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Like being covered in a wet and dark blanket - Parents' lived experiences of losing a child to cancer

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Abstract

Purpose: The aim of this study was to illuminate parents' lived experiences of losing a child to cancer.

Method: Interviews and a narrative about parents' experiences of losing a child to cancer were gathered from six parents of children whom had participated in a longitudinal study across the child's illness trajectory. The analysis of the data was inspired by van Manen's hermeneutic phenomenological approach.

Results: One essential theme emerged: *Like being covered in a wet and dark blanket*, as well as six related themes: *Feeling conflicting emotions*, *Preparing for the moment of death*, *Continuing parenting after death*, *Recollecting and sharing memories*, *Working through the sorrow* and *New perspectives in life*.

Conclusion: There is a need for good palliative care. If not, there is a risk that the parent will persevere and blame themselves for not being a good parent during the suffering child's last time in life. Meetings with the parents six months and two years after the child's death might facilitate healing through the grief process.

Key words: Parents, paediatric cancer, palliative care, death, lived experience, nursing

Highlights

- This study contributes to knowledge regarding parents complex and sometimes conflicting experiences through the grief process when losing a child to cancer.
- After the child's death, the parenting role continues as it is impossible to turn off the parental protective instinct.
- Parents want to remember their child by recollecting and share memories.

Introduction

Among those children diagnosed with cancer living in Europe, the overall 5-year survival is approximately 80%. However, there are disparities in survival between the different countries (Gatta, Botta, Rossi, Aareleid, Bielska-Lasota et al. 2014). Yet, despite increased survival rates, there are parents every year that lose their child to cancer. To have a child suffering from cancer who later dies from it is one of the most difficult situations a parent can experience and it will emotionally affect them for the rest of their lives (Epelman, 2012).

The child's palliative phase is for the parents a distressing time in which the child can be depressed, experience fatigue, be in pain or have a loss of appetite (Heath, Clarke, Donath, McCarthy, Anderson & Wolfe, 2010; van Cleve, Munoz, Savedra, Riggs, Bossert, Grant & Adlard, 2012). Sometimes, in this palliative phase, the child gets so sick that their ability to communicate fails (Hunt, Valdimarsdottir, Mucci, Kreicbergs & Steineck, 2006). In this situation, the likelihood of mothers thinking that death would be the best for the child increases. This is also the thought among fathers the longer the duration of the child's illness (ibid). However, Epelman (2012) argues that while parents do not want their child to suffer any longer, they cannot accept the thought of terminating curative treatment.

Parents to a child with a severe malignant disease experience it as difficult and demanding to talk with their child about his/her imminent death. Kreicbergs, Valdimarsdottir, Onelöv, Henter and Steineck (2004a) found that parents who have lost a child to cancer, who sensed that their child was aware of their upcoming death, in hindsight regretted not talking to the child about it. This was more likely for parents of older children compared to parents of younger children. Those parents who regretted not having talked about death with their child had higher levels of anxiety. However, most parents had not talked about death with their severely ill child and they did not regret their decision (Kreicbergs, Valdimarsdottir, Onelöv, Henter & Steineck, 2004a).

After a child's death, reactions of parents are multifaceted and distressing (Epelman, 2012) with parents often holding onto their good memories of experiences they have had together with the child. Nuss (2014) found that when these memories lived on and parents talked about the child, they saw a purpose to their child's shortened life and that the child would not be forgotten. Wender (2012) means that it was a great fear for many parents that they would forget their

memories of the child, so they felt compelled to keep talking about their child in order to allay these fears.

The duration of grieving the loss of a child is often acknowledged to be a year by many religions and cultural practices. However, many parents experience considerable grief for much longer and it is usually measured in years (Wender, 2012). Hazzard, Weston, & Gutierrez, (1992) found that parental grief remains deep for at least four years. Several years after a child's death, it is still painful for the grieving parent to hear that they should put their child's death behind them and get on with their lives (Wender, 2012). Historically, the grieving literature suggested that the parents should emotionally disengage from the dead child to be able to move on with life and achieve closure. This has changed towards working through the loss and learning to live with the loss (Packman, Horsley, Davies & Kramer, 2006). However, grief seems to be individual and ongoing with no fixed ends (Price, & Jones, 2015).

