



Feeling excluded and not having anyone to talk to: Qualitative study of interpersonal relationships following a cancer diagnosis in a sibling

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ABSTRACT

Purpose: To explore experiences related to interpersonal relationships following a cancer diagnosis in a sibling. **Methods:** Respondents (n = 7 females) were recruited by means of convenience sampling during a camp for children affected by childhood cancer and their siblings. Data from children and adolescents with a sibling diagnosed with cancer was collected through individual face-to-face interviews and analyzed using systematic text condensation.

Results: Two categories portrayed the experiences related to interpersonal relationships following a cancer diagnosis in a sibling. *Feeling excluded while wanting to maintain a relationship with their ill sibling and be involved in the care* portrayed that trying to be involved in the care of their ill sibling was a stressful and difficult experience, since they were simultaneously expected to also manage household chores and attend school. *Feeling stigmatized and exposed in social contexts while needing an allowing space to talk about their experiences* portrayed the emotional difficulties evoked by social situations and behaviors of others, which left respondents feeling exposed and mistreated. Having the possibility to talk about their experiences and receiving social support was described as essential in order to cope with the situation.

Conclusions: Health professionals need to take into consideration the emotional difficulties and vulnerable situation that children and adolescents who have a sibling diagnosed with cancer are at risk of experiencing. Stigmatization and social exposure present a risk of psychological distress. Having an allowing space to communicate feelings and experiences is desired. Interventions may be necessary to help these individuals psychologically cope.

1. Introduction

The incidence rate of childhood cancer ranges between approximately 130 and 160 per million children, and survival rates for children diagnosed with cancer have dramatically increased over the last decades, with a five-year survival of approximately 80% (Gatta et al., 2014; Kaatsch, 2010). When a child is diagnosed with cancer, their family members are presented to an unfamiliar and psychologically stressful situation that requires them to be mentally and physically involved in the care of the ill child (Björk et al., 2005). Children and adolescents who have siblings diagnosed with cancer are at risk of developing psychological distress following the diagnosis (Gerhardt et al., 2015; Sloper, 2000), and research indicates that the diagnosis may result in considerable challenges related to family routines and social

interactions (Woodgate, 2006). Indeed, insufficient social support, reduced communication with family members, and low family cohesion are all acknowledged risk factors for psychological distress (Eilertsen et al., 2018; Wang and Martinson, 1996; Yu and Bang, 2015). Interventions that provide social support are desired among members in this population (Murray, 2002), and suggested in the literature as appropriate strategies to achieve psychological adjustment (Long et al., 2018). However, there is still room for in-depth explorative qualitative studies that investigates dimensions and meaning related to interpersonal relationships and social support (Murray, 2002; Yu and Bang, 2015). Such in-depth knowledge has the potential to be valuable for health professionals, so that they may provide holistic family-centered care. The aim of this study was to explore experiences related to the interpersonal relationships following a cancer diagnosis in a sibling. In

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this study, interpersonal relationships refer to reciprocal interactions between two or more persons, such as siblings, parents, peers and health professionals.

2. Methods

2.1. Study context

In Sweden, six pediatric oncology centres and one hospice provide care for children diagnosed with cancer and their families. All centres have multidisciplinary teams consisting of various professions such as medical doctors, nurses, specialist nurses and social workers. In addition, all centres also have sibling supporters who offer support and arrange activities for family members. The sibling supporters are partly funded by charities/private organizations, including the Swedish Childhood Cancer Fund. The Swedish Childhood Cancer Fund arrange recurring camps for children diagnosed with cancer and their family members, so that they can meet health professionals and peers with the purpose to receive support and learn more about their situation. The Swedish Childhood Cancer Fund arranges joint camps for all family members, as well as camps specifically for siblings of children diagnosed with cancer, family members who have lost a child due to cancer, and youths who have cancer or are siblings of children/youths diagnosed with cancer. During the camps, family members can attend lectures, seminars and discussions about various topics related to childhood cancer, such as medical information, psychosocial aspects, available support from the society, and potential consequences of being a family member of a child with cancer. Children and youths who attend the camps exchange experiences with peers and learn about cancer-related aspects through conversations and other activities.

