychosocial interventions such as camp for siblings of cancer are complex phenomena that require investigators to use multiple methodologies to properly understand them (Steckler et al. 1992).

REFERENCES


