Children with Cancer and Their Siblings: Social Support and Health-Related Quality of Life

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BACKGROUND

- Each year, approximately 12,400 children and adolescents are diagnosed with cancer in the United States (CureSearch, 2003).
- Children with cancer and their families face a variety of challenges.
  - Social support, elevated levels of distress (Vannata & Gerbardt, 2003).
  - Lower health-related quality of life (HBQOL; Varni et al., 2002).
  - Siblings at an increased risk for developing anxiety or depression (Kierman & MacLachlan, 2002).

Social Support

- Could be an important contributor to positive adjustment to chronic illness or having a sibling with a chronic illness (Belbin et al., 2009; Olson et al., 2003).
- Few studies have examined whether social support from different sources (e.g., chronic illness camp versus home) or whether social support regarding different issues (e.g., cancer versus non-cancer) predict adjustment or outcomes such as HBQOL.

Camps

- Therapeutic recreation camps are a common intervention used to improve campers’ psychosocial functioning while providing for basic medical needs and a fun, “normalizing” camp experience.
- Existing research suggests that children who attend chronic illness summer camps derive beneficial effects (e.g., increased self-esteem, improved behavior, better attitude towards illness, decreased anxiety). (Brery & Rabian, 1999; Hunter et al., 2006; Williams et al., 2003).
- However, few studies have examined whether specific features of the camp experience, such as social support, may influence children’s outcomes (Brown, 2005).

Aims of the current study:

- To examine children’s perceived social support about cancer vs. non-cancer issues and at a chronic illness camp vs. at home.
- To investigate whether higher perceived social support predicts QOL outcomes.

METHODS

Participants:

- Children with cancer, siblings of children with cancer, and their parents.
  - Children attended week-long summer camp sessions for children with cancer or their siblings.
  - Number of years attended camp ranged from 0 to 11, average number of years = 4.2 (SD = 3.2).
  - 415 families participated (76 children with cancer, 93 siblings of children with cancer, 8 bereaved, 103 mothers, 10 fathers, 2 legal guardians).
- Children ranged in age from 5 to 18 years.
- 48% male.
- Ethnicity: Caucasian (70%), African-American (7%), American Indian (4%), Asian (4%), Other (13%).
- Mean age of pediatric oncology patients when diagnosed = 6.5 years (SD = 4.2 years).
- Majority underwent chemotherapy (93%).
- Current health status: off treatment (88%), on treatment (12%), relapsed (5%).
- Siblings were on average 3.6 years old when their siblings were diagnosed with cancer (SD = 2.9 years).
- Parental education: Ranged from receiving graduate degree (20%) to 9th grade education or less (26%)
- Median = college graduate.
- Median annual income between $30,000 and $100,000.

Procedures:

- Families who consented to participate in the study received study questionnaires via mail at least two months after camp sessions ended.

Measures:

- Demographics: Parents/guardians provided information on campers’ age, ethnicity, socioeconomic status, oncology patient’s medical history (e.g., past treatment, current health status, age at diagnosis), and parent education level.

Pediatric Quality of LifeGeneric Core Scales (PedsQL Generic): Parents and children completed this multi-dimensional HBQOL measure. Scores on the PedsQL range from 0 to 100 (higher scores indicate higher QOL).

Social Support: 8 years of age and older completed a modified version of the Social Support Scale for Children (Harrier, 1985). The current scale contained 42 items (each on a 5-point likert scale) assessing social support at home and at camp, and about cancer and non-cancer related issues. Scores on the subscales measuring social support at home range from 12 to 60 and scores measuring social support at camp range from 9 to 40 with higher scores indicating higher perceived social support.

RESULTS

Social Support: Means

<table>
<thead>
<tr>
<th>Social Support</th>
<th>Oncology Camp</th>
<th>Sibling Camp</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Cancer Home</td>
<td>43.4</td>
<td>43.1</td>
</tr>
<tr>
<td>Cancer Home</td>
<td>39.8</td>
<td>39.2</td>
</tr>
<tr>
<td>Non-Cancer Camp</td>
<td>33.9</td>
<td>34.0</td>
</tr>
<tr>
<td>Cancer Camp</td>
<td>33.8</td>
<td>34.3</td>
</tr>
</tbody>
</table>

* SDs were approximately 6.2 for camp and 8.7 for home.

Social Support (about cancer and non-cancer related issues) predicted QOL in several domains for both oncology patients and their siblings.

Oncology patients

- Both home and camp-based social support predicted higher, parent-reported QOL (total, social, psychosocial).
- Siblings

- Increased social support at camp predicted decreased parent-reported QOL and increased child-reported QOL.
- Perhaps children reporting higher social support from camp are more likely to be striving at home (assuming for the lower parent-reported QOL).
- Camp social support predicted QOL whereas home social support did not.
- Summer camps for children with cancer or their siblings may be an important intervention for increasing QOL.
- Increased social support may be a factor accounting for the reported benefits of chronic illness summer camps.

Future Directions

- Compare reports of QOL pre- and post - camp.
- Determine whether any demographic characteristics are related to QOL or social support levels.
- Examine the additive effects of camp support, over and above home support.
- Investigate the potentially different effect sizes for non-cancer vs. cancer support, and home vs. camp support (in predicting QOL and other outcomes).

CONCLUSIONS

- Chronic illness summer camps may be particularly important for siblings.
- Siblings in the current sample had lower emotional QOL than other samples of healthy children (e.g., Varni et al., 2002).
- Social support

- Social and cancer-related issues predicted QOL in several domains for both oncology patients and their siblings.

- Oncology patients

- Both home and camp-based social support predicted higher, parent-reported QOL (total, social, psychosocial).
- Social Support

- Cancer, camp P-social -.82 .036
- Non-cancer, camp P-total -.714 .012

- Non-Cancer Camp P-total -.714 .012
- Non-Cancer P-total -.706 .012
- Non-cancer P-psychosocial -.74 .007
- Non-Cancer camp P-psychosocial -.68 .012
- Cancer camp P-psychosocial -.59 .039
- Non-cancer camp C-psychosocial .74 .024
- Non-cancer camp C-emotional .65 .045
- Cancer, camp C-emotional -.74 .024
- Physical: Self-Report 89.7 Parent-Report 90.2
- Emotional: Self-Report 73.8 Parent-Report 70.8
- Social: Self-Report 86.9 Parent-Report 86.2
- School: Self-Report 80.4 Parent-Report 83.9
- Overall: Self-Report 82.7 Parent-Report 82.7

REFERENCES

Conrad & Altmaier (2009) reported that oncology patients attending a summer camp indicated they received more support from individuals at camp than others in their lives.
Preventive interventions that are effective for chronic illness children.
Williams, R. D., Gollnick, K. S., Moos, K., & Dukelow, P. (2001). The PedsQL in Pediatric Cancer: Validity and Utility of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module American Cancer Society.