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Living an everyday life through a child's cancer trajectory- **Four families' lived experiences seven years after diagnosis**

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Authors' Contribution

MB and IH were responsible for the study design and MB for the data collection. AS, IH, KH and MB conducted the data analysis and drafting of the manuscript.

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Introduction

When a child is diagnosed with cancer the entire family is affected over a long time period (Björk, Nordström, Wiebe, & Hallström, 2011; Björk, Wiebe, & Hallström, 2005, 2009; Woodgate & Degner, 2003). During the child's cancer trajectory the family experienced that their lifeworld changed. Each day was experienced as a struggle and a constant swing between worry and relief. Their own family became even more important and to be able to handle the situation, they needed support from family, friends and other close people. They also needed to have a good relation to the professionals (Björk, et al., 2011; Björk et al., 2005, 2009). As more children survive cancer today, it becomes important to generate knowledge about family situations and their needs after the treatment trajectory. Therefore, the aim of this study was to illuminate the lived experience of families with a child having survived seven years post diagnosis for cancer.

Background

Research within the family's perspective of childhood cancer can be viewed from different viewpoints as for example those of the survivors, siblings and parents. Childhood Cancer Survivors (CCS) are found to have both negative and positive experiences from their treatment trajectory. They experienced themselves being different from other healthy young adults and they felt that their body was changed. They strived to live a normal life. Negative experiences were compensated by a positive view on life, and feeling that they had personally matured and grown (Enskär & Berterö, 2010). Long term physical and psychosocial effects of the cancer and cancer treatment were common and affected the adult lives of childhood cancer survivors. The survivors experienced a need for support themselves but they also wanted to offer support to other children diagnosed with cancer (Prouty, Ward-Smith, & Hutto, 2006). Survivors avoided discussing their own experience with their parents as they

found its recollection to be traumatic for their parents (Casillas et al., 2010) and they wanted their parents to get support from health care providers even after treatment had ended (Gibson, Aslett, Levitt, & Richardson, 2006; Prouty et al., 2006). Nevertheless, they experienced the cancer trajectory as being part of themselves (Prouty et al., 2006) and tried to make meaning of their experience as reflecting their cancer trajectory. They also found family, friends and the health care team to be significant for them (Jones, Parker-Raley, & Barczyk, 2011). However, the survivors had to deal with the uncertainty of possible recurrence (Prouty et al., 2006). When meeting new people, the survivors often found it difficult to talk about their cancer experience as they sensed that others felt uncomfortable hearing about it (Jones, Parker-Raley, & Barczyk, 2011).

Buchbinder et al. (2011a) described siblings of CCS as being generally psychologically healthy. Their results are in accordance with Kamibeppu et al., (2010) who concluded that there was no significant difference in siblings with a matched control group regarding depression, anxiety and posttraumatic stress symptoms (Kamibeppu et al., 2010). Nevertheless, when post traumatic stress (PTS) was measured in siblings one to ten years after the end of the treatment it was found that about 50% showed mild PTS and about 32 % reported moderate to severe PTS. Female siblings and those older than six years old at the time for diagnosis experienced more PTS symptoms (Alderfer, Labay, & Kazak, 2003).

According to Casillas et al. (2010) parents felt emotionally distressed when recalling memories from their child's cancer trajectory and it was sometimes difficult for them to talk with their child about his/her memories. They also experienced it as hard to reflect on the experience with people outside the nuclear family as the relationship with the extended family had sometimes become distant and strained during treatment. The opportunities for social life

had been limited and they sometimes experienced being blamed for having caused their child's cancer. Parents also described it as challenging to let the child meet the doctors from the adult care without them (ibid). However, parents of children whose treatment had finished reported better well-being than those whose children were still being treated (Enskär, Hamrin, Carlsson & von Essen, 2011). Lindahl Norberg and Boman (2011) found that post traumatic stress symptoms was reported by the majority of the parents after the completion of treatment.

The family's lived experience during the childhood cancer trajectory has been described by Björk et al., (2011) and Björk et al., (2005, 2009) and this study is a continuation of that longitudinal research project. At the time of diagnosis the family's lived experience was described as breaking their lifeworld and striving to survive (Björk et al., 2005). The family's life was likened to an earthenware pot that broke into pieces. The family started to mend the pot one piece at a time; newly added pieces easily came loose during periods of struggle. As the pieces were assembled, the pot was gradually mended. The family's lived experience during treatment was looked on as an everyday struggle where the family focused on the sick child (Björk et al., 2009). Lastly, when treatment was completed they experienced a return to a changed ordinary life in which they tried to incorporate the trying and contradictory experience they had got from the cancer trajectory (Björk et al., 2011). To date, longitudinal studies exploring the family's experience of having a child who has survived childhood cancer are sparse. Therefore the aim of the present study was to illuminate the lived experience of families with a child having survived seven years post diagnosis for cancer. At that time the children were no longer receiving treatment for their disease.

