

# Siblings of Children with Serious Illnesses

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When a child is diagnosed with a serious illness, the entire family changes and is faced with severe distress.

Anxiety rises and resources are stretched in the face of the life-threatening nature of the illness and its intense and unpredictable treatments and effects. The focus through treatment is necessarily on the child with the illness, yet siblings are typically left in a vulnerable position. Siblings can be referred to as the “forgotten grievers” (Chesler & Barbarin, 1987) or the “forgotten givers” (Karampela, Hatira, & Damigos, 2010).

Siblings are clearly impacted emotionally, practically, and relationally by the ill health of another child in the family. Impacts on siblings include: perceptions of the condition and its symptoms, impact on daily life, emotional consequences, and ways of coping (Malcolm, Gibson, Adams, Anderson, & Forbat, 2014). A sibling’s diagnosis has implications for the siblings’ adjustment and adaptation, emotional impact, coping strategies, and unmet needs (Malone & Price, 2012). The experience of being a sibling of a child with an illness is affected by support of peers and family members, and changes as their sibling’s condition and treatment advances or resolves and as they too grow and develop.

Upon diagnosis of illness of a sibling, the well siblings might assume a caregiving role, leading to decreased social contact, which delays their own personal growth and development. As siblings watch their brother or sister undergo emotional or physical pain, they might internalize their stress and feel guilt, hopelessness, anxiety, and loneliness. Externalizing behavioral problems can also occur, although these do not seem to be much greater in severity than those found in their peers (Havermans, Croock, Vercruyssen, Goethals, & Diest, 2015).

The focus of most camp research in this area is on camps for children with cancer and their siblings. Approximately 15,780 children and adolescents aged 1-19 in the United States are diagnosed with cancer each year. Cancer is the leading cause of disease-related death in the U.S., but because of effective treatments, survival rates for most cancers have reached 80% (National Cancer Institute, 2014). With advances in cancer treatments over the past 35 years, many families have learned to live with a chronic and potentially life-threatening illness as opposed to a terminal diagnosis.

Many camps for siblings are formulated on the concept of therapeutic recreation, defined as, “a purposeful intervention designed to improve quality of life through recreation and leisure” (Martiniuk, 2003, p. 750). Camps for siblings often provide programming based on psycho-education, principles of cognitive behavior therapy, and health promotion (Sidhu, Passmore, & Baker, 2006). Camp goals include providing siblings with peer support, addressing emotional concerns, validating their feelings, and bolstering self-esteem (Packman et al., 2004; Packman et al., 2008). Providing activities designed to reduce levels of distress and improve knowledge about cancer and treatment (Sidhu et al., 2006), camps can have a positive impact and offer siblings of children with cancer a supportive peer environment. Through discussion with peers and health care providers, sibling campers participate in activities that improve knowledge, social confidence, and self-esteem (Hancock, 2011).

## Research Says

- There is tentative evidence that psychological interventions with siblings of childhood cancer patients can effectively reduce psychological maladjustment and improve medical knowledge about cancer (Prchal & Landolt, 2009).
- Perceived social support from family and summer camp, and perceived contextual factors

(e.g., role overload, family adaptability) were significant factors that correlated with siblings' psychosocial adjustment (Zegaczewski, Chang, Coddington, & Berg, 2015).

- Changes in siblings were found from pre- to post-camp in posttraumatic stress, anxiety, quality of life, and self-esteem, and were mostly moderate, with emotionally-laden areas showing the most magnitude of changes, followed by areas for social functioning and social concerns. The rate of PTSD and clinically significant anxiety dropped. These changes were not dependent on the number of times the sibling had attended camp (Packman et al., 2004).
- Siblings who attended camp demonstrated improved mental health outcomes (lower levels of distress, better social competence, greater social acceptance, improved knowledge of cancer and less fear) that were sustained two months after camp (Sidhu et al., 2006).
- Healthy siblings who attended summer camp listed more positive attributes about themselves than healthy siblings who did not attend camp (Murray, 2001).
- At a weekend camp program for bereaved siblings, siblings reported that their camp experience helped them accept their feelings as normal and that they left camp with a circle of support they did not have before (Creed, Ruffin, & Ward, 2001).
- After camp, significant improvements in health-related quality of life were reported by siblings as well as their parents, and both parents and siblings reported overall positive outcomes from attending camp (Packman et al., 2005).
- The camp experience has resulted in positive outcomes for siblings in both the short term and long term with regard to physical symptoms, self-perception, and social support (Kiernan, Gormley, & MacLachlan, 2004).

## Camp Research Says

Research about camping has indicated the essential value of activities that are challenging to young people. Camp is a venue where numerous out of the ordinary and interesting opportunities provide challenge for young people.

- The 2005 national study of the outcomes of camp experiences (American Camp Association) showed that children become more adventurous at camp and that enabled them to try new things. About 75 percent of campers reported that they learned something new at camp.
- Hattie et al. (1997) did a meta-analysis of adventure activities that the use of outdoor activities that were challenging resulted in the strongest effect sizes for self-control such as independence, self-efficacy, assertiveness, internal locus of control, and decision-making. Further, these outcomes increased 25 months later. Hattie et al. concluded that this study showed compelling evidence that structured voluntary challenging activities can have a powerful sustainable effect on development.
- Arnold et al. (2005) studied Oregon residential 4-H campers and found campers said they learned new things that they liked to do, and that camp made them want to try new things. Girls were more likely than boys to learn new things and to want to try new things.
- Garst and Bruce (2003) studied over 8000 4-H campers in Virginia and found that the second most often rated benefit of camp was developing new skills in an area that the camper enjoyed. They also said they learned more about different subjects.
- Brannan et al. (1997; 2000; n.d.) studied over 2000 campers with mild to severe disabilities who were ages 7-21 and found significant growth related to achievement in activities related to outdoor activities. Campers with more severe disabilities also reported enjoyment and achievement in participating in these activities.
- Bialeschki and Scanlin (2005) described the research done with Youth Development Strategies Inc. with over 7600 campers. This preliminary study focused on skill-building and opportunities for challenging and interesting activities as one important element. The findings indicated that 41 percent of the campers were in the optimal category for skill building and opportunities for challenging and interesting activities; however, 26 percent were in the insufficient area. Although camps offer opportunities in skill-building, more work is needed to help children get better at things that matter to them.

## Bottom Line

1. Camp can be an important source for social support for siblings.
2. Social support can increase resilience of siblings and by extension the family.
3. Siblings face many psychological and emotional issues upon their sibling's diagnosis, with the sibling's role in the family and family functioning affected by a diagnosis.
4. Programs and services for siblings are lacking. 48% of hospitals in the U.S. do not offer services to siblings. Nearly every research article contained a strong recommendation that more attention and services be provided to siblings.
5. Research on camps for siblings typically involved camp as an "intervention." That is, intentional programming at camps was measured to assess changes in campers. Intentional programming included professionally-led workshops, activities, or programs aiming to influence various psychosocial outcomes. All camps also included recreational activities. However, very little research was found on camps that provide *only* a recreational experience to siblings.
6. Typical outcomes of camp measured in these studies included social, emotional, mental health, and family communication/functioning.
7. Nearly all research articles on this topic have been about siblings of children with cancer. This should be kept in mind when interpreting the results above and caution is urged in generalizing these findings to siblings of children with other types of illnesses.

## Resources

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Recommended citation:

Gillard, A. (2016). Siblings of children with serious illnesses. Briefing paper prepared for the American Camp Association. [www.acacamps.org/resource-library/research/aca-briefing-papers](http://www.acacamps.org/resource-library/research/aca-briefing-papers).