



LEAD PAPER

Experience of siblings of children treated for cancer

Margaretha Nolbris^{a,c,*}, Karin Enskär^b, Anna-Lena Hellström^c

^aDepartment of Pediatric Oncology, Queen Silvia Children's Hospital, SE-416 85 Göteborg, Sweden

^bDepartment of Nursing Science, School of Health Sciences, Jönköping University, Box 1026, SE-551 11 Jönköping, Sweden

^cInstitute of Nursing, Sahlgrenska Academy, Göteborg University, Box 457, SE-405 30 Göteborg, Sweden

KEYWORDS

Sibling;
Cancer;
Experience;
Relationship;
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Summary

The aim was to obtain an understanding of the experience in everyday life of being a sibling when a brother or sister is receiving treatment for a cancer disease or has completed treatment. In order to illuminate the experience of the siblings themselves a phenomenological-hermeneutic method was used. Ten siblings were asked, in the form of a broad-based, open question, to tell about their experience of being the sibling of a brother or sister in this situation. There was an awareness of sibling-ship as a special relation since the brother or sister had got cancer. This feeling was very strong and close, and when needed the sibling admitted a protective and advocacy role. The siblings felt difficulties to always be loyal with the brother or sister needs and demands from other interests. They lived a new life and periods of ups and down following the condition of the brother or sister. Everyday life varied from joy to a life filled with worries and anxiety. Siblings experienced feelings of an existential nature, such as quality of life and death.

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Zusammenfassung

Das Ziel bestand darin, die alltäglichen Erfahrungen einer Person zu untersuchen, deren Bruder oder Schwester wegen eines Krebsleidens behandelt wird oder eine Krebsbehandlung erhalten hat. Um die Erfahrungen der Geschwister selber zu evaluieren, wurde eine phänomenologisch-hermeneutische Methode angewandt. Mittels einer allgemeinen offenen Frage wurden zehn Geschwister aufgefordert, über ihre Erfahrungen als Geschwister eines krebserkrankten Bruders oder einer krebserkrankten Schwester zu sprechen. Es stellte sich heraus, dass das Geschwisterverhältnis angesichts der Krebserkrankung des Bruders oder der Schwester als eine besondere persönliche Beziehung empfunden wurde. Dieses Gefühl war sehr intensiv, und die Geschwister gaben zu, bei Bedarf die Rolle eines Beschützers und Verfechters einzunehmen. Die Geschwister empfanden es als schwierig, sich zu jedem Zeitpunkt gegenüber den Bedürfnissen und Forderungen des Bruders oder der Schwester loyal zu verhalten. Parallel zur Entwicklung des gesundheitlichen Zustandes des Bruders oder der Schwester durchlebten die Geschwister psychische Höhen und Tiefen, und im Alltag hatten die Geschwister sowohl Phasen der Lebensfreude als auch Phasen voller

*Corresponding author. Department of Pediatric Oncology, Queen Silvia Children's Hospital, SE-416 85 Göteborg, Sweden.
Tel.: +46 31 3434 22; fax: +46 31 2154 86.

E-mail addresses: margaretha.nolbris@vgregion.se (M. Nolbris), karin.enskar@hhj.hj.se (K. Enskär), annalena.hellstrom@fhs.gu.se (A.-L. Hellström).

Sorgen und Ängste. Die Gefühle der Geschwister waren existentieller Natur, beispielsweise im Hinblick auf Lebensqualität und Tod.

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Introduction

A sibling's relationship is intensive, complex and has infinite variety. It is usually the longest relationship that an individual will experience in his/her lifetime. There are emotional bonds between brothers and sisters and the sibling bond has been described as fluctuating between warm and sensitive or negative and filled with rivalry. Anything that affects one sibling in a family also has some effect on other members of the family. The earlier the access and the more prolonged a sibling relationship, the more intensive the relationship will be between siblings (Cicirelli 1995; Bank and Kahn 1997). The family feels best when all members are together and the siblings know that the parents are equally fond of all siblings. The relationship between siblings has an impact on the emotional climate in the family (Dunn and McGuire, 1992).