For parents, the death of a child breaks down their expected world and symbolizes the loss of both their present and futures lives (Price and Jones, 2015). To be able to support parents, additional knowledge is needed about their own lived experience of losing a child to cancer. Therefore, the aim of this study was to illuminate parents' experiences of losing a child to cancer.

Method

Design

This study used a qualitative descriptive approach and is part of a longitudinal research project in which families with a child diagnosed with cancer were included. In the longitudinal research project, the families were interviewed when the child was diagnosed with cancer (Björk, Wiebe & Hallström, 2005) during treatment (Björk, Wiebe & Hallström, 2009) right after treatment was completed (Björk, Nordström, Wiebe & Hallström, 2011) and seven years after the child's diagnosis (Sundler, Hallström, Hammarlund & Björk, 2013). During the time of the longitudinal research project some children in the included families died. This paper focuses on those parents who lost a child to cancer.

A hermeneutic phenomenological method inspired by van Manen (1997) was chosen. Van Manen (1997) stated that the phenomenological component of a hermeneutic phenomenological study attempts to capture the lived experience of a certain phenomenon by

trying to make meaning of the lived experience. The hermeneutic component tries to interpret the lived experience to determine the meaning embodied in the lived experience and then transfer it into scientific text.

Participants

In the beginning of the longitudinal study, 17 families with a child newly diagnosed with cancer were included. Of these, four children died during their cancer treatment. These families were invited to participate in the present study. The parents of one of these children agreed to participate. Three children died after treatment was completed and four of these parents (two families) agreed. None of the parents wanted their deceased child's sibling to be interviewed. This resulted in six parents from three families being interviewed. One family was interviewed one year after the child died, the second family after two years and the third family after seven years. At the time of the interviews, the ages of the parents ranged from 34 to 43 years old.

Data gathering

The first author (MB) contacted the seven families, whose child had died, by a letter and invited them to a final interview. Three of the proposed participants did not respond to the initial invitation letter, and one family did not want to participate due to not wanting to “dig up their sorrow again”. Those who wanted to participate were contacted by phone, at which point they were given more information about the interview. After having had time to consider their participation, the parents gave their written informed consent and decided a time and location for the interview to take place. Three of the parents wanted to be interviewed individually, and two of the parents wanted to be interviewed together. The final parent did not want to be interviewed, but was happy to write down a narrative of the lived experience of losing the child to cancer. One of the parents was interviewed at the hospital, while the other parents were interviewed at home. The interview started with the parent telling the interviewer what had happened since the last interview and then moved onto their experience of losing their child to cancer. When the interviewee had difficulty describing their experience, follow-up questions like “what do you mean?”, “can you please explain this further?”, “how did you feel?”, and “what happened next?” were asked. The interviews lasted between 90 – 120 minutes, and were audiotaped and transcribed verbatim.

Data analysis

Van Manen (1997) inspired the hermeneutic phenomenological analysis. Two of the authors (MB, KH) performed the analysis, starting with a selective, highlighting approach (van Manen, 1997) described in the following steps. In the first step, the interview text was read through several times in order to gain an overall picture of the text and to become familiar with the content. In the second step, statements that seemed to reveal something about the parents' experiences of losing a child to cancer were underlined and cut out from the text in an attempt to uncover the thematic aspects of the phenomenon being studied. In the third step, the writing process started where we reflectively attempted to make the parents' experiences of losing a child to cancer understandable. When re-reading the chosen statements, the meaning of the parents' experiences of losing a child to cancer was sought and transformed into written text. Tentative themes were formed. Van Manen (1997) states that a theme gives control and order in the writing process. Similarities, as well as differences, for example, variations of similar aspects of the phenomenon, were put together and new reflected written text began to emerge. The text was written and re-written several times, and the analysis went back and forth between parts (phrases and statements) to the whole (the entire interview text). The writing process can be described as an act where the researchers are trying to make contact with things of our world (van Manen, 1997), i.e. parents' lived experiences of losing a child to cancer. The tentative themes were discussed among the authors and continually revised. This entailed the text being written and re-written several times. Finally, six related themes; *Feeling conflicting emotions*, *Preparing for the moment of death*, *Continuing parenting after death*, *Recollecting and sharing memories*, *Working through the sorrow* and *New perspectives in life* emerged, and they were linked together in one essential theme *Like being covered in a wet and dark blanket*. The essential theme is described by a metaphor emerging from the parents' own stories in order to generate greater insight and understanding of the parents' lived experiences. In addition, the related themes further explore the parents' experience of losing a child to cancer (van Manen, 1997).

