Understanding grief in children who have lost a parent with cancer: how do they give meaning to this experience? Results of an interpretative phenomenological analysis

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ABSTRACT

Though the adjustment of bereaved children is increasingly investigated through quantitative studies, their intimate representations regarding the loss of their parent remain unknown. This qualitative study aims at exploring how they give meaning to this experience. Non-directive interviews with bereaved children were conducted and submitted to an Interpretative Phenomenological Analysis. Fourteen children (8 boys, 6 girls, mean age= 8.5 years) were recruited. Seven major themes depicting their grief experience were identified. The importance of the surviving parent is critically highlighted. Findings suggest that the remaining parent could become a fundamental actor in providing grief support for the bereaved children.

Introduction

Cancer figures among the leading causes of death accounting for more than 8 million deaths in 2015 worldwide (World Health Organization, 2017). However, the exact number of children who become orphans after the death of one of their parents affected by cancer remains unknown. Because of this critical prevalence and the impact of such a loss, the adjustment of bereaved children due to cancer is becoming gradually studied. The early loss of a parent is indeed considered a major traumatic event for a child, whatever the cause of death of the parent, with psychological and physiological consequences in the short and long terms (Dopp & Cain, 2012; Feigelman, Rosen, Joiner, Silva, & Mueller, 2016; Luecken, 2008; Oltjenbruns, 2001; Stroebe, Schut, & Stroebe, 2005; Stroebe, Zech, Stroebe, & Abakoumkin, 2005). The most

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common short-term consequences are anxiety, depression, behavioral problems, poorer school attainment, social withdrawal, and feelings of insecurity and vulnerability (Feigelman et al., 2016; Luecken, 2008). Some risk factors can increase this vulnerability: the surviving parent's depression and the poorer quality of care he/she gives the child (Langrock, Compas, Keller, Merchant, & Copeland, 2002). In the long term, psychiatric disorders can occur: adults who have lost a parent during childhood may present higher depression levels than those who grew up in unaffected families (Luecken, 2008); Rostila et al. (2015) indicated that exposure to parental bereavement in childhood was associated with suicidality later in life. Persons who had lost a parent to an external cause/substance abuse-related death had the highest risk of being admitted to a hospital for a self-inflicted injury/poisoning. Risks were also increased for parental death due to natural causes (as cancer), but at a lower level. According to another study, the premature loss of a parent during childhood could be associated with a higher risk of anxiety disorders, especially among women (Kendler, Neale, Kessler, Heath, & Eaves, 1992). These research works also suggested that all children who had experienced the loss of a parent did not necessarily develop disorders, and that various factors may influence their adjustment to the loss in these children (e.g., Feigelman et al., 2016).

The specialized literature has designated the quality of the parent-child relationship (support and discipline) as a fundamental resource, fostering resilience to adversity during childhood (Howarth, 2011; Luecken, 2008). A strong bond may determine self-regulation skills and contribute to resilience. Family cohesion, as well as concurrent positive events, could also contribute to resilience (Luecken, 2008). The bereaved child's resources are: good self-esteem, expression of feelings, understanding among family members, and the ability to maintain a positive meaning in an adverse context (Haine, Ayers, Sandler, & Wolchik, 2008). The social

support of same-age peers seems positively correlated with better adjustment in children and teenagers who have lost a parent as well as negatively correlated with intrusive thoughts related to their grief (Dopp & Cain, 2012).

Very few studies have qualitatively investigated the very nature of children's grief. A few descriptive and quantitative studies in parentally bereaved children have shown that younger children worry more than their peers and express themselves more readily than older ones (Haine et al., 2008; Silverman & Worden, 1993). Girls tend to internalize their problems, whereas boys externalize more (Dowdney, 2000; Haine et al., 2008). Lastly, longitudinal studies have suggested that girls are more vulnerable over time compared to boys (Dowdney, 2000). Howarth described various aspects of grief reactions related to bereaved children: emotional and behavioral expressions are often sporadic and shorter in time than in adults, and children are more prone to express their anger or sense of abandonment through their behavior (Howarth, 2011). Strikingly, in the cancer field, the vast majority of data on children's grief due to cancer is based on external assessment (evaluation by parents or teachers) and has been collected through quantitative methods. Although very useful from an epidemiological perspective, these quantitative studies neglect the dynamic and intimate features of grief reactions (Luecken, 2008).

