The Voice of the Invisible - the experiences and consequences of having a brother or sister with cancer during childhood

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In pediatric cancer, for obvious reasons, the focus is on the sick child. However, over the last few decades the impact on the whole family has been increasingly recognized. Yet, this awareness has almost exclusively been confined to the parents, while the siblings have received little attention. The term invisible sibling has been coined to describe the consequences of having a brother or sister with cancer. Despite their bewilderment, stress and fear, the siblings receive even less attention than normally because the critical priority is their sick brother or sister. Both parents and healthcare professionals are guilty of this understandable omission, and although it might be difficult to widen their focus to the siblings, this may prove to be of decisive importance for the long term recovery of the family as a whole. Notably, the SIOP guidelines emphasize this whole-family approach to the management of children with cancer.(1-3)

The prognosis for children with cancer has improved over the last decades to a cure rate close to 80% in the developed world. However, this fact does not alleviate the strain on the families during the child’s treatment, not even after cure has been reassured by the oncologist. In many cases, the fear of recurrence remains for some time to come. In addition, persistent side effects may be a constant reminder of the trauma imposed by the cancer and its treatment. In families losing a child to cancer, the bereavement commonly affects both parents and siblings for the rest of their lives.

Although, there are a number of studies on the experiences of families having a child with cancer, information on siblings is limited, and in particular on those bereaved. In fact, much remains to be known regarding the psychological, social and educational outcomes of siblings of children with cancer. Many questions remain unanswered, e.g.: which are the most stressful moments; what factors in daily life are the most challenging for the siblings; what are the effects on their relationships within and outside the family; what symptoms are elicited by the situation; what special needs in conjunction with the disease of their brother or sister and its treatment do siblings themselves perceive; what could be done to mitigate their stress and suffering; and what measures should be taken by parents and health care staff?

In a review of the literature on siblings of a brother or sister with cancer, Wilkins & Woodgate (6) concluded that siblings have many unmet needs. They perceive their life as changed, both within and outside the family. They sense that the previous family dynamic has been disturbed, and feel separated from their parents. In some cases it has been described that siblings lose their sense of self during this traumatic period. They commonly experience intense feelings of anger, guilt, jealousy, sadness and anxiety. Positive feelings, such as empathy, can also emerge. In their review, Wilkins & Woodgate emphasized that siblings usually seek open communication and involvement in the care of the sick brother or sister, but also want to be supported in their efforts to continue their own interests and activities. They want to feel recognized.

In a study of siblings of a brother or sister newly diagnosed with cancer, Lahteenmaki et.al (7) analyzed the risk of behavioral and psychosomatic problems among the siblings,
and whether that risk decreased over time. Age was also considered in the analysis. Among older, school-aged siblings, learning, psychosomatic and behavioral problems were reported by the parents. In siblings below school age, behavioral and psychosomatic problems, also assessed by their parents, did occur but decreased over time. Thus, even young siblings were found to express feelings of jealousy, envy and loneliness. Most often it seems taken for granted that the young siblings’ needs will be met within the family, and therefore they may be overlooked by health care professionals.(8)

Houtzager et al. (9) studied family functioning following a pediatric cancer diagnosis and found that siblings are most distressed during the first months following the diagnosis. Older siblings, especially girls, are at increased risk of psychosocial problems. Alderfer et al. (10) had reported similar results in an earlier study. Indeed, childhood cancer appears to be associated with considerable difficulties in keeping the family together and in taking care of each other. In particular, siblings’ sense of self is often shaken by the diagnosis and treatment of their brother or sister. Yet, it remains to be determined whether this loss of self is reversible or not. On the whole, data on the long term effects on siblings is very sparse. In this context, it would be of considerable interest to assess whether there is a significant difference in outcome between bereaved and non-bereaved siblings.

Interviews of bereaved parents suggest that siblings suffer a great deal following the loss of a brother or sister to cancer.(11) Suicide attempts and repeated accidents have been reported among bereaved siblings, although the relationship between these events and the bereavement has yet to be explored. Bereaved siblings have had to endure the protracted illness of their brother or sister as well as the end-of-life period and, finally, the loss. All these experiences are bound to have a negative effect on the siblings’ long-term psychological health. According to interviews by Nolbris & Hellstrom (12) siblings were dissatisfied with the information given to them and felt that they had not been involved in their brother or sister’s dying process. They expressed loneliness and the need to mourn in their own way by randomly over time entering and exiting their grieving process. In a review by Giovanola (13) on siblings’ involvement at the end-of-life, the author examined the sibling relationships, children’s perception of death, grief and bereavement. Findings revealed that health care professionals often fail to recognize siblings’ needs at end-of-life, while parents attempt to protect the siblings from involvement at end-of-life. In both cases there is a failure to meet the siblings’ needs. They are left out and remain “invisible”.

Most studies on siblings with a brother or sister with cancer have been exploratory and descriptive in nature. Although a few quantitative studies have been done on non-bereaved siblings, none has been conducted on the long term effects of loss of a brother or sister. Such studies are sensitive by nature, and thus, challenging to carry out, raising ethical concerns about reopening old wounds. Yet, such concerns may be unfounded. Kreibergs et al encountered hesitation among professionals within pediatric oncology as well as ethical boards about the appropriateness of approaching parents who had lost a child to cancer several years earlier. However, after IRB approval and completion of the study it was found that the vast majority of the parents perceived the follow up as valuable and were positively affected by their participation. (14) This would seem to suggest that also bereaved siblings would not mind being approached for possible participation in a similar study in attempts to identify health care related factors that can be avoided or modified. Findings from such a study could be helpful in designing strategies to prevent or mitigate sibling’s suffering and reduce the psychological morbidity in the long term perspective.

Health care professionals have an important role not only in supporting parents, but also in encouraging them to involve the siblings in their brother or sisters’ illness from diagnosis to treatment and for some even to the unavoidable death.

References