Ethical considerations

The study was given formal ethical approval by the Research Ethics Committee at the Medical Faculty, Lund University, Sweden (LU 476-01), and the Regional Ethical Review Board, Lund University, Sweden (2009/127). This study only has six participants and in order to protect the confidentiality of these parents we have changed the names of the children and do not include their ages or diagnosis. We have also tried to be gender neutral and used the word parent more

often than mother or father. When the word mother and father are used, we have sometimes switched the gender.

Results

Like being covered in a wet and dark blanket

Losing a child to cancer can metaphorically be explained as being covered in a wet and dark blanket. The blanket was already present and covered the parents when the child was in its palliative phase. To see the child suffer was emotionally arduous, but facing the child's imminent death could be even more difficult. Despite the blanket, it seemed important to the participants to find the strength to talk to the child about the child's forthcoming death. When death appeared, the emotional and cognitive process of moving from a living child to that of a deceased body was hard to comprehend and the child still needed to be treated with dignity. The grief was at this moment intensified and thus the blanket was experienced to become even wetter and darker. To cling to the good memories gave some comfort and seemed to make it easier. Gradually, the blanket dried little by little, but it still felt overwhelming. Sometimes, when emotionally hard memories came forth, it "rained" grief and pain and the blanket would once again become more wet, dark and heavy. With time, the rain did not come as often as before. A way of handling the grief could be to live in the moment since the future felt too uncertain. As years pass, the blanket became drier and life became brighter and less oppressed, but in some ways it would always be present.

Feeling conflicting emotions

The child's last time in life was experienced as difficult and exhausting for both the child and the parents. The child's bodily functions were often worsened. The child could, for example, no longer walk or eat and some children experienced convulsions and severe infections. During this painful time, the parents were caught between conflicting emotions as they neither wanted to lose their child nor wanted to see the child suffer.

You are torn between these two things, that it would have been more comfortable and easier for her (to die) four weeks earlier, but at the same time you desperately wanted a little more time with her, that's the way it is.

Despite understanding that the prognosis was poor and that the child would not survive, parents experienced difficulties in comprehending this as death approached. Parents understood that the

child would die, even though they were unprepared when the doctors declared that there were no more to do to help the child survive. The last period in life came like a shock to the parents.

I thought we had five years left, five months and then I realised that now is the time. Before I knew it would happen, but then I realised that it is happening now.

If the parents experienced the child's palliative care as very emotionally difficult, the feeling stayed with the parents and became heart breaking for them. In this situation, parents could also feel that they failed in their parental role and blamed themselves for not being a good parent. They also stated that they reflected on their parenting after the child's death and asked themselves if they had been a good parent and done everything they could.

It was enough with just lifting her, and then she started to yell. She had pain in her neck despite a continuous morphine infusion. That you don't wish anyone, especially not your own child. As a mother, you feel that your job is to protect your child and try to take care of her and make life good to her... I feel it like a radical failure as a mother.

Preparing for the moment of death

The parents described difficulties talking with the child about the child's imminent death. One father related that he had asked if the child felt like the body was giving up. The child then started to talk about the body as a third person, like stupid stomach, or stupid leg that did not function. The father then interpreted this as the child was describing its body as a shell that did not do as the child wanted. After that episode, the parent stated that he got strength to talk to the child about their journey towards death. They (parent and child) also talked about deceased relatives that the child thought were in heaven. One parent related;

The child says to the nurse "I am longing for grandfather". But you are soon going to meet him, the nurse says. The child then answers that it will be a bit delayed because she wants to stay with mummy and daddy for a while.

The parents related that one way to prepare their child was to use stories for children and situations narrated in fairy tales. A father described that his child understood that she was going to die before her parents. The parent then stated that the child wondered where the parent was going to be when she died. The father said that he would sit and fish when the child came looking for him as they do in a book for children that they had read together. After that, the father asked where to find the child. The father related that the child answered without hesitation, which the father interpreted as the child must have thought about it earlier;

“I will sit in the field of sun flowers or I will be picking strawberries.”