2.2. Sample

Respondents were recruited by means of a convenience sampling, which took place during a camp for children affected by childhood cancer and their siblings, arranged by the Swedish Childhood Cancer Foundation. In total, 17 persons who had siblings with a medical history of cancer participated at the camp. The camp program offered one group discussion led by the first author. During this discussion, potential respondents were invited to participate in this study by signing a list where they articulated an interest to participate in an interview. To be eligible for inclusion, respondents needed to speak Swedish, have experience of being a sibling to a child with a medical history of cancer, and be 15–25 years of age. Three potential respondents signed this list. After the camp was concluded, an invitation to participate in the study was sent to all who participated at the camp. An additional four persons contacted us and were included in the study. In total, seven persons were included and interviewed. All were females, with a median age of 22 years (range = 18–23 years). The median time since their sibling was diagnosed with cancer was 10 years (range = 5–18 years). None of the participant's siblings were on active cancer treatment at the time of recruitment.

2.3. Data collection

Data were collected through individual face-to-face semi-structured interviews, performed by the first author. The respondents were encouraged to tell their story in as much detail as they desired. Probes and follow-up questions were used, in order to explore their experiences as much as possible. Only the respondent and the first author were present at the interviews. None of the respondents had any personal or professional relationship with the interviewer. The respondents decided where the interview would take place. One interview was performed at the camp where the recruitment took place, and one started at the camp and continued at the workplace of one of the authors. Another interview was in full performed at the workplace of one of the authors. Two

interviews were conducted at hotels, and two were conducted at the respondent's home. The interviews lasted for a median time of 76 min (range = 26–96 min), were audio recorded, and transcribed verbatim by a professional transcribing agency. The transcribed data consisted of 181 pages transcribed text in a digital word processing file.

2.4. Data analysis

The data were analyzed using systematic text condensation, described by [Malterud \(2012\)](#). The first author conducted the primary analysis. In the first step, all transcripts were read to get an overview of the content and search for preliminary themes. Preliminary themes were defined as starting points for organizing the parts of data that corresponded to the aim of the study. In the second step, the transcripts were carefully read line by line and meanings units were identified, defined as fragments of the whole text that contained some information related to the aim of the study. These meaning units were processed through coding, i.e. given a code as a label of its content and structured into code groups. Code groups were derived from the preliminary themes. In the third step, the contents of each code group were reduced and decontextualized to condensates, defined as an artificial quotation written in first-person format that portrayed the condensed content of the code group. During this step, illustrative quotes that portrayed the content of the condensates were identified. In the fourth step, condensates were reconceptualized as analytical texts written in third-person, which reflected the interpretations made by the analysts. Lastly, the essential aspects of code groups were formulated in category headings, defined as brief and expressive statements that illustrated the most significant interpretations made by the analysts. [Table 1](#) presents examples of the analytic steps. In order to structure the data from meaning units to codes and code groups, Nvivo version 11 for Windows was utilized. During all steps of the analysis, joint discussions were held between the first author and last author. The last author read all transcripts and aided in the identification of preliminary themes. He scrutinized all identified meaning units, condensates, and code groups identified by the first author. In the later stages of analysis, he also aided in the identification of category groups and headings.

2.5. Reflexivity and backgrounds of researchers involved in the analysis

The first author is a PhD student and social worker, with experience of social work at hospitals. She has conducted focus groups discussion with persons who have siblings diagnosed with cancer, and has experience of narrative analysis of text-based data from blogs written by persons who have siblings with a medical history of cancer. She is a female in her 40's and has no personal experience of childhood cancer. In order to become aware of her own preconceptions and background, she wrote diary notes before and after the interviews. The last author is a specialist intensive care nurse, midwife and a researcher with previous experience of conducting qualitative analyses. He is a male in his 30's and has no personal experience of childhood cancer. He has worked clinically with pediatric patients in hematology, oncology and intensive care.