Method

Design

This study is part of an inductive and longitudinal research project of childhood cancer (Björk et al., 2011; Björk et al., 2005, 2009) where family members' lived experiences has been illuminated during the cancer trajectory. The study includes families with a child who has survived cancer and focuses on the experiences described by the children and their families seven years after diagnosis. A hermeneutical phenomenological approach (van Manen, 1997) was used to gain a deeper understanding of the experiences of the survivors and family members.

Participants

Seventeen Swedish families (Björk et al., 2005) with a child diagnosed with cancer during a ten-month period in 2002 were then followed during the child's cancer trajectory. This study corresponded to seven years after diagnosis. At that time seven of the original children had died and one had relapsed. In nine families the child was assessed as being in remission and was contacted for a follow-up interview. Five of the nine families did not participate: one family was unreachable, another did not respond and three families had children who did not want to be interviewed and therefore the entire family chose not to participate. That left four families. Interviews were carried out with four mothers, three fathers, three siblings and three children from those families. Three of the children had been diagnosed with leukemia and one with a brain tumor, and were no longer under treatment. At the time of this study, the original patients were 8, 11 and 18 years old, siblings ages were 9, 11 and 17 years old. Two of the mothers were 38 and the others 42 and 43 years of age. Lastly the fathers were 39, 42 and 43 years of age. This means that siblings and former patients were between 1 to 11 years of age at the time of diagnosis.

Ethical considerations

The Regional Ethical Review Board at Lund University (2009/127) gave formal approval. The families were given both oral and written information about the study. Written informed consent was obtained from all participants over the age of 12 and younger children gave their written assent. Each family was asked if the members wanted to be interviewed together or individually. The family chose date and place for the interview. Considerations were made according to ethics and the study followed the ethical principles of the Declaration of Helsinki (MFR, 2003). After the interviews, the family members were given contact information to a consultant nurse, sibling nurse, psychologist or social worker if support were needed after the interview. Most of the participants were grateful when given the telephone numbers but said that they were not needed.

Data gathering

Conversational interviews were performed with the families, and according to members' wishes, during late 2009 by one of the authors (MB). In one family the survivor and the sibling chose to be interviewed together but without their parents. Their parents were later interviewed together. In two families all family members were interviewed together, with the survivor and sibling participating during the early part of the interview and then departing. In one family the survivor and the sibling did not want to participate. All families chose to be interviewed in their homes. The interviews started with the family recalling and narrating their story about what had happened since the last interview ranging 62 to 78 months ago (mean 67 months ago) (Björk et al., 2011) and how life was today. During the interviews the family members were asked follow-up questions for a fuller description of their experience. Examples of follow up questions were, "What do you mean?", "How was that?", "How did

you feel?”, “Can you give me an example?”. The interviews were tape recorded and transcribed verbatim.

Data analysis

Data were analyzed with a hermeneutic phenomenological approach (van Manen, 1997). This approach allows phenomena to be described and interpreted in order to illuminate the meaning embodied in lived experiences. According to van Manen a phenomenological description can be viewed as one possible interpretation, even if others may be possible. In the analysis we tried to understand the meanings embodied in families' experiences seven years after their child had been diagnosed with cancer, which they had survived, and treatment had ended. The analysis started from a holistic approach in which the interview texts were read through several times by all authors in order to become familiar with the content and to get an overall picture. Sentences and phrases corresponding with the aim were highlighted from the text. These were then organized into structures of experiences. According to van Manen (1997) structures of experiences can be described as the experiential structures that make up experiences. In the analysis, we went back and forth between the parts and the whole of the text. Both the writing process and the repeated discussions among the authors took the analysis forward and deepened the understanding of what it is like to be a family with a child who has survived childhood cancer. The analysis finally resulted in one essential theme and three related themes. Quotations are used to further illustrate lived experiences and the participants are given fictitious names. In the final step of the analysis the metaphor of the earthenware pot, first described by Björk et al. (2005), was further developed in order to deepen the understanding of the essential theme in this study. In the results, the experience of the family as a unit was formed from the experiences contributed by each individual within the family.

