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Siblings of children with cancer – Their experiences of participating in a person-centered support intervention combining education, learning and reflection: Pre- and post-intervention interviews



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A B S T R A C T

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Purpose: To evaluate a person-centered intervention, directed to siblings with a brother or sister newly diagnosed with cancer that combines education, learning and reflection about cancer.

Method: Qualitative methods with pre- and post-intervention semi-structured interviews were conducted. Fourteen siblings aged 9–22 years participated. A qualitative content analysis was carried out.

Results: The result comprises of five themes: 'grasping for knowledge about cancer', 'thinking for hours and having nightmares', 'experiencing physical pain', 'being emotional in several ways', 'waiting for a normal, good life despite the uncertain future'.

Pre-intervention; a low level of knowledge of cancer treatments and its side effects was revealed; siblings slept poorly, lay awake thinking and had nightmares about cancer; they felt pain in different parts of their body; they felt emotional and angry and were anxious as cancer is life-threatening; in the future the sick child will finished treatment and recovered.

Post-intervention; siblings described having specific knowledge, felt more informed, and that it was easier to understand the sick child's situation; they slept better, but still had a lot on their minds regarding the sick child; most siblings said they no longer experienced pain, felt better and were happier but could still get sad; in the future the sick child would be healthy, not exactly as before, but almost.

Conclusion: Person-centered intervention helps siblings to be more knowledgeable about the sick child's cancer, leading to a more realistic view about treatments and consequences. Further studies of person-centered interventions for siblings are important.

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Introduction

This study focuses on the siblings of children with cancer, and their experiences of participating in a person-centered support intervention combining education, learning and reflection via Internet and cellphone. The new situation when a brother or sister has cancer can present the sibling with variety of problems, such as anticipatory grief when the loss of a close one is threatened (Hines Smith, 2005; Lindemann, 1944). In a study comparing 29 sibling, aged 8–24 years, of a child with cancer, all described experiencing anticipatory grief shortly after the diagnosis or in connection with their sibling's treatment (Jenholt Nolbris et al., 2013).

Other consequences for the siblings, described in various studies, are psychosocial changes (Alderfer et al., 2010), and worries (Enskär and von Essen, 2007, 2008; Nolbris et al., 2007; Woodgate, 2006). The child with cancer can suffer pain and anxiety, and it is hard for both parents and siblings to watch this (Jalmsell et al., 2010; Nolbris et al., 2007). All family members are affected when a child gets a cancer and their everyday and social lives are irreversibly changed (Björk et al., 2005; Nolbris et al., 2010, 2007; Pöder and von Essen, 2008; Scout-Findlay and Chalmers, 2001; Sidhu et al., 2006; Wilkins and Woodgate, 2005). For this reason it is not only the sick child who needs care, but the situation of the siblings also has to be acknowledged.

Person-centered care (PCC) described by Ekman et al. (2011) revolves around the patient's own story and their everyday lives in a partnership with healthcare staff (Zoffmann et al., 2008). Starting point with PCC, makes it possible to give the professional carer, e.g. the nurse a wider remit and allow them in turn the possibility of

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broadening the care to include siblings and other members of the sick child's family (Ekman et al., 2011). PCC for siblings could, therefore, open a way for reflective communication between siblings and nurses. Providing knowledge about the siblings' needs, can help the nurses to provide support for them (McCormack and McCance, 2006). One important aspect is to make sure that the sibling has sufficient information about their brother's or sister's cancer and their state of health, and also knowledge about the own health (McCormack and McCance, 2006; Mead and Bower, 2000b).

The strategy of using a variety of visual art methods in health-care might help patients in general, regardless of gender and age, and those close to them to communicate, understand and explain complex situations about health and treatment (Ferm et al., 2010; Lepp et al., 2003; Nabors et al., 2004; Nolbris et al., 2010; Rollins and Riccio, 2002; Rollins, 1990; Wikström, 2001). Since 2002 in Sweden information has been given to children with cancer and their parents, using a special See-Hear-Do method (SHDM) based on cartoons consisting of 100 pictures. The cartoons explain a child's cancer diagnosis, its treatments and the side-effects, the healthy body and the organs, the examinations in connection with the illness, how a reduced immune defense system functions, and family relations (Gustafsson and Nolbris, 2006). The method was implemented as a form of education. Most siblings, however, do not receive this education, which means that they do not have the same information as the other members of their family.