This qualitative study aims to capture the intimate experience of grief in bereaved children and explore how they give meaning to this specific experience. Focusing on these features could enable us to offer relevant psychological care to bereaved children. In fact, many guidelines in the cancer field (e.g. American Cancer Society, 2016; INCa, Institut National du Cancer, 2014; NICE, National Institute for Health and Care Excellence, 2011) recommend undertaking further studies on grief to underpin the psychological follow-up for bereaved relatives of cancer patients. It thus seems essential to return to the description of the grieving

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phenomenon as it is perceived and described by the children themselves, in order to understand better its subjective progress.

Methods

Participants

The present research is a sub-study of a broader research dedicated to the adjustment of children of parents diagnosed with cancer. All children who participated in an information group on parental cancer during the last four years in a Comprehensive Cancer Care Center (Paris) were invited to participate in the study. All the children, as well as their parents, received an information letter and a consent form at the end of the group, to participate in a survey about the evolution of children's psychological symptoms after the group. Younger children (those aged less than 10 years) gave their oral consent while older children and all parents signed the consent form. Parents and children were seen again 6 and 18 months after the group, as planned in the systematic follow-up of the cohort, with the aim of studying the evolution of anxious and depressive symptoms. Fourteen parents (9 mothers and 5 fathers) died between the 6- and 18-month follow-ups. The 14 bereaved parents were contacted and were asked if their children could be to be interviewed about their grief, which is the subject of the present qualitative study. Sixteen children were then invited to participate to these interviews. On these 16 children, 14 accepted to participate; for the remaining two, the parents (one father and one mother) refused permission for their children take part to the study because of the concern that returning to the center could be too distressing. Thus, participating children had lost their parent more than a year and less than 2 years before the interview. The ethics committee of the Comprehensive Cancer Center as well as a National Research Ethics Board (CNIL) approved this research.

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Materials and procedure

The children were interviewed in the cancer care center. Interviews lasted from 30 to 45 minutes. The interview started with the following instruction: "You have agreed to participate in this interview because your father/mother has died. Can you tell me about yourself today and about what you think or feel? How are things since he/she has gone?". According to the recommendations of the Interpretative Phenomenological Analysis (IPA) literature (Palmer, Larkin, de Visser, & Fadden, 2010; Smith, 2004, 2007), there was no pre-established interview grid, the interview was not directed and reformulations were used to go deeper, but the goal was always to try to obtain spontaneous speech about the child's experience.

Analyses

Interviews were recorded for later transcription and Interpretative Phenomenological Analysis (IPA) was chosen to explore their content. This analysis strategy was designed to understand the complex system of meanings attached to a unique, subjective and eminently intimate phenomenon (Smith, Flowers, & Larkin, 2009). It seemed the most appropriate to investigate the experience of losing a loved one, even more so for children whose subjective representation system may be very specific and beyond verbal maturity. That is, even if the syntax and the use of logical connectors are not perfect, children are able to express their feelings and their cognitions (Brockmeier, 2005). This method relies on a double hermeneutic wherein the researcher attempts to make sense of the way the participant makes sense of his/her own subjective experience (Eatough & Smith, 2008; Fade, 2004; Smith et al., 2009). The researcher adheres closely to the participant's discourse and uses knowledge from the literature to propose

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an in-depth analysis. The aim of IPA is not to develop general rules but to remain attentive to the subtleties of experience, in all its complexity.

A standardized procedure ensures the methodological rigor (Smith et al., 2009). First, every interview in our sample was read and the main themes were coded by the first author (CF). Discourse themes were identified (sufficiently characteristic topics, implying that the researcher could see a common and stable sense in them). The connections between the themes were then studied and the major themes were identified by CF; these themes are presented in the results section. Lastly, an interpretative account was produced that highlights and analyzes the experience through experiential themes, by illustrating the discourse. Following the example of other IPA studies (e.g., Rassool & Nel, 2012) the second author (LF) audited the documentation for the first 5 interviews to check the analytic process. This involved her repeating part of the analytic process described above, reading through the 5 interviews to identify themes, and checking whether her themes corresponded with those of the first author CF. In line with IPA methodology, the aim here was not to seek inter-rater reliability; rather, the intention was to provide an independent audit (as supervisor) at this stage of the analytic process to ensure that the interpretative account produced was a credible one, legitimized by a systematic and transparent analytic procedure (Smith et al., 2009). Throughout this study, we took great care to meet the scientific rigor criteria established by qualitative analysis (Fossey, Harvey, McDermott, & Davidson, 2002; Yardley, 2000).

Results

Fourteen 7 to 11 year-old children took part in this study (4 children were aged 7, 3 were aged 8, 3 were aged 9 and 4 were aged 10). There were 8 boys and 6 girls. Two sets of siblings

participated in this research (2 boys aged 7 and 9, and a girl and a boy aged 9 and 10, respectively) and the interviews were conducted separately. Ten children had lost their mother and 4 their father to cancer. Note that, according to the French legislation, (Loi Informatique et Liberté, CNIL, 1978), it is strictly forbidden to collect and record directly or indirectly information indicating the ethnic origins and religious affiliations of the people, and such these details are not provided.