2.6. Ethical condensations

Ethical approval was obtained from the Regional Ethics Committee Uppsala, Sweden (approval number: 2014/251). The respondents were informed about the purpose of the study, that participation was voluntary, and that they had the possibility of withdrawing their participation at any time. Written and oral informed consent was obtained from all respondents.

Table 1
Examples of the analytic steps.

Preliminary theme	Meaning unit	Code	Decontextualized condensate	Reconceptualized data	Category heading
The importance of being seen and not feeling excluded	When people at school found out that she was sick ... Well, I kind of lost all my friends. Um ... Everyone stopped spending time with me and stopped talking to me. Already before this, I only had a few friends. Um ... I have always been exposed in school, but it didn't become better when ...	Alienation	When people at school found out she had cancer, no one stayed as my friend. Already before this, I had few friends. But people stopped spending time with me and stopped talking to me.	One respondent felt that classmates in school stopped spending time with her when they found out about the cancer diagnosis.	Feeling stigmatized and exposed in social contexts while needing an allowing space to articulate own experiences

3. Results

The analysis resulted in two categories: “feeling excluded while wanting to maintain a relationship with their ill sibling and be involved in the care” and “feeling stigmatized and exposed in social contexts while needing an allowing space to talk about their experiences”.

3.1. Feeling excluded while wanting to maintain a relationship with their ill sibling and be involved in the care

Following the diagnosis and onwards, the relationship between themselves and their sibling was considered an important aspect in their lives. During the treatment period, feeling sufficiently involved in the situation related to their ill sibling was thus regarded as an essential part of everyday life, and was described as vital for maintaining the quality of the relationship with their ill sibling. Respondents desired to provide emotional support for their ill sibling. This included taking part in joint activities together with their sibling, such as playing with them and planning events together at the hospital. At times, respondents went to great lengths to support and improve the emotional situation of their ill sibling. For example, one respondent made arrangements so that the sibling could meet their idols. Having the chance to provide support for their sibling and feeling involved in family matters required them to be present at the hospital. However, respondents felt restricted to visit the hospital, and thus, felt excluded from spending time with their ill sibling and their family members that stayed at the hospital, while they lived alone at home or together with relatives. This time period was experienced as long and challenging, with significant implications on the sibling relationship dynamics and functioning.

I attended school in another town [than where the hospital was located]. It took one hour and twenty minutes to take the bus to the hospital, I think. And it was not always possible to travel by bus, either. So, because of that, I was not able to visit them [the family members staying at the hospital] very often. (Respondent 4: 23 years of age, 5 years since diagnosis)

Respondents also described changes in the relationship with their parents, including experiences of reduced parental responsiveness and attention. Several found themselves in a situation where their parents needed to be together with the ill sibling at the hospital, leaving them to take full responsibility of household chores. Thus, they felt like they had to grow up fast and attend to chores otherwise managed by their parents. Living everyday life while simultaneously trying to be included in the family process was experienced as a very difficult challenge. They felt that their parents expected them to keep full attendance in school, and some felt like they missed out on many things at school because of their other responsibilities and overall strains in everyday life.

It was horrible, because you had to grow up, suddenly you were seventeen years and had to learn how to cook and fix with the backyard, like, mow the lawn that was completely overgrown, or suddenly mom wasn't around to wash your clothes. (Respondent 4: 23 years of age, 5 years since diagnosis)

Respondents also brought up that they felt insufficiently involved due to poor interpersonal relationships with health professionals and parents. Access to truthful information during the course of the treatment period was perceived as an essential aspect in order to feel sufficiently involved. This included information about the disease and prognosis, based on their own preferences, and opportunities to ask questions to health professionals. However, respondents expressed that they were excluded from important information about their sibling, from health professionals as well as from parents. This lack of information resulted in feeling insufficiently involved and ill prepared for the future. For example, one described that she felt excluded from vital information that her ill sister would soon die.

