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Childhood Cancer Research Group

University of Lucerne

Team:

Prof. Dr. Gisela Michel
Dr. Eddy Carolina Pedraza Salcedo
Dr. Eva de Clercq
Dr. Peter F. Raguindin
Anna Katharina Vokinger

Coping strategies after the loss of a child to cancer

Losing a child is a devastating experience. Emotions overwhelm parents, siblings, family members, and friends. Grief is personal, and the way someone copes with it is unique. Our study aimed to describe the coping strategies families embrace after the loss of a child due to cancer. We systematically reviewed and synthesized findings from previous studies. We found 5 main groups of coping strategies:

- **Continuing bonds:** bereaved families may maintain the connection with the child, for example, by thinking/talking about them, remembering the child through photos or special objects (keeping his/her belongings), or visiting the graveyard.
- **Meaning-making:** bereaved families may develop a new worldview, by appreciating the little things in life, prioritizing family time, and being more sensitive towards others going through similar situations or changing careers. Some families might focus on spirituality and find support in religion.
- **Emotional expression** may include crying, shouting or being angry, but also talking about one's feelings or writing them down.
- **Distraction and refocus:** bereaved families may try to focus on new tasks at home, at work, or at school to distract themselves from their grief.
- **Taking care of others:** bereaved families may care for bereaved siblings and other family members or participate as volunteers in the care of other bereaved families.

Various factors can affect coping strategies, such as the age of the deceased child, their relationship with each family member, but also parental roles, or the family's cultural background. Importantly, there is no ideal coping style, and different strategies might be helpful at different times of the grieving process. The results of our study can help support healthcare teams in improving bereavement care.

The study was published in April 2023 in the journal EJC Paediatric Oncology. The full article can be read here: <https://doi.org/10.1016/j.ejcped.2023.100011>

Lack of palliative care and bereavement care in paediatric oncology across Europe

Despite the advances in treatment of childhood cancer patients with great improvement in survival, around one in five children in Europe still dies from the disease. This is a devastating experience for parents. Support for children with advanced cancer and their parents in coping with medical, psychological, and social problems is an important source of help for many of those affected.

The research group, led by Prof Dr. Gisela Michel, investigated the availability of palliative, end-of-life, and bereavement care in paediatric cancer clinics across Europe. A total of 158 clinics from 27 European countries participated in the study. Results revealed that more than half of the paediatric cancer clinics offer palliative care with multidisciplinary teams as well as options for care at home. Around half of the surveyed paediatric centres offer bereavement services. However, it is concerning that one third of the centres admit that their palliative care capacity is insufficient to meet demands. This shows that there is still a lot of potential to improve the availability of palliative, end-of-life, and bereavement care.

Eddy Carolina Pedraza, co-author of the study, emphasises that improvements require efforts at various levels: "In order to meet the need for support services and close existing gaps, political initiatives are needed to improve the funding of specialised facilities. Equally important is the effective communication between the healthcare professionals involved, affected children and families, researchers, and political decision-makers to raise awareness of the relevance and benefits of the services."

The study "Palliative care services in paediatric oncology centres across Europe: A cross-sectional survey" was published in November 2023 in the journal *EJC Paediatric Oncology*. The full article can be read here: <https://doi.org/10.1016/j.ejcped.2023.100125>

Long-term effects of grief and needs of parents after the death of their child with cancer

Little is known about the needs of parents in Switzerland who have lost a child and how they cope over time. In our study, we therefore want to explore these needs more deeply.

For this study, we used two methods: a survey (103 participants) and in-depth interviews (23 participants). All participants are parents who lost a child to of cancer (at least 1 year before participation in the study).

Support needs of bereaved parents after the loss of their child to cancer

Losing a child has an enormous impact on parents' lives. The grief parents experience after the death of their child to cancer may differ from that of parents who have lost their child in other ways. This is due to the uncertainty of the prognosis, aggressive treatment, hope for a cure, and possible regrets about treatment decisions. Unfortunately, support for grieving parents is limited and we do not know how to best support them. Therefore, this study aimed to understand the experiences, needs, and wishes for support of parents who lost their child to cancer.

For this study, we talked to 23 bereaved parents (7 fathers, 16 mothers) in 18 interviews. The findings show that bereaved parents received both informal (family, friends and the parents' social environment) and professional support. Parents often had mixed feelings about the informal support they received. These feelings were due people's lack of understanding about grief and how to best provide support. Parents also acknowledged that they sometimes struggled to express what kind of support they really wanted.

Support provided by healthcare professionals, institutions and organizations can be inconsistent. Factors like personal efforts by professionals or the impact of the Covid-19 pandemic often mean that parents did not receive the needed support services or received it only temporarily.

The study shows that improved communication about grief, death and available support can help friends and family members provide better informal support. Institutional measures, education and training, and networking among professionals can help to ensure that support from professionals, institutions and organizations is more consistent. The study further recommends combining informal and formal support more closely in order to offer parents long-term support.

