

RUNNING HEAD: CHANGES IN FAMILY FUNCTIONING

Parents' perspectives of change within the family functioning after a pediatric cancer diagnosis:

A Multi Family Member Interview Analysis

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Abstract

Pediatric cancer is a life threatening disease that challenges the life of the diagnosed child, the parents and possible siblings. Moreover, it also places considerable demands on family life. The aim of the current study was to explore changes in the family functioning after a pediatric cancer diagnosis. Ten couples that had a child with leukemia or Non-Hodgkin Lymphoma were interviewed individually about their experiences. Interviews were semi-structured and the data were analyzed using Multi Family Member Interview Analysis. Three themes emerged from the data: (1) Family Cohesion: Strengthened vs. Fragmented; (2) Educational Norms and Values: Overindulgence vs. Being Stricter, and (3) Normality: Loss vs. Preservation. The conflicting dynamics present in these emerging themes exemplify the complexity of this process of family adaptation. The current study illustrates the need to take into account the family level, as well as the conflicting feelings parents may experience after a pediatric cancer diagnosis.

Introduction

Pediatric cancer is the second most common cause of death in children in developed countries (Kaatsch, 2010). Although this disease used to be mostly fatal, an increasing number of children now survive – currently around 82% of all cancer affected children survive for five or more years (Cancer Research UK, 2010). Like all chronic diseases, cancer may have a significant impact on the life of the diagnosed child (Kazak et al., 2001; Kestler & LoBiondo-Wood, 2012) and the family members (Alderfer et al., 2010; Grootenhuis & Last, 1997; Pai et al., 2007). Therefore, a growing number of studies have focused upon detrimental and protective factors for the adaptation of patients (e.g., Gliga, Balan & Goloiu, 2016), siblings (e.g., Barrera, Fleming & Khan, 2004) and parents (e.g., Caes et al., 2014; Wijnberg-Williams, Van De Wiel, Kamps & Hoekstra-Weebers, 2015), in order to promote long-term resilience in all family members and help families cope with the disease more effectively. In addition, according to recent systematic reviews, certain family characteristics (e.g., cohesion and adaptability) may determine the family members' ability to adapt to life after diagnosis (Long & Marsland, 2011; Van Schoors et al., 2016). Indeed, according to the family psychology literature (Carr, 2012) children are embedded in a family, and within families, individual family members influence each another. This idea is also embedded within various family-systems models often applied to chronic illness populations (Van Schoors et al., 2016). For example, the Social Ecology Model (Bronfenbrenner, 1977) illustrates how the child is nested within and influenced by the family system in addition to other social systems; whereas the Double ABCX-Model (McCubbin et al., 1980) posits that certain aspects of family functioning can either foster or undermine individual adjustment to illness or disability. In the case of a childhood cancer diagnosis, families must be flexible in their roles and responsibilities, communicate effectively, manage emotions and successfully work as a team in order to meet treatment demands (Kazak et al., 2004; Marcus, 2012), demonstrating the impact

on the family level and the role of family functioning as predictor of individual family member adaptation (Van Schoors, Caes, Verhofstadt, Goubert, Alderfer, 2015; Van Schoors et al., 2016).

Existing research into pediatric cancer is limited in three ways. First, most research on the subject to date has assessed the connection between detrimental and protective factors and the participants' adaptability to life after diagnosis, using questionnaires and heterogeneous samples, covering a broad range of diagnoses, child ages, and time periods since diagnosis or treatment (Van Schoors et al., 2015). These methods, however, cannot capture the unique experience of a family confronted with such a diagnosis, as well as the meaning that family members give to their unique situation (Smith, Flowers & Larkin, 2009). Second, despite a growing awareness regarding the role of family functioning in the context of pediatric cancer, most studies tend to overlook the family system-level, and focus solely on the individual level (e.g., the diagnosed child or their parents). This approach has limitations when applied to a clinical context or screening strategies, as, for example, literature has already revealed associations between (mal)adaptive family functioning and child adjustment problems (Van Schoors et al., 2016). Third, the majority of studies that focus on the family functioning only included responses from a single family member. This approach, however, may not adequately reflect the family life in its entirety (Van Schoors et al., 2015).

In order to address these limitations, the current qualitative study was conducted among parents of children with leukemia or non-Hodgkin lymphoma (1) to provide insight into personal accounts of parents' experiences, and (2) to obtain in-depth descriptions of parents' perspectives on changes in family functioning after a pediatric cancer diagnosis. In addition, (3) one-to-one interviews were conducted with the mother and father separately. This allowed each parent to provide their own perspective on shifts in family life post-diagnosis (Eisikovits & Koren, 2010), without having to factor in their partner's feelings (Morris, 2001).

Methods

Multi Family Member Interview Analysis (MFMIA; Van Parys, Provoost, De Sutter, Pennings & Buysse, 2017) was used as a methodological framework to analyze the individual interviews, focusing on the couple as the unit of analysis. This approach takes into account ethical and methodological challenges inherent to interviewing couples (Taylor & de Vocht, 2011; Ummel & Achille, 2016) and has proved effective in studies that analyze experiences shared by a couple, particularly when assessing sensitive topics such as adjustment to an illness (Eisikovits & Koren, 2010).

