

Siblings' experiences of everyday life in a family where one child is diagnosed with blood cancer: A qualitative study

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Abstract

Background: Childhood cancer not only presents challenges to the life of the child with cancer but also to the siblings' daily family life. The aim of the current study was to gain a better understanding of siblings' experiences of living in a family where one child has been diagnosed with blood cancer. **Methods:** Ten siblings of children with leukemia or non-Hodgkin lymphoma completed a semi-structured interview about their everyday family life experiences post-diagnosis. The verbatim transcripts of the interviews served as the data for an interpretative phenomenological analysis. **Results:** The results showed that overall the siblings experienced a continuity in many aspects of their family life: they still experienced their family as an important source of support and information/communication, as warm and loving and as a safe harbor where family members aim to protect each other. However, at the same time, the participating siblings also expressed that some things felt unmistakably different post-diagnosis: they felt that their family as a whole had been ripped apart, with a greater focus on the diagnosed child and changing responsibilities for each family member. **Conclusion:** This study informs parents and clinicians about the daily family life experiences from the siblings' perspective, a perspective that is often overlooked. A focus on challenges as well as continuities within family life, the wish for connection expressed by the siblings, and the uniqueness of every sibling's experiences is what can be taken away from this study by psycho-social workers in the field.

Keywords: Cancer, Siblings, Family, Qualitative research

Introduction

Pediatric cancer is a major life event that presents many challenges to the life of the child receiving the diagnosis, the parents and any siblings (Alderfer & Kazak, 2006). To date, plenty of research has focused on the impact of a pediatric cancer diagnosis on the physical and psychosocial well-being of the different family members. The current body of literature shows that, across family members, most adjust well over time, with a minority of patients, parents and siblings showing social or emotional problems during or after treatment. For example, symptoms of anxiety, depression, antisocial behavior (Brinkman et al., 2016) and distress (Michel, Rebholz, von der Weid, Bergstraesser & Keuhni, 2010) can be found in patients, post-traumatic stress symptoms, emotional distress and anxiety (Grootenhuis & Last, 1997; Patino-Fernandez et al., 2008) in parents, and worry, sadness and post-traumatic stress symptoms (Alderfer et al., 2010; Long et al., 2018) are sometimes reported by siblings. To optimize interventions for those experiencing difficulty, it is important to better understand the impact of a pediatric cancer diagnosis on all family members.

Within the past decade, research on sibling adjustment has steadily grown (Long et al., 2018). However, up till now, most of the research on pediatric cancer still focuses upon the diagnosed children and their parents (Kaplan, Kaal, Bradley & Alderfer, 2013). As siblings are embedded in the family and therefore influenced by the illness as well as by the way in which the other family members respond to pediatric cancer (*Social Ecology Model*; Bronfenbrenner, 1977), more research on siblings is needed in order to best capture their unique experiences.

Previous literature on siblings

The adjustment and experiences of siblings of children with cancer are – to date – summarized in different systematic and integrated reviews (Alderfer et al., 2010; Long et al., 2018;

Van Schoors, Caes, Verhofstadt, Goubert & Alderfer, 2015; Van Schoors et al., 2017a; Wilkins & Woodgate, 2005; Yang, Mu, Sheng, Chen & Hung, 2016; Zegaczewski, Chang, Coddington & Berg, 2015), illustrating a predominance of quantitative compared to qualitative studies (Long et al., 2018). Quantitative studies on siblings showed that, overall, mean levels of anxiety, depression and general adjustment are similar across siblings and comparisons (Long et al., 2018). However, for a significant subset of these children, negative emotional reactions (e.g. fear, worry, sadness, helplessness) and poor quality of life in emotional, family and social domains were found (Alderfer et al., 2010; Zegaczewski et al., 2015). Moreover, two-thirds of the siblings endorsed moderate to severe levels of post-traumatic stress symptoms, illustrating their risk for psychosocial adjustment problems when facing pediatric cancer (Long et al., 2018). In addition, school-aged siblings show poorer academic functioning and more absenteeism compared to peers (Alderfer et al., 2010; Long et al., 2018). In qualitative studies that have examined siblings' views of the effects of pediatric cancer on their lives, there are two predominant themes. First, most qualitative studies have focused on the impact of the cancer diagnosis on the self (individual level), indicating worry about the diagnosed child and fear of death (Nolbris, Enskar & Hellstrom, 2007; Prchal & Landolt, 2012) as well as the presence of negative emotions like sadness, anger and jealousy (Woodgate, 2006). Indeed, the cancer experience is emotionally potent for siblings and intense negative emotions are often elicited (see Wilkins & Woodgate, 2005 for an overview). Second, some studies have examined the impact of the cancer diagnosis on family life as perceived by the siblings (interpersonal level). For instance, there is a preliminary evidence on siblings' perspectives on the impact of a cancer diagnosis on specific aspects of family life (e.g., family communication - Sloper, 2000 or family support – Woodgate & Degner, 2003) and on the changes within family functioning post-diagnosis (Björk, Wiebe, & Hallström, 2005; Long, Marsland, Wright, & Hinds, 2015; Van Schoors et al., 2015; Yang et al., 2016). Qualitative research from the