Parents sometimes stated that they experienced that the child wanted to protect them from sadness and to keep their spirit up, not giving up hope. Some parents experienced that their child searched for their “permission” to die.

It was like she had to get our permission to die. Then she should not feel that it is a failure on her part, its ok.

Continuing parenting after death

During the child’s last part of life, the parents had protected the child from pain, discomfort and emotional distress. When the child finally took the last breath and died, the parents stated that they could not turn off their parental protective instinct, like flipping a switch. An example of this is a description from a mother that became worried when she saw that the healthcare staff had left her deceased child alone. Even if the child was not alive any more, she instinctively thought that her child could fall down and hurt herself.

It was just a thought coming through my head, although I knew it could not happen.

Parents also said that it was difficult to answer the question of how many children they had. Their answer depended on what relationship they had to the person asking the question. When they did not include the deceased child in their answer they felt it as a betrayal. They also stated that they had a sense of fear to discourage people and make them feel uncomfortable when they talked about their deceased child.

It is a question that you are afraid of getting. Do you have children? How many children do you have? What should I answer? I feel split every time.

Another example is associated with the child’s security blanket where it was of great importance for the parents that the blanket was handled with care and in the same way as when the child was alive.

We have many photos of him when he was deceased. On these, he has his security blanket on the wrong side. He always had his security blanket on the left side.

Recollecting and sharing memories

The parents also wanted to remember the child by recollecting and sharing memories. Therefore, they for example made the funeral very personal. Toys, drawings and child songs were often a central part of the funeral. This was an ongoing experience where the parents, in different ways, kept on remembering the deceased child's birthday, or communicated with the child when looking up at the stars.

I often talk with Sarah when looking up at the stars. I imagine she is sitting in "the Plough" looking down at me.

Working through the sorrow

The parents stated that they found it hard to grieve just around the time after the child's death. They could barely cry or show any sadness. The parents compared this phase to a blurred grey period, where their brain stopped working and that they were not really present. After a while the parents stated that their sorrow came in waves, where there was a swing between feeling "much" sadness and grief, to feeling "less" sadness and grief. To be able to survive the sometimes-paralyzing grief, the parents, in different ways, started to work through their sorrow. The parents stated that they felt as if they lived two parallel lives; one everyday life that contained hobbies and duties, and the other life that contained the unmistakable and endless loss of their deceased child.

Parents also described that they avoided working through the sorrow by, for example, keeping themselves busy all the time, or altering their environment either by changing dwelling place or moving abroad for a while.

If you run fast enough over the canyon and not look down, then you come over, just don't think about it.

Different ways of working through the sorrow were described, for example, writing a web page, meeting families they had met at the hospital or just resting in idleness. The parents also stated that they experienced a need to meet the healthcare staff at the hospital some weeks after the child's death, and that such a visit could help them to let their feelings out. However, it could also be a visit associated with many sad memories. They described that they would have liked to receive an invitation for such a visit via a letter with a date and time between six months to two years after the child death. They described that this would be a good time because the grieving process had progressed, which could be a subject to discuss.

...some sort of invitation, much longer after, like half a year, a year, two years later... if we had got an invitation that you are welcome on Tuesday that date and time... it would have been a concrete suggestion that we could say yes or no to. It would have been much easier instead of us calling a number. It does not work for us.

Just after the child's death, parents stated that the loss was more physical; they missed the child's smell, skin and their sounds, but also physical episodes, like the child crawling into the parent's bed or even arguments and disagreements. The parents stated that they after a few years could see a future that they could not have seen earlier, but it was a long time before they could accept that their child was deceased. One parent related a metaphor with "memory pearls", where the black pearls symbolised bad memories and the white pearls symbolised the good memories.

You have your "memory pearls" that you thread on a string, the white are good memories and the black are bad, but you thread them both up. Finally, you can thread a bit without using a black pearl.

As time passed, the parents experienced that life worked better and better, and that their grief did not come as suddenly as before. However, the sorrow was ever-present, and the parents did not want to forget the child. One way to remember was to provoke memories by reviewing photos connected to the child.

New perspectives in life

The parents experienced that the "compass" had changed concerning priorities in life. Before the child became sick, the parents took more consideration of other people's opinions. Several things had also diminished in importance, for example, work. Some even reduced their working hours and episodes that earlier were experienced as catastrophes at work, often concerning economic or material values, were now seen as less important. The parents also stated that time passed quickly and that they wanted to spend more time together with their family.