Participants

Ten married couples with children diagnosed with leukemia or non-Hodgkin lymphoma participated in the study. They were all Caucasian, living in the Flemish part of Belgium and aged between 37 and 56, representing a reasonably homogenous sample that conforms to the requirements of Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). The children (seven males, three females) were either diagnosed with Acute Lymphoblastic Leukemia ($N = 6$), Acute Myeloid Leukemia ($N = 1$) or non-Hodgkin lymphoma ($N = 3$). The diagnosed child's age ranged from 4 to 16 years. Time since diagnosis varied from six to 33 months ($M = 21.6$). In two families, the diagnosed child was their only child. The remaining families had either two (three families), three (three families) or four (two families) children. Ethical approval from the University Hospitals of Ghent, Brussels, Antwerp and Louvain had been secured for the study and the appropriate informed consent forms were obtained.

Data Collection

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, families of children diagnosed with leukemia or non-Hodgkin lymphoma between the age of one and eighteen years were invited to take part in a longitudinal survey. Exclusion criteria were: 1) not speaking Dutch, 2) expression of a developmental disorder in the diagnosed child and 3) relapse. All participating parents ($N = 173$ individuals, including 55 couples) were subsequently invited to complete an interview about the impact of the cancer diagnosis on the functioning of their family. In 33 of the participating couples (60%), both partners agreed to attend an interview. Ten of these couples were randomly selected and contacted by Hanne Morren. All interviews were conducted by the same interviewer (Hanne Morren), were audio recorded and lasted 60 to 120 minutes. Verbatim transcripts of these interviews served as the raw data for this study. All interviews were based on an interview schedule and consisted of open-ended questions about (a) the experience of the diagnostic and treatment process, (b) the impact of the diagnosis on the parent, (c) the family relationships and (d) the family functioning (interview details available upon request). The participants' experiential accounts were facilitated by prompts, in order to encourage the participants to give personal accounts (Smith et al., 2009).

Analysis

Data consisted of one-to-one interviews with each mother and father separately about the impact of the cancer diagnosis on their family functioning. In addition to the transcripts, further data were supplied by a task that required the participants to demonstrate the emotional bond between their family members through arranging puppets (i.e., figural technique based on the Family System Test; Gehring & Wyler, 1986): the closer they positioned the puppets, the stronger the family cohesion. The results of the task were referred to throughout the interview and informed data analysis.

Inspired by IPA (Smith et al., 2009) and Dyadic Interview Analysis (Eisikovits & Koren, 2010), Multi Family Member Interview Analysis (Van Parys et al., 2017) allows detailed and systematic analysis of shared family experiences (Smith, 1999; Van Parys et al., 2017). In a first phase, all interviews were analyzed separately, using the principles of IPA. Each transcript was read a number of times by M.V.S. in order to familiarize herself with the participant's account. The transcript was then annotated with her initial observations. Next, these initial notes (e.g., "it seems important for this father to continue the siblings' hobbies") were translated into more general themes (e.g., "life should go on"). Then, parallels were explored between these emerging themes. This analytical and theoretical step results in a clustering of themes for each of the cases. This process was repeated for each case. At the second stage, when each individual transcript had been analyzed, themes that were relevant to each couple, so *within couples*, were identified by combining the themes of both partners. In a third phase, we searched for parallel themes between couples from different families. The final list of subordinate and superordinate themes reflects patterns of convergence between different couples, so *across couples*, based on analysis of unique aspects of each parent's and each couple's experiences. As a consequence, we were not interested in gender differences, but only in the complex feelings experienced by a couple following a pediatric cancer diagnosis. Finally, all themes were translated into a written account, elaborating on the analysis and illustrating it with direct quotes from the participants. Pseudonyms were given to protect the anonymity of the participants.