siblings' perspective clearly indicates that childhood cancer disrupts the functioning of the family in various ways, e.g., decreased parental attention, family separations and disintegration of familiar family dynamics (see Van Schoors et al., 2015 and Wilkins & Woodgate, 2005 for an overview). Surprisingly, however, (1) less research has looked at siblings' experiences of *daily family life* after facing a pediatric cancer diagnosis. In addition, (2) in the majority of the existing qualitative studies, the specific aspects of family functioning that were included in the study were selected by the researchers. As a consequence, the siblings themselves got little freedom to talk about what really mattered to them, and therefore those unique aspects of family life that felt unmistakably different for siblings post-diagnosis could possibly have been missed.

The present study

The aim of this study was to gain an increased understanding of (1) how siblings experience their *everyday family life* post-diagnosis, (2) allowing them to put their *own* emphasis on particular family aspects that *matter to them*. To this end, a qualitative study with interpretative phenomenological analysis (IPA; Smith, Flowers, Larkin, 2009) based on in-depth semi-structured interviews was selected. IPA is a qualitative research method which draws on the theoretical principles of phenomenology, hermeneutics, and idiography. This approach comprises of an in-depth exploration of the participant's lived experiences and how participant makes sense of these experiences (phenomenology), while emphasizing the active role for the researcher in the process of interpretative activity (hermeneutics). An idiographic focus means that only a limited number of cases are included and that each case is scrutinized in its own right before moving on to an analysis on a group level.

IPA has been applied successfully in the context of health psychology in general (Smith, 2011) and living with cancer more specifically (Reynolds & Lim, 2007), as well as on the lived experiences of children (Kvale & Brinkmann, 2009). Interviewing children allows them to voice

their own experience and helps us understanding their lifeworld. In addition, IPA studies are often about experiences that have a strong impact on people's lives. In this context, we focus on the lived experience of a sibling becoming ill, the moment of diagnosis, the period of intense treatment and the consequences for family life. The central research question was: "How do siblings of children with cancer describe their everyday family life when one child had been diagnosed with cancer?"

Method

Procedure

The present study is part of a larger ongoing study in Flanders (Belgium) examining the impact of a pediatric cancer diagnosis on families, i.e. the 'UGhent Families and Childhood Cancer study'. For this large-scale study, children diagnosed with leukemia or non-Hodgkin lymphoma between the age of one and 18 years, their parents and any siblings were invited to take part in a longitudinal survey study. Exclusion criteria were: 1) not speaking Dutch, 2) a developmental disorder in the diagnosed child and 3) relapse. All participating siblings, aged between 10 and 16 ($N = 27$), were subsequently invited to complete an interview about their experiences regarding the influence of the cancer diagnosis on their everyday family life. Fifteen of the participating siblings (56%) agreed to participate in this interview study, ten of whom were randomly selected for participation.

Participants

For this study, ten siblings (six girls and four boys) of children with leukemia or non-Hodgkin lymphoma were interviewed. They were all Caucasian, living in the Flemish part of Belgium and aged between ten and 16, representing a reasonably homogeneous sample appropriate to the requirements of IPA (Smith et al., 2009). Their ill brother or sister was either diagnosed with

Acute Lymphoblastic Leukemia ($N = 6$), Acute Myeloid Leukemia ($N = 1$), Chronic Myeloid Leukemia ($N = 1$), or non-Hodgkin lymphoma ($N = 2$); and aged between three and 16. Time since diagnosis varied from two to 26 months ($M = 8$). In two families, the parents were divorced; the parents of the other siblings were married. More details on the sample are listed in Table 1. Ethical approval from the University Hospitals of Ghent, Brussels, Antwerp and Louvain had been secured for the study. Written informed consent of both parents and assent of the child was obtained before each interview took place.