The study "Support experiences and wishes of bereaved parents after the loss of their child to cancer" was published in the journal *Pediatric Blood & Cancer* in October 2024. You can read the full article here: <https://doi.org/10.1002/pbc.31426>

Bereaved fathers

The bereavement experiences of mothers and fathers can differ. This may be due to their upbringing, how they were socialized to express their emotions and fulfil their roles as parents and at work. Most research on grief and loss has included mothers, with the result that there is little information about fathers' grief experiences and support needs. The aim of this study was to provide insight into the bereavement experiences, coping strategies, and support needs of bereaved fathers. For this purpose, we analysed seven interviews with fathers who had lost a child to cancer.

Our results show how in times of hardship, fathers were able to show kindness to themselves and others, often by reassessing their priorities. At the same time, they also faced feelings of helplessness and failure as they felt they had been unable to prevent their child's death and that they were unable to fulfil their role as fathers. With the death of their child, some fathers felt a sense of relief because their child was no longer suffering, and their helplessness had ended.

Many fathers expressed the desire to be reunited with their child with some feeling that life had lost its meaning without them. For others, it eased their fears about death because they would see their child again. Fathers also noticed that mothers often coped in different ways and used more mental coping strategies (e.g. journaling), while fathers looked for more active coping styles, such as going for a run. In terms of support, fathers expressed a need for support options to be offered, so that they did not have to search for it alone.

Overall, the results show that fathers can be open about their emotions and took care of others. This is in contrast to previous studies that have shown fathers to be more reserved in their emotions. In addition, this study shows how the lack of fathers attending existing support groups might be because these groups do not align with their preferred styles of engagement. Possibly, a more active support group could help fathers to connect and express their feelings. Finally, this study shows how healthcare professionals and support providers should reflect on their perceptions of parental roles to ensure that they remain open to fathers' wishes for support.

Embracing positive changes after losing a child to cancer

The loss of a child is an unimaginable experience that brings intense grief. Many research teams have focused on the negative psychological outcomes that families may develop. However, traumatic events can also give rise to positive changes in some parents. We surveyed 103 parents who lost a child to cancer. This survey explored post-traumatic growth (PTG), that is the positive changes that bereaved parents may develop. We assessed five domains of PTG: appreciation of life, new possibilities, personal strength, relationship with others, and spiritual change. Our results show that parents reported feeling more appreciation for life, increased personal strength, improved connections with others, and a sense of new possibilities. Parents who practiced a religion had higher levels of PTG than others. This can be explained by the support they received from their community, or even by their beliefs and faith that one day they would be reunited with their child, or even that this experience had a purpose in life (meaning-making). In addition, those who had lost their children in the last decade showed higher levels of PTG than those whose child's death was longer ago. Our research shows that grief is unique in both its timing and expression, involving a range of positive and negative outcomes. Recognizing this is crucial for delivering optimal care to these vulnerable parents and families.

The role of cooling facilities in the grieving process of parents facing the loss of a child

Losing a child often leaves parents with deep and lasting grief. To help families during this difficult time, some hospitals use cooling facilities, like air-conditioned rooms or special cots that keep a child's body cool after death. This helps parents spend more time with their child, which can be very important for their grieving process.

We wanted to understand how these cooling facilities are being used, so we reviewed existing research on the topic. Our findings show that in the UK, cool rooms and cold cots play a crucial role in providing care for families facing the loss of a child. They help families create meaningful memories and keep their connection to the child, and allow them to feel like parents even after the child's death. Cooling facilities seem especially beneficial in the case of stillbirth or neonatal death. Sadly, the grief that follows a stillbirth is often overlooked and not fully understood; leaving many parents feeling isolated in their pain. These cooling options can help these parents acknowledge their identity as parents, which is vital during such a painful time. Cooling facilities thus do not just give families more time; they also validate the grieving process and support parents in their caregiving role.

However, while families who have used these cooling options generally feel they are beneficial and help them cope with their grief, we believe more extensive research is needed to fully understand how these cooling facilities affect families' grieving processes and the wellbeing of the healthcare professionals involved in their care. Our analysis revealed in fact that taking care of families in cold rooms can be emotionally difficult for healthcare professionals. They often feel unsure about how to handle certain situations, like how to prepare families for what happens to a child's body after death and how to move and care for the child in those moments. This uncertainty can make an already tough situation even harder for everyone involved.

Studying the experiences of grieving parents can be sensitive and challenging, but gathering this information is crucial for improving support and care for families during their hardest moments.

The study "Cooling facilities in paediatric palliative care: a ritual form of mourning? A scoping literature review" was published in July 2024 in the journal *Mortality*. The full article can be read here: <https://www.tandfonline.com/doi/full/10.1080/13576275.2024.2384875#d1e248>