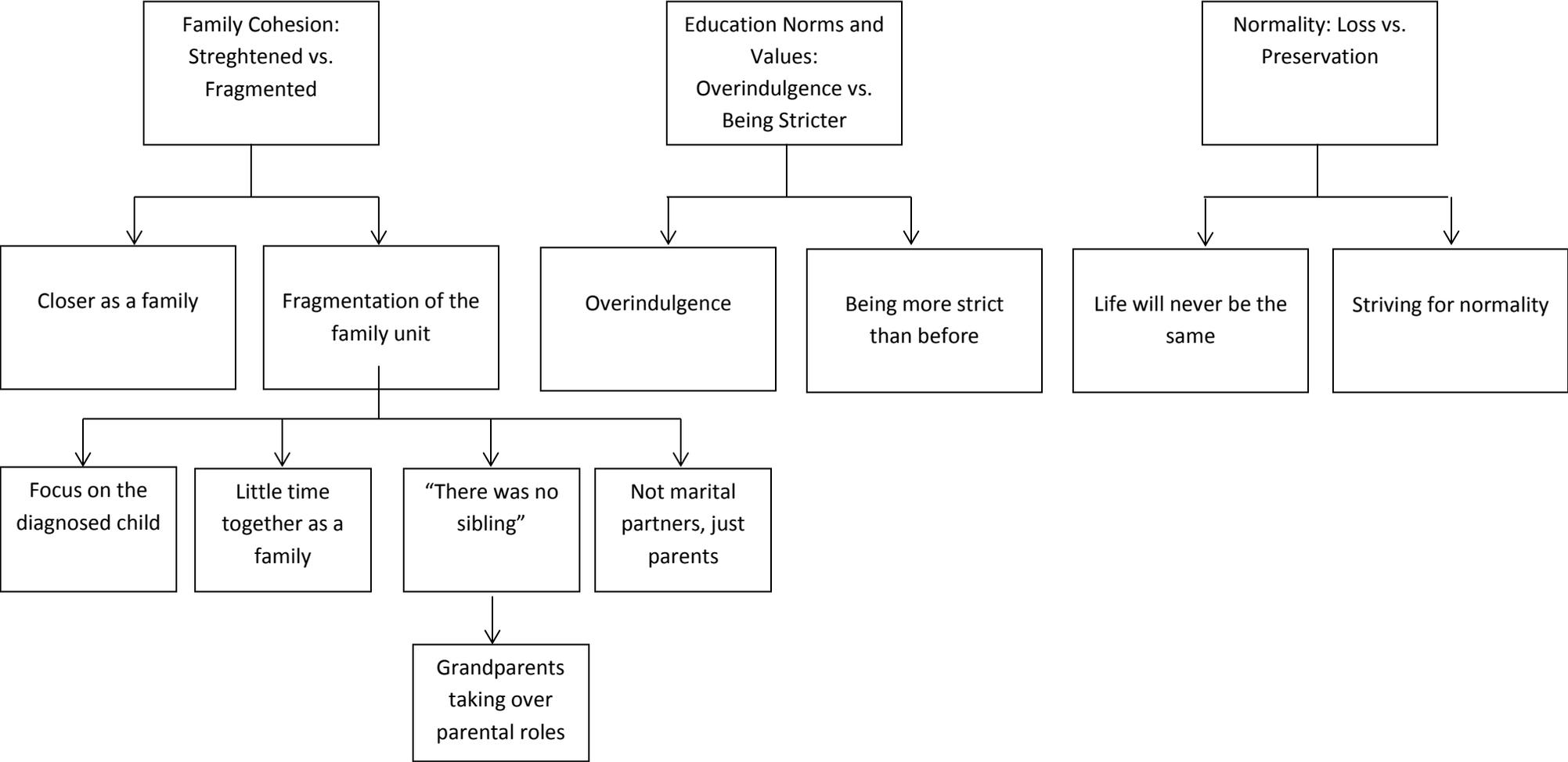
As interpretations may be influenced by personal experiences and one's own theoretical background, a team of auditors (H.V.P. and J.D.M.) was invited to challenge the way M.V.S. constructed themes and subthemes at several points in the analysis (Hill, Thompson & Nutt-Williams, 1997), and to assess to what extent the analysis has been conducted systematically, transparently and credibly (see Smith et al., 2009 for more details on IPA). M.V.S., who analyzed

the transcripts, is a clinical psychologist and PhD student. She is also trained in Psycho-Oncology, and, through her PhD is in regular contact with staff and families in pediatric cancer departments in Flanders. H.V.P. is a clinical psychologist and postdoctoral researcher with experience in qualitative research in the field of family psychology and family therapy. She was the first auditor for this study. J.D.M. is a clinical psychologist and associate professor who specializes in qualitative research. In the study, he functioned as the second auditor and notably contributed to the analysis of emergent themes.

Results

Changes in the family functioning perceived by parents were clustered into three superordinate themes: (1) Family Cohesion: Strengthened vs. Fragmented, (2) Educational Norms and Values: Overindulgence vs. Being Stricter; and (3) Normality: Loss vs. Preservation. Each of these themes comprised several subordinate themes (see Fig. 1). In addition, the complexity of the family adaptation process after a pediatric cancer diagnosis was marked by conflicting dynamics within these emerging themes. Specifically, in the first theme, the family is perceived as a stronger unit. However, at the same time, fragmentations in the family unit are also experienced, including a shift in focus towards the diagnosed child, at the cost of attention on the family as a whole, the siblings, and the couple themselves. In the second theme, parents identify the need for a new parenting approach, one that compensates for the suffering of the diagnosed child by overindulgence. At the same time, however, parents believe the child will heal and feel responsible for the child becoming a responsible adult. Therefore, parents adopt a stricter parenting approach than pre-diagnosis, in order to compensate for their overindulgence.

Fig. 1
Superordinate and subordinate themes



The third theme articulates the overwhelming impact of the cancer diagnosis on the family, which is often described by the parents as “nothing is normal anymore”. However, at the same time, families tend to strive for normality and try to safeguard the normal life of family members.

1.1 Family Cohesion: Strengthened vs. Fragmented

Being closer as a family

For most parents, the illness drew their family members closer together. This increased closeness was, for some parents, most notable at the difficult moments throughout the illness, as at those times family members stuck together and supported each other.

I do think that, in the end, we were a closer family, we were a closed circle and not much could come between us (mother of a boy, 14 year)

For this mother, support was provided by the family itself. Visualized as a closed circle, family members stood close together, with limited space for others to join “the circle” or to come between them. As a consequence, it may be difficult for others (e.g., friends) to understand how these families feel, and how they could help. In addition, some parents not only described their family as growing closer post-diagnosis, but also as playing a more important role. They recalled an increased desire to spend more time together as a family, instead of (for example) focusing on their careers.

The world stopped turning. I enjoy life more. Let’s say, I used to live for my job and my career, but now I want to enjoy things more. Enjoying it for the full 100% and going on a holiday with the children (father of a boy, 4 year)

These parents started to change their attitude to life: their family came to play a major role in their sense of self, and extra-familial things became less important.