Table I. Background Characteristics of Siblings

Name_S ¹	Age_S	Age_DC ²	Diagnosis_DC	Gender_DC	TSD ⁷	Marital status	# Children ⁸
Thomas	10	8	ALL ³	boy	24	Married	2
Daniella	16	16	CML ⁴	girl	5	Divorced	3
Melissa	10	8	ALL	Boy	4	Divorced	3
Nicole	13	12	ALL	Boy	5	Married	2
Barbara	11	3	ALL	Boy	26	Married	3
Ulric	13	16	AML ⁵	Boy	2	Married	2
Una	15	16	Non-Hod ⁶	girl	5	Married	3
Ulfred	14	16	Non-Hod	girl	5	Married	3
Fanny	14	9	ALL	Boy	3	Married	3
Bert	12	9	ALL	Boy	3	Married	3

Note. ¹S = Pseudonym for the sibling; ²DC = Diagnosed Child; ³ALL = Acute Lymphoblastic Leukemia; ⁴CML = Chronic Myeloid Leukemia; ⁵AML = Acute Myeloid Leukemia; ⁶Non-Hod = Non-Hodgkin Lymphoma; ⁷TSD = time since diagnosis (months); ⁸#Children = number of children within the family

Data Collection

Semi-structured interviews were conducted at the siblings' home by the third ($N = 8$) and the last ($N = 2$) author. Both interviewers are clinical psychologists and are trained in psycho-oncology and family therapy, respectively. The interviews were audio-recorded, lasted between 40 to 107 minutes and consisted of three parts (full interview guideline available upon request). The first part included open-ended questions about their understanding of the diagnosis and its

treatment (e.g., “What do you know about your brother/sister’s illness?”). In the second part, open-ended questions were provided about the influence of the cancer on the life of the sibling (individual level; e.g., “How is it for you to have an ill brother/sister?”). The last part included open-ended questions about the sibling’s perspective on living in a family where one child has been diagnosed with cancer (family level; e.g., “How did your family life change post-diagnosis?”). The participants’ experiential accounts were facilitated by means of prompts (Smith et al., 2009). Pseudonyms have been given in order to protect the anonymity of the participants. After interviewing, all interviews were transcribed verbatim. These transcriptions served as the raw data of the study’s analysis.

Analysis

The siblings’ interviews were analyzed one by one by the first author using the step-by-step approach for IPA, as described by Smith and Osborn (2015). First, for each interview separately, the transcript was read a number of times to obtain familiarity with the cases. Second, first interpretations and reflections (‘notes’) were written down in the margin of the text. This annotating in IPA ensures that both descriptive, linguistic and conceptual comments are registered. In contrast to descriptive comments, linguistic and conceptual comments allow for interpretation of the data by the researcher, albeit staying close to the participants’ phrases. Third, combining the three types of notes (e.g., “this siblings emphasize that it is important to talk about emotions”) with the data then guided the phases of initial coding (e.g., code: talking is important) and the construction of emergent themes at a higher level of abstraction (e.g., theme: talking about emotions helps) which resulted in a more interpretative stance. Then, connections between these emerging themes were explored. This analytical and theoretical step resulted in a clustering of themes for each of the cases. This process was repeated for every case. When each individual transcript had been analyzed, the coded transcripts were reviewed for potential themes *across*

siblings. To this end, convergences and divergences between the individual emergent themes were sought. In a final step, all themes were translated into a narrative account, explaining in more detail the data and illustrating them with verbatim extracts from the participants.

To enhance the trustworthiness of the study (Hill, Thompson & Nutt-Williams, 1997) and to assess to what extent the analysis has been conducted systematically, transparently and credibly (see Smith et al. (2009) for more details on IPA), a team of auditors was invited to challenge the way the first author had constructed main- and subthemes at several points in the analysis. The last author was the first auditor for this study. She is a clinical psychologist and postdoctoral researcher with expertise in qualitative research in the field of family psychology and family therapy. The second author was the second auditor and is a clinical psychologist and associate professor in clinical child and adolescent psychology who specializes in qualitative research. In addition to these strategies, the Yardley criteria (Yardley, 2000) were also taken into account to ensure the quality of the study: (1) sensitivity to context (e.g., first author's expertise in pediatric oncology literature; Van Schoors et al., 2015; 2017a; 2017b), (2) commitment and rigour (e.g., the precision/completeness of the analysis undertaken and the appropriateness of the sample), (3) transparency and coherence (e.g., the description of the subsequent steps in the analysis) and (4) impact and importance (e.g., clinical implications of the study).

Results

Based on the IPA, the siblings experiences of their everyday family life when one child had been diagnosed with cancer can be clustered into two main themes: (1) Continuity within Family Life and (2) Beyond the Familiar: Facing Illness Related Challenges. Overall, in comparison to pre-diagnosis, the siblings in our study experienced continuity in many aspects of their family life (main theme 1). More specifically, they still experienced their family as an important source of support and information/communication, as warm and loving, and as a safe harbor where family

members aimed to protect each other. In addition, due to the cancer diagnosis, the siblings indicated that these key features became even *more* pronounced within the family: They became more aware of their families' resources and vulnerabilities. However, at the same time, the siblings also referred to the challenges they were confronted with due to the cancer diagnosis, expressing that some things felt unmistakably different (main theme 2): Many felt that the family as a whole had been ripped apart post-diagnosis, with a greater focus on the diagnosed child and changing responsibilities for each family member (see Fig. 1).