Now, you have seen that it (life) can end really fast. You appreciate things in a different way now... You appreciate the time together with each other much more.

Even if life continued after the child had died, the parents experienced the memory of the deceased child as not aging, neither in a physical nor psychological meaning. The parents'

image of the child would not be older than the child was at the time for their death. The newborn sibling could sometimes be compared with the deceased child. The parents experienced that the deceased child's friends grew and matured compared to their memories of the deceased child. This made the parents wonder how their child would have developed. When the child's friends grew up and got older they did not fit with the paragon of the deceased child, the grief was alleviated.

I cannot change that picture in my head, but they (the friends) have grown up and changed... Sometimes it feels strange but at the same time is nice... The first six months, immediately when I saw Mary (best friend), I saw Julia (the deceased child) next to her or the absence of Julia but I do not feel it the same way now, because Mary (best friend) does not look the same as before.

Discussion

In this longitudinal study families with a child diagnosed in cancer were followed throughout their child's illness trajectory. The present study focuses on the parents that lost their child to cancer. One benefit with a longitudinal study is that a rapport between the researcher and the participant develops over time (Sterling & Peterson, 2005), which may lead the interviews to be deeper and richer. However, one limitation of the present study is the number of participants. The present study only contains parents involved in the longitudinal research project and who had a child that died. Therefore there were only seven eligible families. In the present study six parents from three families agreed to participate. The other eligible families declined participation because they did not want to return to the past and "dig up" their sorrow. Some of those parents wrote a short letter in response describing their situation and thanked for having been able to participate in the research project but kindly declined this last interview. The relationship with the interviewer could have made it easier for them to decline as the interviewer had an understanding for their family situation and also highlighted their right to withdraw if they wanted to.

The four researchers that performed the analysis had a broad experience of paediatric oncology nursing and/or qualitative research (ranging from 15-25 years), which can be both an advantage and a disadvantage. To prevent the researchers' pre-understanding from overriding the analysis of the data, the analysis process was performed in several steps. All the researchers critically reflected on the analysis and meanings described until consensus among them all was achieved.

The present study showed that being a parent to a child in palliative care was demanding and arduous and the parents had difficulties in understanding and assimilating the information about their child's incurability. This is in line with Lannen, Wolfe, Mack, Onelöv, Nyberg and Kriebbergs (2010) who found that approximately half of all parents of children with incurable cancer were unable to fully understand information about their child's forthcoming death. However, most of the parents (about 85%), wanted to know when cure was not possible in order to make end-of-life decisions (ibid).

The parents in the present study described that they tried to prepare both themselves and the child for the child's forthcoming death. One way to talk about death with the child was to use fairy-tales about children dying, and another was to relate the issue of dying to deceased relatives. Dunlop (2008) found that it is difficult for the parents to talk to the child about his/her forthcoming death (ibid). It is nevertheless important to remember that children with life-threatening conditions often are aware of their forthcoming death (Dunlop, 2008; Jalmsell, Kontio, Stein, Henter & Kriebbergs, 2015). However, even if they might be aware of it, they sometimes do not want to talk about it (Dunlop, 2008). They talk around the subject or do not ask direct questions (ibid), as they want to protect their parents from their own suffering (Nuss, 2014). However, if the child is never told the truth, they can feel both fear and isolation (Dunlop, 2008). Talking to the child about the forthcoming death has a positive impact such as lowering the level of anxiety in the parents. The parents who had talked to the child about death did not regret having done so (Kriebbergs et al., 2004a). Children with cancer have expressed that they wanted the information to be truthful even if it implied bad news. They also wanted the information to be given in such way so they could keep up their hope (Jalmsell, 2015). Therefore it is important that the nurses feel comfortable when talking to the dying child and his/her parents. Many years of working experience and going through palliative care education facilitates the approach to such situations (Feudtner, Santucci, Feinstein, Snyder, Rourke & Kang, 2007).