1.2 Fragmentation of the family unit

From the moment of the cancer diagnosis, the diagnosed child became the center of focus in the family. As a consequence, all parental time and attention were focused on this child, strengthening the bond between parent(s) and patient. At the same time, however, this shift in

focus often put a strain on relationships with healthy siblings, and as marital partners, creating fragmentations in the idea of ‘the family as one unit’.

Focus on the diagnosed child

Due to the fatal character of a cancer diagnosis, the parental desire to divide time and attention equally over the children changed in a merely unique focus on the diagnosed child. This was, for example, described by both parents of a 14 year old boy:

You just focus on that child. Like being there for him when he feels down, to cheer him up again (mother).

Rick actually always comes first (father).

In all families, the pediatric cancer diagnosis resulted in a stronger emotional bond between the parent(s) and diagnosed child, while the relationship between parent and siblings remained unchanged.

Victor made me a father, and I’m very grateful to him for that. He used to be a real pain in the ass, believe me. I loved him and he didn’t love me. And what happened with the illness, we became a lot closer. (father of a boy, 6 year)

Parents seemed to struggle with this shift in attention to one child at the expense of the others.

Given that such parental behavior differs from the general normative expectations that each child will be loved in the same way, some parents tried to rationalize their behavior. For example, parents explained the increased closeness between themselves and the diagnosed child as a result of the child’s increased vulnerability. After all, due to the side effects of the treatment, most children undergoing chemotherapy could no longer take care of themselves.

I suppose that now I have a much stronger bond with my son than most parents would have with their eldest child.

Because, right before puberty, so drastic, wiping his bum again ... (father of a boy, 14 year)

In some families, a different impact on the bond between diagnosed child and each of the parents was identified. Parents attributed this to the fact that, on a couple level, one parent became the main caregiver of the diagnosed child and quit his/her job in order to accompany the child to the hospital, while the other parent continued his/her work in order to guarantee financial security.

The bond between the diagnosed child and the main caregiver was strengthened, while the impact on the bond with the other parent was less pronounced.

He's much more attached to my wife these days because she has been at home for the whole period. She's always been with him so. But I think it's normal, that the one they see the most ... (father of a boy, 4 year)

Finally, the continual presence of the carer tended to result in enmeshment. Children may become used to the constant presence and help of this parent, making the transition to autonomy a greater challenge.

Due to the fact that you're together 24/7 for half a year, and also supporting her in difficult moments, because those injections are not much fun. So Mummy's there for everything and in the long run Mummy needs to be there for the stupidest things, things she could do perfectly well herself (mother of a girl, 5 year)

Little time together as a family.

In many families, the parents worked hard to ensure that one of them was always at hospital, accompanying the diagnosed child, while the other stayed at home with the siblings, or went to work. These roles were often switched regularly, so both parents could support the diagnosed child and take care of the siblings.

My husband and I alternated: I stayed with Talia in the hospital for a couple of days and then I went home for a moment so the other children could see me as well and then my husband was in the hospital (mother of a girl, 5 year)

Aside from being preoccupied with the care of the diagnosed child and the desire to spend as much time as possible with this child, parents were also concerned with their parental duty to any siblings. They seemed to struggle with their desire to always accompany the diagnosed child, therefore not providing adequate care for the siblings. In addition, parents reported feeling guilty and obligated to divide their time and attention between all children. This pursuit of a balance was a common theme among the couples.

At the beginning, it's really hard, you need to find a balance between the hospital admissions and time at home with the other children, somehow trying to be *one* family (mother of a boy, 4 year)

The words “trying to be *one* family” are notable and recur in other interviews. However, the impossibility of caring for the diagnosed child and maintaining their parental role towards the siblings could cause fragmentation of the family unit. The emotional struggle aside, it also was practically impossible for parents to be simultaneously at the hospital and at home. Consequently, it seemed unavoidable for most that the family relationships would become strained

In the beginning, your family life falls apart; boom, you fall down an abyss so to speak (father of a boy, 14 year)

“There was no sibling”

The disease not only resulted in less family time, but specifically in less parental time and attention for any siblings. During treatment, siblings were “in the background” of the family.

A huge amount of your time and attention goes to the one child undergoing treatment, and the other children get, yeah, they’re a little bit in the background (father of a girl, 5 year)

Although parental attention was mainly focused on the diagnosed child, families differed in their approaches to the siblings. In two families, the sibling was a newborn baby, and because of breastfeeding, the baby was always with the mother, while the father barely saw them. Both parents of a 6 year old boy reported:

There was no relationship with [name sibling]– that really was something, there was no daughter right (father)

I was at the hospital with two children, because at that time I still breastfed her, so it all was a bit crazy (mother)

In addition, parents indicated that the siblings had to cope with this extreme stressor with only limited parental support. And although parents were aware of this situation and felt guilty about it, they saw no other solution at that time.

The treatment is so intensive and relatively little attention was dedicated to [name sibling]. That’s what I feel guilty about. He had to cope without us. I really struggle with that. I just hope that he will not blame us for it later, that we weren’t there enough for him. And if it gets that far, and he takes it badly, then I will be very humble and not try to find excuses. Then I will say ‘you’re right. But I don’t know how we could have done it differently’ (father of a boy, 9 year)

Apart from feelings of guilt, parents also expressed a worry that they would later be blamed by their other children. This not only seemed unavoidable, but also understandable to the parents. In

addition, we noted that in the context of pediatric cancer, parents are confronted with overwhelming feelings of helplessness and situations in which they need to depend on others. For example, in the case of treatment of the diagnosed child, parents depend on the medical team; and to fully meet the needs of the siblings, parents depend on others to take care of them (see “*Grandparents taking over parental roles*“). Consequently, parents did what they thought was best, and could only hope the sibling would understand, both now and later in life.