Results

Living an everyday life through the child's cancer trajectory

Through the analysis one essential theme was identified; “Living an everyday life through the child’s cancer trajectory”. The families lived experiences were further illuminated through three related themes “Leaving the disease behind yet feeling its presence”, “Being the same yet always different” and “Feeling stronger yet vulnerable”. Their experiences at time of diagnoses have been described in an earlier study (Björk et al. 2005) as a metaphor symbolized as an earthenware pot. Seven years later the pot was rather mended and usable even though some parts of it could be experienced as more fragile than before and it could even be missing some pieces. On the other hand, the stronger parts could compensate for the fragile or missing parts. The mending process could have been managed with more or less struggle, or it could still be ongoing. However, in one way or another the illnesses of all the children were always present in the families’ everyday life. To be able to move forward in life, the family members may need support to reconcile themselves with their memories and experiences deriving from the childhood cancer trajectory.

Leaving the disease behind yet feeling its presence

The families experienced that they had increasingly left the childhood cancer trajectory behind them. However, even though the child had recovered, the memories from the illness were still present and to some degree influenced the family’s day-to-day life. Some family members’ still strived to understand and reconcile the experiences from the cancer trajectory.

Those survivors who were particularly young at diagnosis experienced having vaguer memories from the illness than those who were of school age when afflicted. The younger survivor's memories had faded and many of them had left the disease behind. They expressed not thinking about having been ill with cancer. However, sometimes they wanted their parents to talk about their cancer trajectory. Now and then memories from their cancer period came up in their minds, as for example by seeing physical scars or when visiting the children's oncology clinic. Sometimes that visit could be unpleasant as described by one mother together with her child.

Mother: They always look at your Willy and your testicles. Survivor: Yes. Mother: And they touch your groin. Survivor: Hmm. Interviewer: Is it a little bit uncomfortable and scary? Survivor: Yes.

Like the survivors, the younger the sibling was when the survivor was ill, the vaguer were the memories. Now, several years later, they experienced that it was hard to even think that their sibling had been so sick. One sibling related;

Sometimes I think, it might happen again. I don't remember so much ... so it feels a little bit strange, I was just about two years old, so it is just a few things I remember.

The parents' experienced that they had many memories and experiences from their child's cancer trajectory. Even if their experiences were more or less present in everyday life they had started to leave them behind. The colors of earlier memories seemed to fade away. *"You just keep your fingers crossed; we're done [with the cancer]"*. Yet, the parents experienced concerns about the future and were afraid of relapses. *"But it scares me a bit that I do not*

know how I would react // How will it be if it happens again?" However, they did not want their worry to have an influence on their children or their everyday life.

Being the same yet always different

The families related how the illness had added out-of-the ordinary elements to their lives. Their experience from the childhood cancer trajectory made them feel different with both positive and negative influences.

The survivors and their siblings related how they were faced with experiences which were different from those of ordinary children and that their personalities were changed. One survivor and their sibling discussed how the cancer had influenced the survivor's personality;

The sister [S]: *You are very shy. Not that much now, as you were just after the cancer treatment. ...* Survivor [C]: *Maybe more shy than I would have been otherwise. I don't know why.* S: *Although, you almost lost two years of your life.* C: *Yes, during that period of time people in school get to know each other more.*

Some survivors and siblings stated that other people could not completely understand them. However, they carefully considered who they shared their thoughts with and experienced it as easier talking with other survivors or siblings with similar experiences. One sibling said; *"No, my friends can't understand these things, just Ann who is also a sibling"*. However, mostly they avoided bringing the topic up, unless they were asked about it.

Having a child who had had cancer was a part of the parents' identity. The experiences from their child's illness were not solely negative; they even brought new insights on life. One parent said; *"I have become who I am today from everything I've been through"*. Parents reflected about situations that had occurred during the cancer trajectory and asked themselves whether that had influenced the current behavior of the survivor. They meant that they had

been like a helicopter parent who had hovered over the child and they reflected whether this may have affected the survivor in a negative way. One mother related;

... He is such a bad loser. I think back to the time when he was sick, and we always let him win when we played and you saw how happy he got. // And I can think of it many times. Is it because we did so and so that he has become like he is now?

Another parent describes another example of this.

How can I say, you protect him (the survivor). You want to take care of him, even if you try not to do so. You don't want them to face any barriers.