Analysis of major themes

The 7 major themes depicting the grief experience of the bereaved children are presented below. The underlined themes below are mentioned just as depicted by the children. These are followed by an interpretative account, which condenses the meaning-making processes of the participants, and is the last step of the IPA.

Grief is an announcement that is hard to believe, followed by a ceremony that makes things real

All the children recounted the announcement of their parent's death and particularly the context in which it occurred:

at school:

"Daddy came to school and told me… but it's a thing you don't believe, at school, like that… [What thing?] That mummy is dead (…) I didn't believe it, that you could die like that". (Danielle, 8-year-old girl)

or at home:

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"We were all in the living room and daddy said: "Mummy felt too bad, she's gone". (Jimmy, 7-year-old boy)

All the children associated the announcement with the ceremony, because it is the latter that gives death its reality:

"I didn't know if I should cry, but when I saw her… She was sleeping but in fact she wasn't… (I was) scared because it was true she wasn't here anymore, for real…". (Ben, 10-year-old boy).

Other people's reactions during the ceremony also contribute to giving a meaning to death:

"Everybody was crying, even grandpa... It's really sad you don't come back when you're dead you don't come back (…) You don't come back from underground because you can't get out anymore... You're dead because we take you to church and we put you in the cemetery and we cry that you don't come back anymore...". (Frank, 7-year-old boy)

Children spoke of the strangeness of death and grief and how they observed adults in order to understand their feelings and how to react:

"I had a stomach-ache and mummy told me it's the sadness that hurts... So now when I have a stomach-ache I reckon I must be thinking of daddy and crying is a relief". (Michelle, 8-year-old girl)

Grief means changes

When children referred to their life experience, habits and everyday life spontaneously appeared in their discourse, particularly the changes that reflected the loss and the emptiness:

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"Now I don't eat pasta anymore... Mummy, she didn't always want to but daddy he often makes me pasta (…) [And how do you feel about it?] It's nice... [It's nice to eat pasta with daddy?] Yes... but it was nice also to eat the four of us together even if mummy didn't always want to make pasta because sometimes she made rice...". (Jimmy)

Everyday life was also reported as filled with sadness and dismay when faced with the absence:

"In the evening I don't like... [Tell me what you don't like in the evening] the evening, the night... [Can you explain?] I don't like to go to bed... (…) [Before it wasn't mummy who told you to go to bed?] Yes, it was, but daddy would read me a story...". (Justin, 8-year-old boy).

It seems that children experience grief through more or less positive or negative changes in habits, which become important because they are meaningful.

Grief is also reflected in the affective relationships that change. They become more intense and sometimes more worrisome:

"Daddy, he's often sad because he's lonely... [Tell me] He cries and I wonder why (…). Sometimes it makes me scared... [Scared of what?] I don't know... that he would be too sad and he couldn't help me...". (Amy, 9-year-old girl).

The presence of new people is also included in the changes caused by the death. These people can be reassuring: "I like it when grandma is here, she does things like mummy" (Hugo, 7-year-old boy) or worrying "I don't like it, there isn't just us at home anymore, there's always grandpa and grandma..." (Michelle).

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What has to stay the same

Faced with these changes, the children's experience was also comprised of many ongoing routines that seemed to have to remain identical:

"I like being with friends, we don't talk about that... [Is it difficult to talk about that?] Not now but sometimes yes because we always talk about it at home so it's nice to do things as usual: to play...". (Jennifer, 10-year-old girl)

In addition, it seemed that, for some, maintaining certain habits was a simple way to cope with the loss, and perhaps to reassure themselves about the permanence of certain relationships or activities. Some would sometimes like to go back to a previous situation with their only parent, as if it was possible to erase the absence: "Daddy, he can be mummy if he wants to, but sometimes he doesn't...", (Justin, or by longing for another parent: "Daddy, he will find a new lover... Like that it will be a little like mummy... but he told me it wasn't true" (Sandra, 9-year-old girl).

Grieving is missing someone

However, all the children interviewed spoke about the feeling of emptiness, which they fought against, and which, as seen previously, they experienced throughout their daily lives. They referred to its emotional and relational tonality:

"Mummy, she did the cooking but now it's daddy... It bothers me because when mummy was here it was better (…) now daddy, it makes me sad". (Claire, 7-year-old girl).