Grandparents taking over parental roles

In most families, other family members took care of the siblings, helping them to cope with this life event.

I think the biggest change was for the two eldest, because in that period, they were mostly looked after and brought up by their grandparents (father of a girl, 5 year)

It is unclear from the data whether involved grandparents enabled parents to spend as much as possible in the hospital or whether they merely filled the parental vacuum. Nevertheless, parents always remained committed to the siblings’ well-being, as even in their absence they tried to make the best possible arrangements for them.

I thought it was important that the siblings could stay at home, I didn’t want them to go from one set of grandparents to the other, I preferred that they stayed at home and the grandparents came to them (mother of a girl, 5 year)

Although the grandparent's care was usually practical and exerted little influence on the relationship between the parents and the siblings, one family experienced a degree of estrangement between parents and child.

[Name sibling] has been with my Mum a lot at that time. So, one time when Victor was doing very badly, I tried to go to her. She was afraid of me and she crawled to my Mum... (mother of a boy, 6 year)

It seemed that this mother was rather upset by the observation that her child temporarily formed a closer bond with the grandparent than with her. After all, every parent wants their children to love them, even in the context of pediatric cancer where parents feel obligated to focus their time

and attention on one child. Furthermore, after treatment is completed, parents may have to deal with the aftermath of this disruption to family life. Siblings may have become accustomed to living with the grandparents and difficulties arise when the sibling has to move home again.

He got used to being with his grandparents all the time. And it was very difficult to get him to come back home (mother of a girl, 9 year)

The help and support the parents get from other family members seemed to be necessary to fulfill not only their own needs (i.e., spending as much time as possible with the diagnosed child), but also the needs of the siblings. However, grandparents taking care of the siblings may also disrupt family functioning.

Not marital partners, just parents

The focus on the diagnosed child also has consequences for a couple's underlying relationship. As both parents tried to accompany the diagnosed child as much as possible to the hospital and divided their remaining time between the siblings, their jobs and the household, little time was left to spend as marital partners.

It's been either my husband who came here (to the hospital) or myself, we always split it up, we were seldom here together (mother of a girl, 9 year)

Parents rarely spent time together and they felt like their lives as partners, beyond their lives as parents, had disappeared.

We used to have many shared activities, like going to theatre or making city trips together without the children. We really tried to look for moments where we could 'do our thing' together. This became harder to do. Going out together sometimes is a problem; we always ask ourselves 'is she ok?' Is anything wrong? She also fainted a couple of times and actually that is enough reason to never leave her alone (father of a girl, 16 year)

Rather than a lack of love, parents reported that worries about their child's health prevented them from spending time together. In addition, most parents downplayed the impact of the cancer diagnosis on the couple subsystem, and emphasized that this event was just one of many affecting their relationship.

Whether many things changed? I don't know, I don't think so. Let's say we'd known each other for 15 years and now we've known each other for 17 years. I mean, I don't think so actually (father of a boy, 4 year)

In contrast, for some parents, the disease did mark the relationship and made the couple subsystem less clearly defined. One parent described that their focus was redirected toward the children, resulting in a greater emotional distance between the parents.

As a couple we are a bit distanced from each other these days. While we used to feel like 'we have our three children, and then there's us and then there's the family'. Lynn, well not Lynn but the illness, has meant that my wife and I have grown a bit apart from each other, and that our focus is more on our three children (father of a girl, 16 year)

So, during cancer treatment, it became even harder to combine a parental role with a partner role. Their love and time for the diagnosed child was unconditional, even at the cost of their own intimacy. However, despite these obstacles, almost all of the couples indicated that the cancer diagnosis did not threaten their marital relationship.

2. Educational Norms and Values: Overindulgence vs. Being Stricter

2.1 Overindulgence

Parents indicated that the illness necessitated a different approach to child-rearing.

You need to adapt your parenting style completely, not just a little bit but completely. I don't know, is it 180 degrees, yes – otherwise we're back, so 180 degrees. Completely changing it (father of a boy, 6 year)

Parents started to indulge the diagnosed child more, especially shortly after diagnosis. To justify this overindulgence, several reasons were given (e.g., to compensate for the suffering, to persuade the child to eat). Furthermore, it seemed like this overindulgence was not only an attempt to compensate for the illness, but also to make life easier (both during hospital stays and at home) and to avoid family conflict. Given the demanding nature of a cancer diagnosis, parents may after all lack the energy to maintain their pedagogical principles. On a couple level, couples mainly gave the same reasons for this overindulgence:

Victor used to be raised quite strictly. We intended to do everything like it should be done. No coca cola, dvds, ipad; no nothing. In retrospect this was a stupid idea, but ok. The advantage was that once he had to go to the hospital, he was

allowed for once to watch a movie and... Because there is no other way, you need to keep him busy (father of a boy, 6 year)

With regard to rearing, I think it was harder to determine what was allowed and what not. Victor was allowed to do things that before I could never have imagined for a three or four year old. But you need to keep him busy. That's a form of compensation (mother of a boy, 6 year)

Parents emphasized that this behavior occurred unconsciously: although they did not want to let go of all their pedagogical principles and they did not want to favor one child, the cancer situation forced them to do so.