I didn't know that she was about to ... pass away. I thought that her health was improved, because no one told me that she ... The others knew that she was about to pass away. I didn't get that. I started to suspect it, like, the day before she passed away. (Respondent 5: 18 years of age, 6 years since diagnosis)

Social exclusion was also experienced after the conclusion of treatment, regardless if the sibling survived or not. When the treatment was concluded, and their family members returned home, some felt that their parents expected everyday life to return and continue in the same way as before the diagnosis. However, their own everyday life had changed and evolved since that time, which resulted in a family discordance with regard to expectations of how life would continue. For some bereaved siblings, feelings of social exclusion included experiencing that people in their social networks stopped getting in touch with them and that health professionals no longer showed interest in their psychosocial health. Respondents also expressed a lack of follow-up routines, illustrating that they wanted, but lacked, continued interpersonal relationships with health professionals after the conclusion of treatment.

When she passed away, we did not have anyone, um ... one psychologist talked to us the first day, and I just ... I don't want to talk to you, are you stupid or something [short laugh]. That's how you think at that moment. I don't want to talk to some goddamn psychologist right now, what the hell do you think? Then when you come home and start to process everything, when the funeral is over ... then, at that time, would you appreciate [talking to] someone [...] And then, like, everything becomes quiet. And then it's like, okay ... am I not good enough to receive care now, or what? You feel like that, at that time. So, I would have liked to have someone [to talk to] later on. (Respondent 3: 22 years of age, 10 years since diagnosis)

4. Feeling stigmatized and exposed in social contexts while needing an allowing space to talk about their experiences

Respondents described a considerable need for meaningful interpersonal relationships that allowed them to articulate their experiences and have their emotional situation acknowledged by others. However, various situations of social exposure, mistreatment and even stigmatization were described. These types of negative experiences of interactions and interpersonal relationships included feeling neglected or bullied at school. Respondents described feeling like classmates avoided them, did not talk to them, and excluded them from social interactions at school. For example, one experienced that no one wanted to sit next to her or borrow things from her in school, because they were afraid to get infected with cancer.

People didn't want to sit next to me, they threw away my sunglasses and everything, they didn't want to borrow me pencils because they thought that they would get infected with cancer and stuff like that ... (Respondent 2: 20 years of age, 8 years since diagnosis)

While wanting and feeling a need to be acknowledged for the emotional difficulties that they experienced, respondents simultaneously did not want others to express pity over their situation. Respondents described that their own situation was an excluded topic in conversations with others. From their perspectives, people in their social networks were focused on the wellbeing and health of their ill sibling and parents, and did not express any interest in their own situation as a sibling to the ill child.

Many times, I listened to people who said that they felt sad for my family, that they felt sad for my sister and parents. That they felt sad for my sister who was sick and for my parents who had such a sick child, and then I felt, like, what about me ... (Respondent 4: 23 years of age, 5 years since diagnosis)

Attending camps presented an opportunity to be in an allowing space free of social exclusion and stigmatization. Several expressed that it was beneficial to meet peers at these meetings, i.e. other young people with siblings diagnosed with cancer. Meeting peers through support groups reduced the sense of loneliness, made them feel more understood, and resulted in a sense of emotional relief. Opening up and talking about their experiences together with peers also contributed to an increased understanding regarding how the disease impacted their own situation and their relationship with their ill sibling. Through these meetings, respondents received helpful tips and ideas how to talk to their sibling diagnosed with cancer. The meetings also strengthened their emotional bond that they had with their sibling. Moreover, attending camps meant doing an activity together with their sibling that gave them the opportunity to talk in new ways with their sibling.

It feels like we [me and my sibling] will continue to grow closer, the more we participate in these type of activities [peer support group meetings] together, where we can learn and talk about what we have learned. (Respondent 7: 22 years of age, 16 years since diagnosis)

After the conclusion of treatment, respondents placed a higher value in their relationship with their sibling and experienced existential insights, including thoughts about the fragility of life and a deepened respect of the possibility that life could end at any moment. These insights resulted in taking greater steps to providing care for their sibling and placing a higher value in their relationship. Those who lost their sibling due to cancer described that it felt important to continue to talk about them after their death, to integrate them in their current lives and keep the memory of their sibling alive. For example, this was done by celebrating their birthday or listening to music their sibling used to like.