1. Continuity within Family Life

1a. The family as a source of support.

For most siblings, the family was an important source of support both during times of treatment and pre-diagnosis.

We are always there for each other. Because we really need each other sometimes (Ulfred, 14 years).

For this sibling, family members being available to help each other was deemed self-evident as well as necessary. In addition, most siblings seemed to experience a lot of intimacy in their family. They had the feeling that, within their family, they could count on each other, and that the other family members were available to share worries, emotions and experiences.

Verbal as well as non-verbal methods of support were reported across the siblings' accounts. Moreover, it seemed like families with younger children were more likely to make use of non-verbal support, whereas families with older children tended to combine verbal and non-verbal support. Overall, whatever the age of the sibling, all siblings felt supported by their parents and every family was characterized by their own way of providing support.

When for example, somebody felt bad, we would give a hug. We said things like 'it'll be alright' (Una, 15 years).

Two differences between support provided by mothers and fathers were reported. First, for most siblings in this study, the mother was the most important source of support within the family.

I'm really close to my mum because she always takes care of me and yeah... she's the person I would go to first (Nicole, 13 years).

Second, mothers and fathers seemed to differ in the type of support they tended to provide to the siblings. While the mother was mainly consulted on emotional issues and addressed as a person they could talk to, the father took care of providing distraction or joy in times of worry or sadness.

My mum and I can talk together very well. With my dad it's not the same. But with him I often do gymnastic tricks (Melissa, 10 years).

So, according to the siblings, mothers and fathers engaged in different supportive behaviors and focused on various aspects of the siblings' well-being. Moreover, siblings seemed to know who they could rely on, depending on what they needed (e.g., talking, distraction).

Finally, when confronted with pediatric cancer, the importance of family support was further reinforced.

We supported each other when something was going on. It was also like that before, but now I think it was even more (Ulfred, 14 years).

This sibling described that family support had always been apparent but became even more essential post-diagnosis. Moreover, it seemed that siblings not only needed more support from their parents, they were now also confronted with their parents needing support (emotional or practical).

I gave my mum and dad a lot of support, and my mum actually said that that wasn't necessary, but I just did it (laughs) and they supported me in return (Melissa, 10 years).

This sibling talked about both receiving *and* giving support within the family, describing this mutual support as something obvious to her. And although she expressed this reciprocal process of caregiving as neither needed nor expected by her parents, she believed that she could do her part

too. Indeed, siblings indicated that they not only provided practical support, such as helping in the household, but also provided help on an emotional level as they assisted their parents with coping with the cancer experience. For example, some siblings described that they helped their parents by giving them a hug or by talking; according to others, simply being present was the most helpful.

1b. Talking about difficult issues.

Talking about the cancer diagnosis and its consequences was often perceived as hard by the siblings in our study. They highlighted three things of importance in talking about the illness. First, the siblings found it important to get answers to their questions concerning the illness, either from their parents or from the medical staff.

When we asked questions, they [parents] always tried to answer them directly. And when they didn't know the answer, we went with them to the hospital and then they [hospital staff] explained it to us there (Ulfred, 14 years).

Second, the siblings found it also important that their parents made time for them to talk about the illness and its consequences.

I sometimes wanted to talk myself, because I wanted to know how he was. Sometimes my mum herself said things like "Shall we talk about it?" And then I always answered "yes" because that would be a load off my mind (Thomas, 10 years).

This quote illustrates the beneficial effects of talking about the illness for this sibling.

Additionally, the fact that his mother *invited him* to talk was received positively. Indeed, being invited to talk about the illness possibly lowered the threshold to introduce the cancer subject and therefore facilitated finding a way of coping with the distress it caused in the sibling. However, across the siblings' accounts, it seemed that siblings did not always feel like talking about the illness themselves. Sometimes they preferred not to talk or think about it.

Int: And how do you try to cope with that...?

Bert: By not thinking about it. Even though you know, you just don't even say something about it or think about it (12 years).

Finally, the siblings in our study pointed at a process of regulating the level of information being exchanged within the family. The siblings indicated that, in talking about difficult issues (e.g., problems at school), they had always taken into account the capabilities and the workload of their parents and their brothers/sisters. However, from the moment of the cancer diagnosis onwards, they seemed to take into consideration which and how much information they were willing to share even more than pre-diagnosis. For example, for most siblings, knowing all the details about the illness, the treatment and the prognosis of their brother or sister was not necessary. What they needed was a brief and accurate update.

Well, the doctors tell it to my parents, to my mum in particular. I'm not present there very often. And then my mum and dad sometimes tell me something, but yeah, not everything. And I really don't need to know everything (Nicole, 13 years).

1c. A warm and loving family.

Due to the many hospital stays, the family as a whole spent less time together. As a consequence, most siblings really looked forward to being together with the diagnosed child, and used every free moment to visit their ill brother or sister in the hospital.