Several studies show that siblings lack information about the sick child (Barrera, 2000; Murray, 2002; Nolbris et al., 2007; Nolbris and Hellström, 2005; Sloper, 2000). It has also been shown that it is important for siblings to express the thoughts and feelings they experience in a difficult family situation (Murray, 1998, 2002; Nolbris et al., 2010; Scout-Findlay and Chalmers, 2001; Sloper, 2000; Woodgate, 2001). In an attempt to meet the siblings' needs, Internet support can be offered to improve their health and avoid the risk of ill-health (Ancker et al., 2009; Shoshana and Orgler-Shoob, 2006; Tichon and Shapiro, 2003; Timpka, 2001). A study on the use of person-centered care, took into account the child's own resources, needs, participation and wellbeing, through using SKYPE with preschool children, who were the target participants (Hellström et al., 2012). Results from a study by Boniel-Nissim and Barak (2013) show that keeping a personal diary, has an effect on the relief of emotional suffering, promotes well-being, and helps in developmental challenges.

Earlier studies reveal that the siblings are insufficiently informed, and that they, should in a safe and secure manner, have the opportunity to learn about their sister's or brother's childhood cancer. Siblings' needs to express their thoughts and feelings concerning the sick child and the family's everyday life situation have also been described. There is, however, a gap in the knowledge since few interventions directed towards siblings have been reported, and even fewer are designed as accessible person-centered support combining education, learning and reflection about cancer. The aim of this study was to evaluate a person-centered intervention, directed towards siblings with a brother or sister newly diagnosed with cancer that combines education, learning and reflection about cancer.

Methods

A qualitative design was used for the evaluation of the person-centered support intervention. This study reports the pre- and post-intervention interviews and of the participants reflections elicited by questions (Dochery and Sandelowski, 1999; Patton, 2002; Taylor and Bogdan, 1998). The intervention was conceived as a complement to the ordinary education given in Sweden to children who have cancer and their families (Gustafsson and

Nolbris, 2006), and was especially directed towards siblings. The overarching goal for the intervention was to increase sibling knowledge about cancer and thus reduce their anxiety.

Settings and procedures

The study was conducted in the south of Sweden from April 2010 to March 2011. The intervention took place in a large children's hospital, where the sick child was treated. The healthcare personnel involved in the intervention were the consultant nurses and the sibling supporter.

Intervention

The person-centered intervention started at the earliest within 1 month after the sick child was given his or her diagnosis. The intervention was directed towards each sibling individually and was carried out over a period of 16–28 weeks (Table 1). The educational approach included teaching and learning about cancer. The See-Hear-Do method was used for the learning (Gustafsson and Nolbris, 2006). The lectures about the sick child's cancer diagnosis, treatment and possible side-effects were held by consultant nurses. Reflection was accessed through the 'Reflection journal', which was a personal diary based on questions facilitating reflection. It was intended to be written and read repeatedly by the sibling and was sent by the sibling via E-mail/cellphone to one of the authors (MJN) in an interactive process where the sibling was continuously provided with feedback on his or her questions and thoughts.

Participants

The participants were recruited from a hospital during the intervention period using consecutive selection. The inclusion criteria were: being the sibling of a brother or sister newly diagnosed with cancer; the sick child had been receiving treatment for a maximum of 1 month since the diagnosis; speaks Swedish fluently; aged 7 years or older; access to a computer/cellphone and the Internet. If a family had numerous siblings, they were all asked to participate, and were included if they wanted to do so. Siblings and their families who fulfilled the inclusion criteria were contacted by the first author within 1 month of diagnosis.

In total 27 siblings were asked to participate in the intervention, and 13 declined. Of the remaining 14 siblings, 7 (2, 2, 3) were from three families. All the sick children were receiving treatment throughout the study. The final sample comprised 14 siblings (6

Table 1
Participating siblings and how they participated in different parts of the intervention.

Participating sibling	Interview before intervention	Education	Contacts in between	Interview after intervention	Weeks
1	x	x	3	x	24
2	x	x	5	x	24
3	x	—	2	x	24
4	x	—	2	x	24
5	x	x	10	x	20
6	x	x	6	x	20
7	x	x	3	x	24
8	x	—	—	—	—
9	x	—	—	—	—
10	x	x	2	x	24
11	x	x	—	x	20
12	x	x	—	x	24
13	x	x	3	x	20
14	x	x	7	x	16

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