Sometimes, I bake a cake on her birthday. With green whipped cream. Usually, I do that. I light a few candles and [say out loud] it's your birthday, happy birthday. (Respondent 3: 22 years of age, 10 years since diagnosis)

5. Discussion

The aim of this study was to explore experiences related to interpersonal relationships following a cancer diagnosis in a sibling. The United Nations Convention on the Rights of the Child (UNCRC) highlights the perspectives and rights of children and adolescents, who are regarded as competent individuals with the right to be involved in matters that may affect them (United Nations, 1989), including social situations. The findings of this study illustrate that children and adolescents who have siblings diagnosed with cancer may experience difficulties maintaining an active agency, defined as the ability to intentionally influence one's own life (Bandura, 2006). Parents are often forced to focus their attention towards the ill child, while activities around healthy siblings, such as school attendance, are managed with help of others (McLoone et al., 2013). In line with previous reports (Long et al., 2015), the findings illustrate that a cancer diagnosis in a sibling may result in increased demands in everyday life, involving unfamiliar chores and responsibilities usually taken care of by parents. Indeed, a diagnosis of childhood cancer entail a need for redefinition of the roles among family members (Koch et al., 1996) which may result in role overload for healthy siblings to children diagnosed with cancer (Hamama et al., 2008). Role overload, defined as an imbalance between role demands and the capacity to meet those demands (French and Caplan, 1973), is associated with higher anxiety and increased psychosomatic symptoms (Hamama et al., 2008). In this study, experiences of role overload was linked to feelings of being insufficiently involved in the care of the ill sibling and failure of having a supportive sibling relationship.

Respondents experienced negative reactions, mistreatment and bullying, indicating stigmatization, i.e. disapproval of a person because of an attribute that distinguish them from social norms (National Center

for Biotechnology information, U.S. National Library of Medicine, 2011). This calls attention to the great impact on psychosocial well-being that a cancer diagnosis in a sibling may involve. The findings illustrate the importance of acknowledging the psychosocial support needs among siblings of children diagnosed with cancer, and emphasize the need for family-centered care in pediatric oncology. This is in line with findings of a recent study, which stresses the importance for siblings to be included during the illness experience (Tasker and Stonebridge, 2016). Judging from our findings, health professionals need to be mindful of the potentially vulnerable social situation experienced following the diagnosis, and prepared to initiate appropriate supportive interventions accordingly.

Respondents experienced social exclusion during and after the cancer treatment, including insufficient or lack of interpersonal relationships with health professionals. This involved an experienced lack of information, awareness, and support from health professionals. A substantial body of literature illustrates the importance and challenges of timely and high-quality information from health professionals following a cancer diagnosis (Bakker et al., 2001; Bousquet et al., 2015; Lerman et al., 1993; Norberg et al., 2005; Vetsch et al., 2017). In line with previous studies (Lövgren et al., 2016), this study shows that children and adolescents who have siblings diagnosed with cancer desire accurate information, but are at risk of experiencing unmet informational needs and poor communication with health professionals. A previous study has shown that parents who have children diagnosed with cancer express that health professionals seldom make any attempts to help siblings to their ill child (Ballard, 2004). Age-accurate information offered to children and adolescents who have siblings diagnosed with cancer is an essential aspect of family-centered care, in order to promote their participation in matters that affects them (Skivenes and Strandbu, 2006). The findings illustrate that it is possible that health professionals may fail to acknowledge the informational needs of siblings, and indicates a need for interventions that aim to improve professional information provision to siblings of children diagnosed with cancer.