In Sweden, approximately 300 children are diagnosed with cancer every year (Epidemiological Centre, 2004) and most of them will have siblings. When a child develops a life-threatening disease like cancer and needs treatment, the whole family becomes involved and this new situation often changes the pattern of life for the family and for the healthy siblings. This affect on the whole family has been described by others (Iles, 1979; Spinetta and Deasy-Spinetta, 1981; Marky 1982; Barrera et al., 2002; Woodgate and Degner 2003, 2005). In a study by Freeman et al. (2003), a questionnaire was used with siblings of children with a brain or spinal cord tumor. Forty families with siblings aged 9–30 years participated. It was shown that these siblings had missed being informed about the prognosis of their brother/sister. Siblings' lives will change and they will experience intense feelings and unmet needs. This has recently been highlighted by Wilkins and Woodgate (2005) in a review article. In another study Björk, Wiebe, and Hallström (2005) interviewed 17 families, including five siblings about experiences and thoughts when the child in the family is diagnosed with cancer. They found that what previously had been expected as normal was now broken apart but soon they started to strive for hope and a positive focus for the family. In an earlier study by Nolbris and Hellström (2005), ten siblings who had lost their brother or sister were interviewed; these siblings complained of lack of information particularly during the illness. They felt that the doctors and nurses appeared not to see them as people who routinely and continuously needed to be informed. The siblings had not felt fully involved and missed opportunities to talk about the implications of the disease together with the nurses and doctors responsible for the treatment. Knowledge of the experience of the everyday life of being a sibling in these circumstances is still lacking and siblings clearly need information about the child with cancer (Marky, 1982; Martinson et al., 1990; Murray, 1998, 2002; Barrera et al., 2002; Sloper, 2000).

Aim of the study

The aim of this study was to obtain an understanding of the experience in everyday life of being a sibling when a brother

or sister is receiving or has completed treatment for cancer.

Method and participants

A phenomenological-hermeneutic research approach was used (Lindseth and Norberg, 2004). This method strives to elucidate the essential meaning as it is lived in human experience, in order to obtain an understanding of the phenomenon: "the everyday life of being a sibling when a brother or sister is receiving treatment or has completed treatment for cancer". According to the French philosopher Ricoeur (1976), phenomenological-hermeneutic means understanding and explaining the text in a story and not the person behind it, with the aim of obtaining an increasing understanding of people's life world, and making the content of meaning in the text accessible to others. The study sample therefore consisted of those who have experience and are consequently best qualified to provide information about the aim of the study (Patton 2002; Lindseth and Norberg, 2004).

The participants were recruited from the Department of Pediatric Oncology at Queen Silvia Children's Hospital in Göteborg, Sweden. The inclusion criteria were siblings aged 10 years and older of brothers and sisters who were 6 months from diagnosis and undergoing treatment for a diagnosis of leukemia or a brain tumor. The siblings approached to participate were selected on the basis of age, gender and diagnosis to obtain some concordance in the group of siblings of children on or off treatment. The reason for including the siblings of both children during treatment for a cancer disease and those who had finished treatment was that they might have different experiences, which could illuminate the aim, but we did not seek to study differences. Information about the study was first mailed to potential participants, after which the siblings were telephoned within 14 days to see whether they would like to participate. Informed consent was obtained from participants and, in the case of younger children, also from their parents. They were all informed that participation was voluntary and could be discontinued at any time if they so wished. The Ethics Committee at Göteborg University approved the project.

Ten biological siblings, four males and six females, from the two largest cancer diagnosis groups in children, leukemia and brain tumor, agreed to participate in the study. The healthy siblings ranged in age from 10 to 36 years and 4.6 years in average had passed since the child had received his or her diagnosis. At the time of the interviews, the brothers/sisters with cancer were aged between 7 and 18 years (Table 1). In all, 12 siblings were approached, but two declined for personal reasons.

Interviews

A narrative interview is designed to enable the interviewee to tell his/her own story and to construct expressions of

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