This absence, which was expressed through daily life events and through emotional comfort-seeking, may lead to great distress:

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"If mummy isn't there anymore, no one can be there when I'm upset because it was mummy...". (Amy).

Some children spontaneously mentioned the creation of new bonds with the dead parent to recall his/her presence:

"We can think about her, talk to her and even know what she would reply...". (Carl, 10-year-old boy).

"Daddy, he's in my head" (Michelle).

Grieving is experiencing various deep feelings

All the children mentioned diverse emotions, all of them with a preponderance of sadness: "When your mummy dies, your heart aches..." (Danielle), "It wrenches and you cry..." (Ben). They also all spoke about feelings of anger mixed with injustice "It isn't fair that it's my mother" (Charlie, 10-year–old boy), "Since then, I'm upset and that's it" (Danielle).

They also mentioned a feeling of inability or a loss of self-esteem: "At school I was useless and now it's still hard" (Amy) and a comparison to others, often paired with a feeling of injustice, aggressiveness or envy: "The others, they have their parents even if they're divorced, that's lucky" (Frank). These feelings were accompanied by a sensation of difference and sometimes loneliness:

"Even my friends, they see I'm not like before [They know about your mummy?] Yes, but we don't talk about it... but me I'm not like them... I don't have a mummy anymore..." (Jack, 9-year-old boy).

Guilt was also very prominent in their words:

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"Maybe if I'd been nicer it wouldn't be the same [What do you mean?] Well, she wouldn't be dead or she would come back" (Carl).

This guilt coexisted with feelings of anger against the dead parent: "Why did he go? He could have stayed..." (Jennifer), as well as against the living one: "He could be a nicer daddy since mummy isn't here anymore" (Justin).

Growing up…

Grieving was also depicted as learning new things through changes, taking up new positions and maybe even feeling oneself becoming stronger:

"After the burial I spoke to the class with the teacher and they all listened to me... I was alone saying that... It's like if you were strong... or big..." (Danielle).

Grieving was also linked with another position in the family:

"Since I've been alone with daddy, I do things with him... I help him at home... And it makes me say mum would be proud..." (Charlie).

… Or staying little

On the contrary, 6 children were afraid of growing up:

"I don't want to grow up anymore, after you die and the others die...". (Sandra).

Some talked about the fear of being alone associated with getting older:

"If I grow up, mum won't be there anymore and I'll be all alone". (Jack).

Interpretative account

This interpretative account enables us to gain an insight into the way children make sense of their grief experience, through the experiential themes found in the interview. This account puts forward the convergences and discrepancies between these experiences. Three meaning-making profiles of the grieving experience were developed from the analysis. The first concerns the remaining parent. It seems that the meaning of the experience of longing and loss is felt through the relationship with the surviving parent, sometimes in an emotional closeness: "Since mummy died, daddy is less different from me, we're closer" (Hugo); sometimes in the care/concern that should be given to him/her: "I wonder if daddy is OK because he's the one who is here" (Amy). The children indeed seemed to fear that their remaining parent was too vulnerable, or they feared losing this last living attachment figure. It seems that it is also the comparison with the grieving adult that helps the children to make sense of their feelings as mentioned earlier. The feelings that help children to give sense to their grief experience in their discourse come from adults "At the funeral everyone cried and I cried (…) even grandpa was crying" mentioned Frank. It is important to emphasize that none of the interrogated children referred to his/her brothers and sisters and to their feelings, despite the fact that the majority had siblings. This probably relates more to some kind of support than to the appropriation of the subjective experience.

The second profile of meaning-making is farsighted: grief is an experience that forces you to look ahead with all the anxiety that it involves: "If my daddy dies, who will be here with me?" (Sandra). Looking ahead can also enable the projection of oneself positively in new skills: "Since mummy isn't there I do things at home" (Justin). This meaning-making movement underpins a comparison with peers: the children take up positions as being bigger than their peers: "The others in my class, they're little, they haven't lost their mummy" (Hugo) and define a

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new place for themselves, which can be positive: "Sometimes the others they envy me for losing my dad" (Jennifer).

The third profile of meaning-making reveals an emotional experience marked by negative emotions just over a year after the death of the parent. For these children, grief is first and foremost a feeling of emptiness that is experienced in everyday life: "Mummy doesn't come in the morning anymore", stated Claire. Grief brings negative emotions: anger, loneliness and, for all of the participants, sadness. These negative emotions alternate with very positive moments:

"When I play outside I have fun, I don't think that I'm sad (…) I go for walks with C [the dog] and then I feel super happy" (Jennifer).