Especially during the last hours in class, I would be keeping an eye on the clock, for example on Wednesdays because I knew that in the afternoon, we would go and visit my brother. And then I would be counting down the seconds until the bell rang and, yeah, eating really quickly and then leaving for the hospital (Nicole, 13 years).

In addition, side effects of the cancer treatments (e.g., fatigue or nausea) complicated time together at home. The diagnosed child was often limited in his/her possibilities to play together with the healthy sibling, which sometimes elicited feelings of sadness or loneliness in the sibling.

He can't do anything, so why would I, yeah... I can't have fun then. Because before, I'd done everything in my life together with my brother. He came pretty soon after me, so we know each other very well and we are best buddies (Thomas, 10 years).

However, despite the obstacles for being together presented by the illness or the treatment, all siblings described the love within their family. The siblings felt loved by their parents and the

diagnosed child, and loved them in return. Whether it was in words or simply by hugging each other, each family seemed to have its own ways to express this love.

Finally, most siblings indicated that family cohesion was even strengthened by the illness. The siblings spoke about the illness drawing the family closer together and appreciated time spent together more.

The illness not only has negative influences, you know. Well, there are a lot of negatives, but it can also bring your family closer together. In my case, it was already good, and now it's just really good, let's say even better (Ulric, 13 years).

1d. Trying to protect each other.

Most siblings described that within their family, all family members looked after each other, e.g., by trying to prevent the others from feeling sadness or distress. Parents tried to prevent the sibling from being confronted with the impairment of the diagnosed child: when the ill child was too sick (e.g., nauseous), parents tended to not want the sibling to visit their brother/sister in the hospital.

I myself have never seen hem ill, I've never seen hum throwing up. I only saw him very tired and weak. Most of the times that I wanted to go, my mum and dad would keep me at a distance so that I would not see this (Ulric, 13 years).

The siblings themselves also tried to protect their parents and the diagnosed child. Some siblings believed that by sharing their own worries or sadness, they would make the others more upset. As a consequence, they sometimes did not share their emotions with their parents and the diagnosed child, and tried to cope with it alone or with others outside the family.

I don't talk about the illness with my brother. That makes you, yeah, I don't know. Maybe it could make him feel sad. So I don't see any reason to talk about it (Ulric, 13 years).

Moreover, one sibling not only avoided sharing negative emotions in order to protect her family, but also avoided sharing the positive things she experienced, for instance the contacts she had with others while her sister was in hospital.

And when they [friends] said: "Say hello to her from me" I actually didn't do that. Because... I don't know. I felt sorry for her. Then it would have been like: 'I had to say hello from this person and I talked to that person'. And Nadine didn't

get to see anybody. Maybe it would do her good, but I thought it was hard to tell her when she herself didn't see anybody. I saw a friend who she hadn't seen in a long while and she said 'say hello to her'. Then I answered: "Maybe you could send her a text" (Una, 15 years)

This sibling seemed to believe that if she shared her social encounters, the diagnosed child would become more aware of her own impairment and that this confrontation would be painful for her. The discrepancy between the diagnosed child's daily life and that of the siblings made it hard for siblings to share these experiences, as siblings might feel ashamed that their lives continued, while the life of the diagnosed child temporally seemed to be on hold. Furthermore, this quote also illustrates how this sibling tried to maintain the diagnosed child's social network. By encouraging friends to keep in touch with her ill sister, she tried to ensure that external support for the diagnosed child was sustained.

Finally, in these critical times of cancer diagnosis and treatment, the wish to protect each other became even more pronounced. At the same time, however, siblings felt the impossibility to protect their loved ones all the more. Indeed, from the moment of the cancer diagnosis onwards, siblings seemed to be confronted with the idea that in some cases it is not possible to protect their family. They became more aware of the vulnerability of life and reported having catastrophic thoughts about losing their parents or brother/sister.

I am more worried. My father does 10,000 steps a day, and these days I don't like it when he goes for a walk at night, because I imagine that something might happen to him. And I felt the same when August [other sibling] left for his camp: 'Imagine something would happen to him' (...) And also when mum and Ken drive to the hospital I think 'I hope nothing happens to them'. Before, the fact that something could happen didn't come to my mind. And now that something has happened, it does (Fanny, 14 years).

2. Beyond the Familiar: Facing Illness-related Challenges

2a. Ripped apart by the illness.

Whereas, in the first main theme, siblings described continuity in many aspects of their family life, they were at the same time also confronted with many challenges and expressed that some things felt different post-diagnosis (main theme 2). For example, due to the many hospital stays, the

family members were hardly ever all together. Most of the time, the diagnosed child was accompanied by the parent(s) to the hospital, and the siblings were taken care of by others or took care of themselves.