Of course, the one who's ill keeps on requiring your attention. And that one will be allowed a little bit more than the two others, unconsciously. You will protect him more. But will you privilege him? Consciously? No. Unconsciously? Yes, because he has gone through so many things, our little boy... (father of a boy, 4 year)

Parents seemed to make a distinction between rearing of the diagnosed child and rearing of their siblings. They were not only more concerned about the diagnosed child; they also indulged this child more. In rearing their diagnosed child, the parents had to consider the possibility of losing the child, as well as their responsibility as a parent to set limits. In contrast, when rearing any siblings, parents could focus on their long-term responsibilities – their strict behavior could be justified in the long run and accidental conflicts could be resolved. In addition, this favoritism was not only a parental concern; it also had an actual impact on the siblings' behavior. Some parents described their other children as showing feelings of jealousy towards the diagnosed child, as well as resentment that their parents' attention was exclusively focused on the diagnosed child.

The big ones resent me for that sometimes, especially [name sibling], she tells Talia once in a while "Just because you have cancer doesn't mean that you can do everything" or "that you can claim Mummy" (mother of a girl, 5 year)

In addition, an undermining of parental authority was reported.

Even my authority is affected a little bit, I guess. Although when I really tell him off, he takes it seriously. My wife's authority is affected dramatically (father of a boy, 12 year)

The fact that the authority of the main caregiver was particularly affected, may be linked to the fact that they spent the most time together, and this caregiver was a daily witness to the child's suffering.

2.2 Being more strict than pre-diagnosis

While in the short-term, overindulgence may have positive effects on the child (e.g., comforting the child) and the parents (e.g., avoiding conflict), parents were also worried about the potential negative consequences of overindulgence on their child's development, as this may produce undesirable and immature behavior.

You feel compassion for your child, so you give in more. But also, you realize 'we're aiming for recovery here, so after this, we need to make sure that we can still manage him' (father of a boy, 12 year)

One way to deal with this concern is trying to "find a balance" between overindulgence and setting rules.

It really is an adaptation and it's difficult to find a balance again. Because, he was so sick, you would, let's say, allow a lot of things. Punishing a child is something you don't do in that kind of moment (mother of a boy, 4 year)

Two things are notable. First, finding balance is hard. Parents feel torn between an awareness of the dangers of overindulgence and a desire to comfort their child. While the overindulgence may have a positive short-term effect – it makes the child happy – and a negative long-term effect – behavioral problems down the line – it can be reversed with the adoption of a stricter approach to parenting after treatment. Indeed, setting limits produces desirable behavior in the long-term, but may be difficult to impose in the short term, as it may create conflict between parent and child. Furthermore it seemed that this balance is only achieved *after* the intensive treatment period. Rather than alternating between an indulgent and a strict approach to parenting during the cancer treatment, parents tended to indulge their child during treatment and discipline them after the cancer treatment.

I realize that I'm more strict now, 'cause I think he was spoiled last year and we need to make that right (mother of a boy, 14 year)

Parents try to compensate for all the things they allowed shortly after diagnosis, by adopting a stricter approach to parenting than before diagnosis. Thus both overindulgent and strict approaches are magnified in this context.

3. Normality: Loss vs. Preservation

3.1 Life will never be the same

As a result of the cancer diagnosis, family life changed.

I have moved a stone in the river and the river will never flow in the same way again. That's a song. Actually the illness is the same. We will always be that family, but this has changed the flow and so it's going to flow differently. When Lynn is better, we won't return to the same place (father of a girl, 16 year)

And although parents emphasized that life would be different, most did not mention whether this change was good or bad. For some families, the diagnosis even improved their family functioning.

I'm gonna say something, but I know that at this point, it's a weird or misplaced comment: 'I hope that in one year, I will be able to say that in fact it's been a very bad period, but it has had a positive influence. I can't say I'll be 'glad', because everybody is suffering, especially Lynn. But if it has to be like this, then we've done a good job and we can look back at the course of treatment with satisfaction (father of a girl, 16 year)

When we looked into detail which aspects of life are in particular changed after diagnosis, all families experienced increased anxiety about the health of the diagnosed child. While, previously, child illness was just a part of life, every sign of illness became a reason to panic. Notably, this catastrophizing was only about the health of the diagnosed child, and not that of the siblings.

In the old days, when the other two children had 40 degree fevers, I didn't panic. Now, with him, I panic: I will call the pediatrician and I will insist that his blood is tested (mother of a boy, 4 year)

3.2 Striving for "normality"

Although parents realized that their family life would never be the same as before, they recalled a constant striving for normality. Parents tried to live a normal life, although the diagnosis had changed everything.

There were times when I thought everything was going fine, that everything would be alright. I almost pretended as if we had a normal life (mother of a boy, 6 year)

For these parents, “normal” seems to be the same as their life pre-diagnosis. Striving for normality might therefore be a form of comfort, creating a feeling of stability and hope.

Moreover, “normal” behavior and “normal” situations were seen as a blessing. Parents reported appreciating the smaller things more; they valued their time together as a family more.

She is on a really strict diet. So one cannot go to a restaurant, she cannot sit in the sun, nothing’s normal anymore. So when something *is* normal, then it’s a gift from God. We’re not at all religious, but it simply is a gift (mother of a girl, 16 year)

Parents made a distinction between the impact of the diagnosis on themselves and the diagnosed child on the one hand, and on the siblings on the other.