Feeling stronger yet vulnerable

When the family had gone through a childhood cancer experience they carried painful memories and experiences that made them feel vulnerable. As time passed, they came to understand that these experiences could strengthen the family bonds, as well as them as individuals. In many cases the importance of the family turned out to be even more significant.

The older survivors could now view their experiences in a positive way and as something that had brought them new insights. One survivor recalled; *"When looking back, I don't think it has been that negative, it has been an experience."* Having survived the cancer became a victory, and in some senses the survivors felt as if they were invincible. For example, one of the survivors described how, when he talked with friends about his experiences, he felt as if he were boasting; *"For me, it feels a bit like bragging, when I talk about it actually"*.

Siblings had spent more time at hospital and with adults than with many of their friends, and this had had an influence on their childhood. Sometimes this different experience made it hard

to understand other children. Being able to deal with these differences, with help from other adults e.g. social workers gave them a feeling of being strengthened and they left negative thoughts behind.

The period of cancer was also experienced as something that tied the family together and the siblings believed that the illness had brought the family members closer together. This experience could be positive but also negative. It could be seen as a demand. One sibling related;

We have come closer to each other...yes...we kind of stand there for each other maybe more than you wish. // I think the family is one of the most important things in life, which is not in agreement with what my friends think.

To be able to feel stronger, the parents tried to focus on the positive instead of the negative, meaning that, while they could not change the situation they had lived through, they tried to make the best of it.

We have played the cards we were given. We really played them as well as we could. Fighting on with life. We have tried to see the icing on the cake. It is a great effort, but we didn't have any chance to choose anything else. We tried to live our life the best we could.

The parents also became more aware of the importance of the family and especially about them being important as parents to their children. One mother related; *"I have understood the importance of me being a mum"*. However, some parents still had physical symptoms and felt vulnerable, especially when under stress.

My body reacts, I still get really tired if I have too much around me. I easily get stressed and feel my heart beating fast. I did not have that before.

Discussion

The results showed that the families' experiences from the cancer trajectory still after seven years had an influence on them. Even though the child had ended treatment and recovered, the memories from the illness influenced the family's everyday life. The study revealed that the younger the survivor was at time of diagnosis the vaguer the memories were from the cancer trajectory. Children's memories develop over time. Two-year-old children can keep some memories from special events if parents combine talking and showing photos (von Tetzchner, 2005). This may be a reason why Kazak et al., (2010) found that adolescents diagnosed with cancer had significantly higher psychological distress, as well as less positive health beliefs, than those diagnosed at an earlier age. Even if the survivors in this study had vague memories from the cancer trajectory they were reminded of it by, for example, physical scars. This is in accordance with Enskär and Berterö (2010) who found that the survivors' bodies were changed due to for example scars. Some of the children had accepted their new body whereas others still struggled. Even if most of the survivors in our study were young at the time of diagnosis and treatment they expressed not being completely understood by others as they had lived through something that most other people had not been through. Enskär and Berterö (2010) found that the survivors experienced themselves being both mentally and physically different from other healthy young adults (ibid). However, survivors recounted how they preferred to leave the cancer treatment behind and for it not to be present in their current identity. The reason for this may be that they did not want to be different from their peers (Casillas et al., 2010). Already during treatment it was important for the sick children to retain normality. They did not want to talk so much about the disease and they longed to do normal things (Björk et al., 2009). When meeting new people the survivors also often felt that it was difficult to talk about the cancer (Jones, Parker-Raley, & Barczyk, 2011). In the present study, we found that the survivors mostly did not raise the subject of cancer unless talking with other

survivors who had been through similar journeys or inside their own family where they could understand each other. This led to closer family bonds.

For the siblings it sometimes was difficult to recall the cancer treatment period if they were very young at the time of diagnosis, ie two years old or less. Siblings in our study seemed to feel relatively well and showed no signs of being psychologically unhealthy. Buchbinder et al. (2011a) showed that siblings of CCS are generally psychologically healthy; their results are in accordance with Kamibeppu et al. (2010) who found no significant differences regarding depression, anxiety and posttraumatic stress symptoms between the siblings and a comparison group. Björk et al. (2009) found that during treatment siblings received knowledge from their parents and the sibling supporter, which made them confident about the future. Buchbinder et al. (2011b) argues that open communication between family members can be important for the sibling survivors to prevent anxiety, depression and antisocial behavior. In our study the siblings related that, when they were given time to reflect on their situation with for example a social worker, it made them feel strengthened. A similar feeling occurred when talking to friends with the same experience eg other siblings. The siblings also felt that the cancer trajectory had brought the family members closer to each other.