When Nadine had to go to the hospital, our family was separated. When Nadine was back, we were reunited. So yeah, then there really was a feeling of 'we're back together again'. That was good (Ulfred, 14 years).

This sibling described that he felt most happy when everyone was at home. Indeed, for most siblings, being separated from the rest of their family was hard: They missed (the help of) their parents.

Sometimes we also needed them [our parents], but they weren't there. But we looked after ourselves (Ulfred, 14 years).

In addition, when the siblings talked about their family being ripped apart by the diagnosis, they often referred to all the small things that had changed. In the siblings' daily routine, for instance, the absence of the diagnosed child was tangible.

The couch used to be full in the evenings, and then there was a lot of space available. That was really weird (Ulfred, 14 years).

Experiencing the absence of the family members was alienating for most siblings. They were used to being together and to doing things together, so not being together was not 'normal' for them.

At some points, everybody did their own thing more, and then I had the thought 'this isn't right for our family', because we had always done everything together (Thomas, 10 years).

Subtheme 2b: Focus on the diagnosed child.

From the moment of the cancer diagnosis onwards, all eyes were on the child diagnosed with cancer. The survival of that child became a priority and, due to the life threatening character of the diagnosis, the parents' desire to divide time and attention equally between the children gave way to a greater focus on the diagnosed child.

There used to be more equal attention for all of us children. We know that that is not possible now (Una, 15 years).

Although all siblings showed understanding for this shift in attention, for some siblings this was difficult to cope with.

Sometimes I hated that everything was about Nadine (Una, 15 years).

The diagnosed child was the center of the family, and that sometimes provoked jealousy in the siblings. In addition, some siblings felt pity for themselves. From one moment to the next, they were expected to do things on their own, things they had never done by themselves before.

For example, when it came to studying, I really had to become more independent. I had never learned to study and my mum and dad always helped with that before. Then, I had to study by myself, which was and still is quite difficult (Ulfred, 14 years).

This increased independence and responsibility was also reported by other siblings.

I think we, Tom [another sibling] and I, have become more independent in the things we have to do, you know, we became a little bit more grown up (Nicole, 13 years).

While some siblings saw this increased maturity as one of the few advantages of the cancer diagnosis and continued these new behavior over the course of the cancer treatment, others suffered from this enforced independence and were above all happy when parental help returned after a while.

Subtheme 2c: Changing Responsibilities.

The illness and its treatment resulted in changing responsibilities within the family. Some siblings indicated that they were expected to help more, or to do more little tasks at home. After all, as the parent(s) were in the hospital frequently, and often combined the hospital stays with their jobs, little time was left to manage the household.

Sometimes I have to do more at home, small things, such as cleaning up or doing things in the kitchen (Nicole, 13 years).

The siblings not only indicated changing responsibilities for themselves, but also within the parental relationship. While pre-diagnoses, the parents seemed to have clear roles and expectations

of each other, siblings noticed that this changed after diagnosis. They described that the hospital stays, the emotional impact and the unpredictability of the illness forced their parents to re-think their contributions to family life, and to make new arrangements.

My dad (laughs) does not do very much in the household, so my mum has to do everything. And before that wasn't a problem, but now she has to go the hospital most of the time, he has to do the grocery shopping and then he forgets half of the things and he – well maybe half is a bit exaggerated – but then he forgets a little something which is still quite important and then mum gets angry and so you have fights between the two of them (Nicole, 13 years).

This sibling witnessed marital distress in her parents' relationship that she linked to the changing responsibilities within the parental relationship. Irritation caused by changes in the family routines were also noticed by another sibling whose father lived somewhere else due to a divorce.

We were not really used to him being there every day, but then all of a sudden he [returned into our lives]... And sometimes, my sister and I didn't like it so much because he had his say in everything (Daniella, 16 years).

This sibling was already used to the absence of the father, and her mother taking on a larger parental role. In her opinion, it was her father's increased involvement that caused difficulties, rather than the splitting up of the family or the redistribution of household duties. More generally, it seemed that siblings in particular experienced difficulties when old routines, habits and roles changed, and regretted the fact that the cancer diagnosis changed so many aspects of familiar family life.