Woodgate (2006) showed that palliative care given in a professional way was connected to parents' ability to have positive memories. Parents wanted to feel that they were good parents, which meant making their child's life as happy as possible without too much pain and suffering. This is in accordance with the present study where the parents experienced that if the child's palliative care was painful, this resulted in distressing memories for the parents. The parents felt that it was their responsibility to protect and take good care of the child in their final stage

of life. If they experienced a failure, they could accuse themselves of not being a good parent, which could result in a heart breaking perseverate memory. According to Dunlop (2008), the most important aim for a parent was to ensure the child's survival. When the child was dying, the parents felt they had not protected their child and failed in their essential duty.

Previous research shows that there has been a major shift in the bereavement literature. According to Davies (2004), the former traditional model for grief is no longer accepted. This model focused on the need for the bereaved to emotionally detach their relationship to the deceased child to achieve a closure. Newer models focus on parents remaining involved and connected to their deceased child through continuing bonds (Packman, Horsley, Davies & Kramer, 2006). The latter is in accordance with our study showing that parents tried to keep their memories of the deceased child alive in different ways. One way could be to look upon the stars and "talk" to the child, and other ways were through photos, writing on a webpage or celebrating the child's birthday. By having these memories, they preserved their connection to their child, and the child would not be forgotten.

The parents described that it took years for them to see a future. According to Wender (2012), parents' grief over the loss of a child was longer than most people imagined. Parents related that after a considerable amount of time the grief still could overwhelm them and they remembered traumatic details about their child's disease trajectory. The parents celebrated important dates, such as the child's birthday and they remembered the day of death for several years. During important events in the family, for example graduations and marriages, the grief reawakened. When several years had passed, the parents remembered the deceased child with less pain and the bright memories were found to emerge even more. Barrera, Mammone D'Agostino, Schneiderman, Tallet, Spencer, and Jovcevska, (2007) described that a majority of bereaved parents were able to go on with their lives and to incorporate the experience into everyday life, navigating the fine line between remembering their deceased child and relieving their deep sorrow.

This study also showed that parents changed their priorities in life. For example, things connected to economic or material values were described as less important. These findings mirror research conducted by Bogensperger and Lueger-Schuster (2014), who showed that parents described changed priorities, where work, money and material things were diminished in importance. The same result is described by Barrera, O'Connor, D'Agostino, Spencer,

Nicholas, Jovcevska, Tallet and Schneiderman (2009), who stated that bereaved parents change their life views from materialistic things to quality of relationships and place greater importance of the family.

Another supporting intervention is peer-led support groups. According to Wender (2012) one way of working through the sorrow is to take part in self-help groups for bereaved parents. In such groups, the parents can get the opportunity to share and recollect memories. The peer-led support groups offer an atmosphere that parents are comforted by and make it possible for them to relate their losses, without the pressure to get over it. If these parents do not get the opportunity to talk about their grief, they may have more difficulties in their grieving and their ability to function effectively (ibid).

Conclusions and Clinical implications

To communicate with a child in palliative care is a challenge for both parents and nurses. Therefore it is important that the healthcare staff is trained in communication strategies and palliative care to be able to support the parents in this sensitive situation.

To be able to relieve the grieving process for the parents there is a need for a good palliative care. If not, there is a risk that the parent reword and blame themselves for not being a good parent in the suffering child's last time in life. If the palliative care is not working effectively, this could stay as a painful memory for the parents and make the grieving process even harder and longer. Palliative care for children diagnosed with cancer needs to be holistic and focus both on the child and the family.

Different supporting interventions can be suggested based on our findings. One intervention is based on the parents' need for support after the child had died. The parents in our study suggested an invitation via a letter from healthcare staff that had cared for their child, both at six months and up to two years after the child's death. For them, this was seen as a good time, meaning that they had progressed in the grieving process and felt that they could discuss their child's last time in life and death. This is also in line with the International Society of Paediatric Oncology guidelines (Masera, Spinetta, Jankovic, Ablin, D'Angio, Van Dongen-Melman, Eden, Martins, Mulhern, Oppenheim, Topf & Chesler, 1999), who suggested two years of routine contact with the parents to be desirable. Bogensperger and Lueger-Schuster (2014) also highlighted the need for helping the parents to enhance their understanding of the situation.

In the future, additional important insights could be provided by focusing qualitatively on whether mothers and fathers experience losing a child to cancer in different ways, as it may lead to more nuanced care for families.

Conflicts of interest statement

None declared

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