If the negative emotions, particularly sadness, endure, children can recognize their importance, despite the pain: "When I miss mummy I think about her, but it pleases me…" (Jack). This emotional dimension and the child-parent bond it represents are part of this experience of emptiness:

"Now when I want to talk to mummy I talk in my head (…). I'd like to know what she thinks… So I imagine" (Charlie).

We can propose that these internalized bonds (Klass, Silverman, & Nickman, 2014) account for the almost total absence of discourse regarding where the deceased parent could be, as well as the very scarce evocations of spiritual or religious references. The bond with the deceased parent may be maintained by thought, speech and the emotional experience that the child addresses to the deceased person, whose reassuring presence is perceived.

Discussion

This study highlights children's ease in talking about their grief experiences, even at a young age, for the interviews were detailed and rich. The clinical data, collected with the sociodemographic ones, indicated that none of the children had benefited from specific care such as psychological support. Nevertheless, they all seemed to undergo a normal grief process; it seems they took possession of the interview space to recount their experience, which raises the question of a more systematic offer of a place to talk about their experience. The literature dedicated to the needs of grieving children remains rare; the vast majority of authors recommend that these children should be offered support not only from professionals, but also from their close relatives (e.g., Worden, 1996). However, bereaved parents are often considered particularly vulnerable people (Alam, Barrera, D'Agostino, Nicholas, & Schneiderman, 2012) and bereaved children might also experience personal or interpersonal difficulties in talking about their grief (Doka, 2002).

These results underline the fundamental role of the remaining parent in the grief experience of bereaved children. This point constitutes the major contribution of this qualitative study. In fact, mental health professionals, such as grief counselors and psycho-oncologists, may consider directing their attention towards the detection of problems that the surviving parent may be facing, for their scaffolding role seems central for these children. Attention has been paid to relationships between bereaved husbands and their adult children after the death of their loved one, but not in underage children (e.g., Bernard & Guarnaccia, 2002). Our data favor a view of the grief phenomenon as largely self-soothing; the participants in this study could name their negative emotions related to their loss and maintained a strong bond with the deceased parent, even when it took them through sad moments, which they seemed to integrate naturally into their daily lives. It is often their remaining parent who allows them to understand their own feelings

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through an identification or comparison process. Our data thus constitute an argument for dedicated consultations for parents who, besides their own grief, have to deal with the suffering of their child. Systematic meetings, such as parental guidance sessions, could be offered to parents of a grieving child with psychosocial difficulties. It is important to underline that the meaning-making profiles we have identified appear to be rooted in the views of others, whether of adults or their peers, or in the children's own view when they project themselves as older. In this way, the grief experience, as depicted by the children, seems to be eminently forged in an experience of intersubjectivity, which gives meaning to the grief process, as well as the misunderstanding and revolt it generates. Our results stress the intersubjective nature of grief and the importance of the remaining parent as a "meaning-making guardian" who has to be supported in this function.

This study has several limitations. The first is linked to our sample. The children who participated in this study were volunteers. It is possible that a recruitment bias hindered us from meeting the more vulnerable children who may not report the same meaning-making processes or grief experiences. However, this self-selected sample appeared to be similar in age and sex of the larger group at the center; this point stresses the validity of our results in a generalizability perspective. Second, the relevance of the assessment time can be questioned and whether it was suitable to capture the complexity of the meaning-making processes. Twelve to 24 months after the death of the parent could be too early to investigate the deployment of the processes. One way to mitigate these biases could be to conduct a longitudinal research program, which would be designed to study the evolution of the grief reactions and the meaning-making processes of bereaved children. Future studies should adopt this longitudinal design, would provide an insight into differences in grief experiences over time. Third, the cause of the parent's death (i.e.,

cancer), may have influenced the grief experience of the participants. The disease, the parent's symptoms, and the circumstances of the decease (in hospital or at home) are factors that could critically shape the representations of these children. Our purpose was not to study the characteristics of grief in the context of cancer in comparison with other causes of death. While the themes are likely to be transferable beyond cancer deaths, these findings need be confirmed in further studies. Finally, some authors stressed the necessary careful use of IPA for discourse from children, who might not be able to provide sophisticated articulations of their thoughts, feelings, and behaviors (e.g., Willig, 2008). This articulation is indeed required for the meaning-making process which is central to IPA. However, as mentioned above, the children participating to this study were able to communicate about their feelings and representations, as required for IPA.

Despite these limitations, our study helps gain an insight into the nature of the grief experience of children who have lost a parent due to cancer. To our knowledge, this is the first IPA dedicated to focusing on the subjective experiences of children has enabled us to suggest personalized interventions that correspond to their needs and functioning.

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