Discussion

In this study, we used a qualitative research method in order to gain a better understanding of siblings' experiences of everyday family life post-diagnosis. Two main themes emerged from the current data. In the first main theme, *Continuity within Family Life*, siblings indicated that many aspects of their family life stayed the same post-diagnosis and were sometimes even reinforced by the diagnosis. Four subordinate themes could be distinguished here. In the first subtheme (1a), the family served as an important source of support, a finding that has also been

reported by previous qualitative studies (Sloper, 2000; Woodgate & Degner, 2003; Havermans & Eiser, 1994). Moreover, not only did siblings receive support from their parents, they also described ways in which they supported their parents. This is in line with research on bidirectionality and reciprocity in parent-child relationships (Crouter & Booth, 2003; De Mol & Buysse, 2008; Kuczynski, 2003), in which the co-occurrence of both directions of influence is emphasized (Kuczynski, 2003). Indeed, parents do not only have impact on their children, children too influence many aspects of parent(ing) and family functioning (De Mol & Buysse, 2008; Grusec & Goodnow, 1994). In addition, although the reciprocal support between sibling and parent(s) was commonly described in the siblings' accounts, less was said about the support provided by and given to the diagnosed child. Although the importance of support between brothers/sisters after a pediatric cancer diagnosis has been commonly stressed in previous qualitative research (Havermans & Eiser, 1994), the siblings in our study might not have talked about it because this was not explicitly asked for. One other explanation could be that the physical distance between the diagnosed child and the sibling(s) could have impeded the children from supporting each other: Patient and sibling(s) were often hardly together (see theme 2) living parallel lives instead where the diagnosed child stayed at the hospital, and the siblings were at home, at school or taken care of by others.

In the second subtheme (1b), family communication about the illness was described as helpful in coping with the cancer experience. This is in line with previous qualitative research (Sloper, 2000; Wilkins & Woodgate, 2005) and a recent meta-analysis (Van Schoors et al., 2017a) which has shown that greater family expressiveness is associated with better child adjustment (e.g., less post-traumatic stress, anxiety and behavioral problems). In addition, this study builds on previous research documenting that siblings prefer so-called selective communication. For instance, although siblings generally appreciated being informed about the

diagnosed child's state of health (Woodgate, 2006), our study indicated that they wanted their parents to limit the medical information they disclosed as there was no need to know all medical details. In addition, the siblings sometimes did not feel like talking about the illness, thus, family communication could also be selective in terms of moments in which the illness is discussed.

In the third subtheme (1c), siblings described the love within their family. In addition, in line with previous qualitative research, siblings spoke about the illness bringing the family members closer to one another (Clarke-Steffen, 1997; Van Schoors et al., 2015). This increased level of cohesion is sometimes seen as one of the few positive things associated with a pediatric cancer diagnosis (Prchal & Landolt, 2012; Sloper, 2000). However, based on existing literature, we know that this increased degree of closeness is not always perceived as inclusive of the siblings (Van Schoors et al., 2015). In other words, siblings can feel that they are at the periphery of the family as family life after the cancer diagnosis is determined by the ill child's treatment and this can result in regular absences of parents and diagnosed child and a reduction in time spent together as a family (Prchal & Landolt, 2012).

In the fourth subtheme (1d), the siblings described that within their families, all family members looked after each other. One way to do this, was by trying to protect the others from feeling sadness or distress. For example, the parents protected the sibling from confrontation with impairment of the diagnosed child and did not want the sibling to visit the ill child when s/he was extremely sick. We could question, however, whether siblings feel protected by this parental behavior, or it rather caused feelings of exclusion from the family (Van Schoors et al., 2015). In addition, the siblings also tried to protect their parents and the diagnosed child, believing that by sharing their own worries and emotions, they could make the others (more) upset. Two remarks can be added. First, it is possible that siblings are less likely to share their emotions with their

parents because they find it difficult to handle the emotional impact of the illness on their parents, as well as the emotions evoked by such conversations (Prchal & Landolt, 2012). Second, as the previous literature has illustrated that after a pediatric cancer diagnosis siblings often suffer from intrusive worries about the ill child's health and prognosis (Nolbris et al., 2007; Woodgate, 2006), other sources of support for siblings may be of great value, such as other relatives, friends or teachers (Havermans & Eiser, 1994; Sloper, 2000; Van Schoors et al., 2018).

In the second main theme, *Beyond the Familiar: Facing Illness-related Challenges*, the siblings described the challenges they were confronted with due to the cancer diagnosis. Some aspects of their family life felt different from the moment of the diagnosis onwards. Three subordinate themes could be distinguished here. In the first subtheme (2a), the siblings experienced their family as being ripped apart by the illness. They were separated from their ill brother or sister, as well as from their parents, as typically one parent stayed at the hospital long-term, and the other parent spent considerable time there on visits. This is in line with the findings of previous qualitative research (Prchal & Landolt, 2012) and systematic reviews (Alderfer et al., 2010; Wilkins & Woodgate, 2005). In addition, the apparent conflicting dynamic of feeling closer together (subtheme 1c) as well as feeling ripped apart as one family (subt2a) is in line with a recent qualitative study in parents of children with leukemia and non-Hodgkin lymphoma (Van Schoors et al., 2018), illustrating the complexity of the process of family adaptation after a pediatric cancer diagnosis.

