SUPER SIBS!

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When a child is diagnosed with cancer, everyone in the family needs support — including the siblings. Existing research describes siblings as the most emotionally neglected and unhappy of all family members during serious childhood illness. Siblings have a strong need for ongoing information and support, but it is often limited, inconsistent and not readily available. Qualitative and quantitative findings are presented below from an independent study of children and parents who have been a part of the SuperSibs! program. Evidence-based outcomes will be shared and recommendations for education and ongoing program support are as follows.

METHODOLOGY:

In order to measure effectiveness of individual support materials provided by SuperSibs! to siblings of children with cancer and their families, an independent study was conducted by Impact Consumer Research.

METHODS:

Study Design: SuperSibs! Comfort and Care programs and overall impact on its constituents — the Brothers and sisters of children with cancer — were studied via the following:

Qualitative Component: Sib focus groups were held in the Chicago area, January 20–21, 2008 with 45 total participant groups as follows:

• Siblings 7-11
• Siblings 12-13
• Siblings 14+
• Siblings who are bereaved
• Parents of younger kids
• Parents of older kids

Focus groups were 90 minutes each.

Quantitative Component:

Online survey:

• Three separate surveys were designed (one for parents, one for children ages 7-11, one for teens/12-18)

• SuperSibs! Comfort and Care materials

SuperSibs! Program:

Parents, siblings, and caregivers of children were invited to participate. A total of 432 completed surveys were obtained from the U.S. and Canada:

• 290 Parent surveys
• 95 surveys completed by children (doctors and nurses)
• 46 Tween/Teen surveys

Data was collected between February 2–18, 2008.

Current Research:

• 53% of siblings ages 6-18 (within 2 years of diagnosis) reported moderate to severe Post Traumatic Stress Symptoms; and 27% qualify for diagnosis of Post Traumatic Stress disorder (Atleshoff, 2007).

• Siblings with more social support indicated significantly fewer symptoms of depression, anxiety and fewer behavior problems than siblings with less social support. (Barrosa, 2004).

• Older siblings are at increased risk for internalizing disorders (depression, anxiety, obsessive compulsive symptoms). (Spinetta, 1981).

• Younger siblings were reported to have more externalizing behavior problems (aggression, regression, school performance). (Ferrari, 1998).

• Siblings of children with cancer are particularly vulnerable to depression, anxiety, and social isolation. (Spinetta, 1981).

Research Objectives:

Combined qualitative and quantitative techniques used to:

• To measure effectiveness of SuperSibs! Comfort and Care programs and overall impact on its constituents — the Brothers and sisters of children with cancer

• To understand additional needs of siblings that might not be fully met from their own, as well as their parents’ perspectives

• To hear from siblings and their parents, what additional programs and services are needed.

Results:

Qualitative: Comfort and Care interventions appear to have an extremely positive impact on the lives of the siblings of children with cancer and their parents.

Quantitative: 75% of siblings noted they felt stronger and more hopeful after receiving accept-appropriate Comfort and Care services over a period of 1-4 years.

Research Implications:

Impact of sibling support programs can be tracked in longitudinal studies to minimize long-term psycho-social health and/or post-traumatic growth for siblings and optimize total family healing.

Clinical Implications:

These study results indicate the positive impact of targeted interventions addressing siblings’ needs, and the need for further integrated sibling support as standard operating procedure for hospitals, organizations and professionals serving the pediatric oncology community. The study also supports the October, 2007 IOM Report and the 2008 National Call to Action Against Cancer.

CANCER AND THEIR PARENTS.

The current research reveals that the following are among the most commonly reported issues siblings experience:

• Feelings of happiness, strength, and hopefulness improved dramatically among younger children, while among teens/teens, more than 75% noted that they felt stronger and more hopeful after receiving SuperSibs! Comfort and Care services

• Equally important — the negative feelings so prominent among both age groups just after their sibling was diagnosed were significantly reduced — especially feelings of sadness, fear, confusion, anger, and of being forgotten

• From parents’ perspective, children receiving SuperSibs! support have been managing much better now, versus prior to their enrollment in the program

• 80% of parents felt that SuperSibs! had a positive impact on their child/children

• Among parents, one of the greatest benefits of SuperSibs! has been the positive impact on the family. Nearly two-thirds said that impact has been greater than other organizations.

SuperSibs! does an extraordinary job of bridging the gap between parents and hospital professionals (doctors and nurses) in helping both younger and older children understand their sibling’s cancer

Over two-thirds of siblings name the organization as one that has helped them better understand their brother/sister’s cancer.

SuperSibs! was second only to parents in helping them develop an understanding — well above both doctors and nurses.

Both younger children and teens/students showed significant increases in their understanding of their sibling’s cancer after receiving SuperSibs! Comfort and Care materials.

The relationship between SuperSibs! and the Hospital is truly symbiotic. 70% of families currently learn about SuperSibs! through hospital personnel and material.

Parents of siblings fully recognize the positive changes in their own lives as a result of receiving SuperSibs! Comfort and Care materials:

• Parents noted a dramatic reduction in the child’s feelings of isolation (feeling like s/he was the only child who had a sibling with cancer). A substantial increase in the child’s feelings of being recognized as special and important by parents/other was also noted.

• Displays of anger/aggression were also greatly reduced.

Parents notice great improvement in their child’s ability to communicate his/her feelings:

• Parents noted that siblings actively use tools such as journals and pictures substantially more now versus prior to SuperSibs! support.

• Proportion of parents who noticed their child talking openly about his/her own feelings nearly doubled after the child has received SuperSibs! support materials.

Conclusions:

While the opportunity for improvement exists, the Sibling and Parent surveys as well as the Focus Groups are consistent in their findings:

Based on these results, professionals can implement complementary sibling support services for institutions at their institutions to further promote total family survival and healing.

Parents’ Perceptions of Usefulness ofSuperSibs! Materials for Providing Insights and Ideas to Help Siblings

Vey Highly Useful, 54%

Somewhat Useful/Not Very Useful, 10%

Not Useful, 36%

CONCLUSIONS: The positive impact of the lives of both siblings of children with cancer as well as their parents' families.