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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.
- **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 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 a third of the centres admit that their palliative care capacity is insufficient to meet demand. 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

To date, little is known about the needs of bereaved parents in Switzerland and how they fare in the long term. In an ongoing study, we therefore want to describe the needs of bereaved parents.

For this study, we used two methods of data collection: a questionnaire survey (103 participants) and qualitative interviews (23 participants). The participants are parents whose child died of cancer (at least 1 year before participation in the study).

Preliminary analyses of the interviews reveal several coping strategies used by parents after the death of their child, such as rituals that support parents in their grief, maintaining the bond with the deceased child, and the importance of certain objects that represent a connection to the child. Parents also expressed instrumental needs (such as information or help with household chores) and care needs (besides others including professional bereavement counseling or small gestures such as cards, candles, and other). Parents especially wish for support from their social environment, health professionals, and organizations.

We are currently in the analysis phase and expect the first publications in the second quarter of 2024. The results of our study will provide valuable insights into the long-term psychological and socioeconomic impact of grief on families who have lost a child to cancer and describe their needs for support from healthcare professionals and their social environment. This will help to better support these families after the death of their child.