The illness has had a very big impact and then again not, because life did go on. For the other children, everything needs to continue as normal as possible, their lives cannot be turned upside down because our lives have been turned upside down or because Talia’s life has been turned upside down (mother of a girl, 5 year)

Parents strived to preserve a normal lifestyle for the siblings, even though the impact of the cancer was undoubtedly present. However, this ‘normal lifestyle’ was based upon going to school and hobbies, outside of (changes within) family life.

Discussion

Pediatric cancer is a life threatening disease, one that is extremely difficult for the diagnosed child, his/her family members, and the family as a whole to adjust to (Alderfer & Kazak, 2006). The aim of this study was to explore how parents perceive changes in functioning of the family after a pediatric cancer diagnosis, using MFMIA (Van Parys et al., 2017). The analysis has provided insight into the conflicting dynamics parents experience in association with

these changes. In the first theme, *Family Cohesion: Strengthened vs. Fragmented*, we saw, on the one hand, that family cohesion was strengthened by the illness, and that parents reported valuing their family more. This is in line with previous qualitative studies (Clarke-Steffen, 1997; Woodgate & Degner, 2003), quantitative studies (Beek, Shappin, Gooskens, Huisman, & Jongmans, 2015; Trask et al., 2003) and systematic reviews (Van Schoors et al., 2015). However, at the same time, the strength of the family unit was threatened by an overwhelming parental focus on the diagnosed child. Parents felt the need to shift all attention towards the diagnosed child (cfr. previous qualitative studies; e.g., Prchal & Landolt, 2012), even at the cost of time and attention allocated to any siblings, the family as a whole or their couple-subsystem.

Consequently, these parents may struggle to meet prevailing cultural values and standards of “good parenting”. Indeed, while West-European parents are expected to divide their time and attention equally among all children, and love each child equally (Ganong & Coleman, 2017), these principles are challenged in the context of pediatric cancer and may result in parental feelings of guilt, shame, frustration and distress (Long & Marsland, 2011). Moreover, the parents in our study seemed to question whether, in this context, a ‘good parent’ is one that accompanies the diagnosed child no matter what or one managing to care equally for all their children. In addition, previous research into multiple roles (i.e., the role-strain approach; Goode, 1960) has revealed that the greater the number of parental roles, the greater the demands and role incompatibility and the greater the strain and psychological distress (Voydanoff & Donnelly, 1999). We could posit, however, that in the context of pediatric cancer – in which one parental role dominates all others – parents experience the same emotional strain. Indeed, these parents indicated that their paid worker role, their partner role, their friend role, etc., had been subsumed by their parental role, and their parental duty to the diagnosed child in particular. Although this predominance of the parental role may seem self-evident, it may also give rise to negative

feelings or thoughts, for example the idea that they are letting their other children down (Grootenhuis & Last, 1997). In conclusion, the findings of the first theme are consistent with those of other studies. However, this study contributes to the current body of evidence by showing that both subordinate themes emerge *at the same time*, and that it is specifically this dialectical experience that parents grapple with. In the second theme, *Educational Norms and Values: Overindulgence vs. Being Stricter*, parents described the impact of the cancer diagnosis on the rearing of the diagnosed child. As with the first theme, parents were confronted with two conflicting dynamics. Specifically, shortly after diagnosis, parents started to spoil their child; a finding that has been reported in other qualitative studies as well (e.g., Enskar, Carlsson, Golsater, Hamrin & Kreuger, 1997; Norberg & Steneby, 2009; Quin, 2004). Parents wanted to comfort their child and alleviate their suffering. In addition, parents might want to compensate for their own feelings of powerlessness. After all, a stricter upbringing may seem irrelevant and undesirable when their child is suffering from a life threatening illness. However, at the same time, parents claimed to believe that their child could recover and to be aware that this spoiling may be beneficial in the short term, but also may produce undesirable behavior in the long term. Once they had realized this possibility, they tried to compensate for their overindulgence by being even stricter with the child than they had been pre-diagnosis. Consistent with previous research, the study found that this indulgent behavior is only applied to the diagnosed child and not to the siblings (e.g., Van Dongen-Melman, Van Zuuren, & Verhulst, 1998). In conclusion, this study builds on previous search with the finding that both behaviors (i.e., overindulgence and being strict) do not appear simultaneously, but rather occur in succession, as well as that both behaviors are magnified compared to pre-diagnosis standards. In a third theme, *Normality: Loss vs. Preservation*, parents described the idea that the family is irreversibly changed due to the cancer diagnosis. This change in family functioning has already been extensively documented in

existing research (see several systematic reviews: Long & Marsland, 2011; Pai et al., 2007; Van Schoors et al., 2015). At the same time, however, parents described striving for normality. The concept of normality or the life they led pre-diagnosis may comfort the parents, as well as giving them hope and courage. In addition, parents strive above all to maintain a sense of normality for the siblings. They seemed to believe that by maintaining normal routines, the impact on these other children could be minimized. However, research has shown that the experiences of siblings cannot be separated from that of the family (Carpenter & Levant, 1994), and that they too can struggle to adjust to life post-diagnosis (Alderfer et al., 2010). Therefore, we can posit that siblings may not experience ‘normal’ life but share the overwhelming impact of the cancer diagnosis on the family. Future research should try to document the experiences of siblings post-diagnosis through in depth interviews. In conclusion, this study not only confirms the major impact of cancer diagnoses on family functioning, it also highlights parents’ desires to preserve normality within their families and outlines the dialectical experiences of parents post-diagnosis.