Peer support, defined as mutual social and emotional support between persons with similar experiences (Solomon, 2004), has the potential to provide emotional, appraisal and informational support from someone who is considered an equal (Dennis, 2003). Positive effects of social support from peers were described among the respondents, including reducing feelings of loneliness and feeling understood. In oncology populations, cancer camps are increasingly popular, and have been shown to have positive effects on social acceptance, self-image, independence, social skills and self-esteem among adolescent cancer survivors (Meltzer and Rourke, 2005; Peikert et al., 2018). While there is limited research concerning the effects of attending camps for those who have siblings diagnosed with cancer, studies indicate positive effects on psychosocial outcomes (Gerhardt et al., 2015), that camps are experienced as an appreciated way to get a break from daily life at home, and that it is perceived as a way to receive support in an accepting atmosphere (Wu et al., 2011). An important aspect to consider is that the recruitment of respondents in this study took place at a camp. Thus, the findings concerning the positive experiences related to peer support might be expected. Nevertheless, our findings calls attention to the potential positive effects on psychological health that peer support may result in for persons within this population. However, there is still a need for future research that investigates the possible effects of peer support for siblings. Such studies should include larger and more varied samples than our study.

5.1. Methodological considerations

There are some methodological limitations that need to be taken into account when interpreting the findings. First, the respondents were recruited by means of convenience sampling, which took place during a camp arranged by the Swedish Childhood Cancer Foundation. Thus, the

sample represents a subgroup of individuals who chose to participate in the camp. It is possible that siblings who do not desire to be involved in such activities have different experiences. We failed to recruit males, and the sample consists of 7 respondents in total. The median time since the diagnosis was 10 years, implicating a possible risk of recollection bias among the respondents. On the other hand, the range in time since the diagnosis indicates that our sample was diverse in that regard. Taken together, the transferability of the findings may be limited to sisters who have had time to reflect on their experiences related to the treatment period. Saturation, i.e. the achievement of no new findings when more data is collected from new respondents (Tong et al., 2007), is a debated and often vague concept in the literature (Carlsen and Glenton, 2011). Malterud describes that rich and varied data is prioritized over the actual sample size, and argues that the aim of an explorative study is not to deliver a complete presentation, but rather to contribute with a new understanding regarding a certain phenomenon (Malterud, 2012). The data used in this study consisted of 181 pages of transcribed text, and the respondents were encouraged to share all the information they wanted during the interviews. We argue that the data used in this study is information rich, and that the findings should be regarded as hypothesis generating related to the explorative aim. Second, it is possible that the respondents did not disclose all types of experiences related to interpersonal relationships during the interviews. To confront this possibility and promote the respondents to feel comfortable, they were interviewed in private one-to-one face-to-face settings according to their preferences. Third, the analysts may have been unsuccessful at identifying all aspects of experiences described in the interviews. In qualitative studies, researchers are the instruments used to analyze the data. Thus, all qualitative analyses include a risk of misinterpretation and bias (Patton, 2002; Tong et al., 2007). Two researchers with different backgrounds were involved in the analysis, both with different professional backgrounds and with previous experience of conducting qualitative analyses, implicating that the interviews were approached from two different perspectives. Nevertheless, we acknowledge the risk that some information may have been unnoticed or misinterpreted during the analytic process.

6. Conclusions

The findings of this study illustrate the overall complexity related to interpersonal relationships following a cancer diagnosis in a sibling. When children and adolescents are presented with a cancer diagnosis in their sibling, being sufficiently involved in the process is an essential aspect in order to achieve family-centered inclusive care. However, involvement in the care of the ill sibling may be hindered by having to take responsibility of household chores and to attend school, resulting in feelings of social exclusion. Feelings of stigmatization and social exposure present a risk of psychological distress following the diagnosis. Having an allowing space where they are free to communicate their feelings and experiences is highly appreciated and desired. Social support from peers with similar experiences may be particularly appreciated and could be a potentially effective psychosocial intervention in need of further investigation. Health professionals need to take into consideration the emotional difficulties and vulnerable situation that children and adolescents who have siblings diagnosed with cancer are at risk of experiencing due to changed interpersonal relationships. The results highlight the importance of providing professional psychosocial support for families, so that they may cope and help each other during this stressful period. This includes facilitating communication within the family, helping parents understand the situation of healthy children in the family, and informing parents how they may support their family members. The findings call attention to the importance of acknowledging and supporting a continued relationship between sick children and their siblings during and after hospital admission. Interventions may be necessary to help persons who have siblings diagnosed with cancer cope with increased responsibilities in everyday life and social

exclusion.

Conflict of interest

None declared.

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