In the second subtheme (2b), the central focus on the diagnosed child was experienced as a major change to the daily family life post-diagnosis. While pre-diagnosis, parents divided time and attention equally between the children (Ganong & Coleman, 2017), this inevitably changed to a merely unique focus on the diagnosed child; a finding that has also been reported by other

qualitative studies (Prchal & Landolt, 2012; Alderfer & Hodges, 2010). In addition, the physical impossibility of parents being both at the hospital and at home sometimes forced siblings to manage alone at home. This experience of increased responsibility can be seen as an example of posttraumatic growth (D'Urso, Mastroyannopoulou, Kirby, 2017; Kamibeppu et al., 2010).

In the third subtheme (2c), the siblings indicated a shift in responsibilities within the family due to the cancer diagnosis. From the cancer diagnosis onwards, daily routines were challenged, as family life became determined by the health of the diagnosed child. More specifically, siblings reported that they took over household duties, such as cooking and cleaning (cfr. previous qualitative research: Prchal & Landolt, 2012). In addition, siblings also witnessed tension between their parents, related to changes in the division of tasks. This finding is in line with a recent systematic review illustrating that a pediatric cancer diagnosis impacts on a couple's relationship as well (Van Schoors, Caes, Alderfer, Goubert & Verhofstadt, 2017b).

Limitations of the study and suggestions for further research

Some limitations of the current study need to be addressed. First, as we report on a small-scale qualitative study of siblings, we do not intend or claim to be representative. Rather, appropriate to the requirements of IPA (Smith et al., 2009), a small number of participants was included to understand specific processes in a specific context. Second, also in line with IPA (Smith et al., 2009), we selected a homogenous sample (e.g., diagnosis). Although this homogenous sample can be seen as an advantage of our study, it is important to highlight that siblings of children with other cancer diagnoses may have different experiences. In addition, we also limited the age range of the included siblings from ten to 16. We can assume that younger or older siblings may have different experiences. Second, our focus was limited to only the sibling's experiences of daily family life post-diagnosis. As there may be discrepancies in perceptions across family members (Alderfer,

Navsaria & Kazak, 2009; Peterson, Cousino, Donohue, Schmidt & Gurney, 2012), interview studies with parents and/or the diagnosed child are needed to get insight into their experiences as well. In addition, to better understand experiences on a *family* level, we need to include and integrate the experiences of different family members, for example by making use of Multi Family Member Interview Analyses (Van Parys, Provoost, De Sutter, Pennings & Buysse, 2017). This might further our understanding of the complexity of families (Van Parys et al., 2017) and broader family dynamics (Reczek, 2010). Third, the design of our study was retrospective and cross-sectional. As time since diagnosis varied from two to 26 months, siblings' reports may be limited to their memories as well as by the extent to which they are willing to share their experiences about the cancer experience. Fourth, the reporting of our interpretations of the siblings' accounts was challenged by language differences: While the interviews were conducted in Dutch, the results were written in English.

Clinical Implications

This study affirms that the life of all family members is impacted by a pediatric cancer diagnosis and that the psychosocial needs of siblings too should be recognized and addressed by professionals (Alderfer et al., 2010). Three specific recommendations arise from this study. First, awareness of both the continuity and the challenges within family life that siblings are confronted with may help clinicians to better understand how siblings adapt. Moreover, as siblings emphasized that overall their daily family life stayed the same as pre-diagnosis, and that this continuity helped them to cope, clinical workers as well as parents should strive to retain this continuity within the siblings' lives. In addition, clinical workers and parents should be aware that some key features (support, communication, love and protection) become more pronounced within the family post-diagnosis (e.g. support is more needed or love is more palpable), and this awareness can help in normalizing siblings' feelings and behavior. Second, across the themes, the

(importance of the) connection between the siblings and the other family members was stressed. Moreover, in the second theme, every challenge can be reframed as a call for togetherness. For example, in the first subtheme *'Ripped apart by the diagnosis'* (2a), a call for pulling together as one family can be recognized, as siblings described the feeling that their family was being split in two. In the second subtheme *'Focus on the diagnosed child'* (2b) a call for togetherness between sibling and parents can be recognized, as the siblings felt a shift in focus and questioned their own position within the family. In the third subtheme *'Changing responsibilities'* (2c), a call for togetherness between the parents can be noticed, as siblings linked the revision of parental tasks to witnessed relationship stress. As a consequence, given the centrality of this concept, clinicians are encouraged to screen and focus on (difficulties in) family cohesion, taking into account evidence-based standards for family therapy and psychosocial care in pediatric oncology (Wiener, Kazak, Noll, Patenaude & Kupst, 2015). Third, clinicians working with families affected by pediatric cancer find evidence in this study to (further) take into account the fact that every family and every sibling is unique. For example, while some siblings prefer to talk about the cancer, others prefer not to talk or think about it. Taking this individuality into account would therefore foster the family adaptation.

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Fig. I. Main themes and subthemes