In the present study parents experienced the cancer trajectory as having been internalised as a part of their identity and having brought them new insights on life. Some parents described new ways of viewing life that were considered as positive. This might be explained by Forinder and Lindahl Norberg (2010) who stated that small things did not get so much attention for the parents as before the child became ill. Björk, et al. (2009) found that parents' perspectives changed during treatment. When treatment was completed, parents did not take things for granted and they became less concerned about trifles (Björk et. al., 2011). This

study showed that the parents felt that the cancer was still more or less present in their lives. They still sometimes worried about the child's future and about relapses but they did not want these worries to influence their child's everyday life. Other studies have also shown that parents had difficulties leaving the cancer behind. Earl, Davies, Greenfield, Ross and Eiser (2005) found that parents wanted to protect their children from knowledge about future risks; according to Forinder and Lindahl Norberg (2010) the parents' fear of relapse had become an ever-present part of their lives. For some parents, their basic sense of security had been disturbed and this worry dominated their lives and as soon as the child showed physical symptoms that could be related to the original disease they got more concerned. They wanted to put everything about the cancer trajectory on one side and enjoy life, but this was not completely possible. Sometimes it was hard for the two parents to find the same coping strategies, for example one among the couple wanted to verbalize their emotional distress while the other tried to accept the situation and focus on normalizing things (ibid).

According to Casillas et al. (2010) it is hard for the parents to discuss the family's cancer experience with people outside the nuclear family. Several parents revealed a perception that other people did not understand what they had been through (Forinder & Lindahl Norberg, 2010). Earlier studies generated from this longitudinal research project highlight the importance of the own family. As for example, when the sick child was during treatment, it meant a lot when the family was able to do things together (Björk, et. al., 2009) and when treatment was completed they wanted to continue to prioritize their own family and retain the feeling of being close (Björk, et al., 2011). The present study showed that survivors, siblings and parents expressed that it was only inside the nuclear family that their outlook on the cancer trajectory could be completely understood. Karian, Jankowski and Beal (1998) state that according to the survivors the experience improved the family relationship as it brought

an appreciation of spending time together. Maybe it is because of the life-threatening period the family had been through together that the bonds within the family are still expressed as having been strengthened.

Method and limitations

This study deepens the understanding of families' lived experiences following a childhood cancer trajectory. This knowledge is needed when caring for families in such situations. When evaluating qualitative data it is important to consider the trustworthiness of both the data and the findings (Lincoln & Guba, 1985). The families eligible for this study were contacted through a letter. As all of them did not answer the letter, was not reachable or did not want to be interviewed this resulted in a small number of included participants. This can be seen as a consequence of the longitudinal study design and a limitation of this study.

The interviews were performed with the researcher (MB) who had met the family before during this longitudinal research study. Earlier studies have shown that trust develops over time (Sterling & Peterson, 2005) and, in this study, that was the case for most of the parents. Interviewing children several times but at long intervals does not necessarily bring as much benefit, probably because of their young age at the time of the earlier interviews, as well as the long time lapses between the interviews. Therefore, in this study it seemed as if they felt little or no connection to the interviewer.

Undertaking qualitative analysis requires researchers to be aware of their pre understanding in order to achieve openness for meanings shown in the data (Dahlberg, Dahlberg & Nyström, 2008; van Manen, 1997). The researchers involved in this study had different backgrounds whereby two of them (but not the other two) had earlier experiences of childhood cancer

research. However, all four researchers were well experienced in undertaking qualitative analysis. The researcher critically reflected on the analysis and meanings described.

Conclusion and nursing implication

The result concludes that family members in this study still feel vulnerable even when a long period of time has passed since completion of the treatment. To varying degrees they still may need support. To be able to move forward in life, the family members are helped if they can reconcile themselves with their memories and experiences deriving from the childhood cancer trajectory. It is important for nurses to be aware of that even if a long period of time has passed some families still feel that the cancer trajectory has an affect on them. When the consultations concerning late effects from the cancer treatment are conducted, there may be needs for psychosocial and psychological assessments of family members.

There are few qualitative longitudinal studies in this area. This study contains only four families. Therefore we stress the need for further longitudinal studies with more families included to further deepen the understanding for these families' situations.

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