We aimed to resolve three specific limitations of the existing research. First, by delving into parents’ personal accounts of life post-diagnosis we were able to understand their perspectives on changes in family functioning in greater depth, significantly contributing to the current body of research. Second, we affirmed the importance of the family level in the context of pediatric cancer, and its impact on family functioning, and third, by using MFMIA, we were able to produce dyadic interpretations from the individual interviews, using couples as the unit of measurement.

Methodological considerations

Some limitations of the current study need to be addressed. First, as we report on a small-scale qualitative study of parents, we do not intend or claim to be representative. Rather, we tried to understand processes using a specific sample in a specific context, which could help uncover

some of the processes underlying the impact of a pediatric cancer diagnosis on the family functioning. Second, conform to the requirements of IPA and MFMIA, our sample consisted of a homogenous group: only parents of children with leukemia or non-Hodgkin lymphoma were included. Although this homogenous sample can be considered an advantage of our study, it is important to highlight that parents of children with other cancer diagnoses may have different experiences. Third, time since diagnosis varied between the couples, ranging from six to 33 months. As all parents were questioned about the first six months after diagnosis, the potential biases inherent in such retrospective methods could have influenced their responses (e.g., forgetting, defensiveness). Fourth, we focused exclusively on a sample of Belgian, Caucasian parents. As Belgium is only a small country, it is likely that the experiences of parents in other countries or with other nationalities differ (Chapple & Ziebland, 2017). In addition, every country has its own system of medical insurance or treatment procedures, which will also influence families' experiences. Fifth, in this MFMIA study we focused on the couple's experiences after a pediatric cancer diagnosis. Although this approach has many benefits (Van Parys et al., 2017), it does not take into account gender differences within a couple. Given that research has already revealed that mothers and fathers may respond differently to a cancer diagnosis (Hoekstra-Weebers, Jaspers, Kamps & Klip, 1998; Yeh, 2002), it is probable they would report different experiences of the impact on the family functioning too. Sixth, by focusing on the couples' experiences, we did not include the perspectives of ill children and healthy siblings. Discrepancies in perceptions across family members (Alderfer, Navsaria & Kazak, 2009; Peterson, Cousino, Donohue, Schmidt, Gurney, 2012), however, speak to the need to collect data from all individuals. And lastly, this study does not take into account other family structures than nuclear two-parent families. As families with same-sex parents, multi-generational caregivers,

and single-parent households become more represented within the society (Galvin, 2006), more research is needed to explore their unique experiences.

Clinical Implications

This study confirms the impact of a pediatric cancer diagnosis on the family functioning, as well as the necessity of routine assessment of family functioning (Long & Marsland, 2011; Van Schoors et al., 2015). Three specific recommendations arose from the study. First, awareness of the conflicting dynamics parents are confronted with may help clinicians to better understand these parents, while helping them to normalize their own behavior and feelings. For example, parents may feel guilty about devoting disproportionate attention and time to the diagnosed child and not the siblings, and/or about their difficulties in finding a balance between indulgent and strict parenting. Helping the parent to understand the extremity of the cancer context may therefore not only reduce negative parental feelings, but also assist the child's adjustment (Robinson, Gerhardt, Vannatta & Noll, 2007). Second, across the three themes, parents made a distinction between the impact of the cancer diagnosis on the diagnosed child and themselves on the one hand, and their other children on the other hand. In the first theme, an increase in perceived connectedness was only described between parent(s) and patient, not with the siblings. In the second theme, parents only discussed the impact of the diagnosis on the rearing of the diagnosed child, and in the third theme, parents indicated that, in contrast to their own lives and the life of their diagnosed child, the lives of the siblings were rather unaffected by diagnosis. As a consequence, clinicians should be aware of possible enmeshment between the parents and the diagnosed child. Furthermore, together with the parents, they can explore the meaning and impact of the illness for the siblings, and broaden the idea that a cancer diagnosis particularly impacts the parent-patient dyad. Third, clinical work with families affected by pediatric cancer should be aware that certain individuals and relationships might be vulnerable, for example the siblings or

the couple subsystem. Throughout the study, siblings were described as being on the periphery of the family. As some siblings may also experience difficulties as a result of the cancer diagnosis (Alderfer et al., 2010; Houtzager, Grootenhuis, Last, 1999), this subgroup should also be addressed. In addition, as marital satisfaction may seem secondary to the support of the diagnosed child, marital issues may be overlooked by psychosocial providers in oncology or even downplayed by the couple themselves. However, as these problems might negatively impact the adjustment of the child and his/her treatment, it is also important to screen for and remedy such problems (Van Schoors et al., 2016).

Conclusion

The results of the current study revealed that after a pediatric cancer diagnosis, family functioning changes and that these changes are marked by conflicting dynamics. Using MFMA, three themes emerged. First, the family is perceived as a stronger unit, while at the same time, fragmentations occur within that unit. Second, parents struggle to find a balance between overindulgence and discipline. Third, the overwhelming impact of a cancer diagnosis changes family life forever. However, at the same time, families try to maintain a sense of normality. Clinical work should therefore take into account these conflicting feelings in order to better understand the experiences of parents after a pediatric cancer diagnosis.

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