

**PSYCHOSOCIAL AND SUPPORTIVE CARE:
RESEARCH ARTICLE**

If only I could turn back time—Regret in bereaved parents

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Abstract

Introduction: Regret about loss is one of the most intense types of regret experienced in life. Little is known about the bereavement regret of parents whose child has died of cancer. Although knowledge about parents' experiences after their child's death is vital for supporting these families, parents' regret is mostly hidden from the treating clinical staff. This study aimed to explore these parents' regret themes and their impact on their future lives.

Methods: An explorative questionnaire was sent to bereaved parents who lost a child to cancer. A total of 26 parents responded to the questionnaire. Data were analyzed using the constant comparative method.

Results: Regret experiences were shared by almost all participants. The focus of regret issues include parenting and interaction with the child, reflection on existing values, dealing with the disease, and neglecting the remaining siblings. The regret experience had an impact on prioritizing values, future lifestyle and contacts.

Conclusions: Regret seems to be a general phenomenon among bereaved parents and strongly influences the grieving process, in the sense of reflecting on past experiences to reorient for future actions. As this study was explorative, it is significant toward deepening the understanding of bereavement regret in future. These insights are crucial when working with affected families to help them decide important issues they can care about now and will not regret later.

KEYWORDS

bereavement, palliative, psychosocial, qualitative study, regret

1 | INTRODUCTION

When a child dies of cancer, parents recall the time when their child was healthy, as well as the period of illness, therapy, and terminal care. They remember pleasant times and reflect on regrettable circumstances. These thoughts and emotions have an influence on the grieving process and on the living.¹⁻³ Less is known about their content, or impact of regret, which is this study's focus.

1.1 | Definitions of regret

Regret is the feeling a situation would have been better if it happened differently. Definitions of regret have several common factors. Regret is inherent and universal in humans and a highly negative emotion with

a large cognitive component, based on theoretical concepts such as counterfactual thinking and cognitive dissonance. Regret is the sensed result of the discrepancy between an aspiration, an action, a wish, or a decision and the reality in the past, present or future. Although similar, regret is distinct from other feelings like disappointment, guilt, or remorse, and it concerns actions (a feeling that one would have behaved differently) or inactions (having failed to act).⁴⁻⁶

1.2 | Grief-related themes of regret

Regret emerges from the difference between an experienced and the best possible outcome.⁷ While regret is felt more intensely for action than for inaction,⁸ regret for inactions lasts longer.⁵ Regret is also influenced by the ease of comparing actual with counterfactual

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decision outcomes, and the importance, salience, and reversibility of the discrepancy.⁶ Confronted with the irreversibility, regret stemming from loss is one of the most intense types in the bereaved.⁹ Better quality of patient care reduces the risk of bereavement regret in caregivers of adult cancer patients.¹⁰ Widowers whose wives died of cancer display a higher risk for regret and guilt. If they failed to talk with their wife about the impending death and felt there was no closure. Similar feelings are seen in those who could not spend as much time with their wives, as they wanted.¹¹ Parents of children who died of cancer gave advice to do everything necessary, spending and cherishing the time with their child, so that there are no regrets.¹² Further, parents regret, that they did not pay the usual amount of attention to their other children.¹³

1.3 | Effects of regret

Regret is associated with anhedonic depression and anxious arousal across demographic variables.¹⁴ Older adults drawing images to represent life regrets showed sleep disturbance, poorer health and life satisfaction, abnormal cortisol profiles, and more depressive symptoms.¹⁵ Bereavement regret can be closely connected to feelings of self-blame and guilt and might lead to complicated grief.^{16,17} Feelings of regret toward a decedent have a positive association with depression¹⁸ and are suggested to be a unique marker of difficulties in the grieving process.¹⁵ Guilt, similar to, yet distinct from regret was reported by 70% of the parents who lost a child, underlining the relevance of this issue.¹⁹ Regret is considered beneficial to making sense of past experiences, facilitating approach and avoidance behaviors, gaining insights into the self, and preserving social harmony.²⁰ Self-compassion modulates acceptance of regret experience and personal improvement.²¹

1.4 | Aim of the study

Although bereavement follow-up care is appreciated by bereaved families and the child's medical team, care often ends after the death of the child due to a lack of resources.²² Therefore, the clinic team does not get to know much about the impact of regret in bereaved parents.

Bereaved parents were more likely to work through their grief when health care staff already offered them counseling during the last month of their children's life.²³ In order to support these families during this time of critical and palliative care, it is vital to have knowledge about parents' experiences including their regret issues.¹² To better accompany affected families during all phases of treatment, our study aimed to improve the understanding of bereavement regret in these parents by identifying major regret themes and the impact on their future.

2 | METHODS

2.1 | Study design

In this cross-sectional qualitative study, 200 questionnaires were sent by post to bereaved parents in April 2017. These parents had a child under 18 who was treated in pediatric oncology and died of cancer at least 6 months previously. Addresses were found through the

TABLE 1 Questions

- a. When you think about the shared time with your child **before** the illness, is there anything you would have done differently? Is there something you regret?
- b. When you think about the shared time with your child **since** the illness, is there anything you would have done differently? Is there something you regret?
- c. Does this experience of regret have repercussions on you? Would you do things differently now?
- d. Is there something you would have liked to hear in your situation? Is there anything you would like to say to families with children with cancer?

register of the local pediatric oncology department, grief support groups for parents who lost a child (group leaders were requested in advance), and children's hospices in Germany.

The questionnaire was designed with four questions and further demographics concerning the participant and the departed child. These questions covered the following areas: *themes of regret* (regarding time with the child before and after the disease diagnosis), *consequences of regret experience* and *advice to other parents with an ill child* (see Table 1). We declared that their answers would be anonymized and treated strictly confidential in accordance with data protection. Parents were asked to answer in as many or few words as they wanted. To phrase these questions in the most sensitive way, we asked a bereaved parent to edit the questionnaire and integrated the annotations. The local ethical committee (EA2/008/17) approved the study and informed consent was obtained prior to the study's start.

2.2 | Data analysis

Data were analyzed using the constant comparative method,²⁴⁻²⁶ aiming at a theoretical understanding of parents' regret. This method involves data collection, analysis, and coding with theoretical sampling. The essential strategy is the consistent and systematic comparison of individual cases or groups based on existing knowledge. Theoretical sampling in this process refers to collecting, encoding, and analyzing data while deciding which data should be collected next.

First, each questionnaire was read in its entirety to identify categories and dimensions. Second, codes were compared interindividually, allowing connections between categories and determining related subcategories. Finally, the most significant category was identified and systematically connected to other categories until theoretical saturation was reached. Analyzing all questionnaires led to a saturated understanding of the research theme as the last questionnaires did not add further knowledge. To increase the intercoder reliability, two coders read the answers independently and discussed and compared the codes until a convergent interpretation was found.²⁷ As the word load was not heavy, data were analyzed via Excel.²⁸

3 | RESULTS

Overall, 26 bereaved parents responded to the questionnaire. Most were mothers ($n = 21$), married ($n = 21$), and had other children ($n = 24$).

TABLE 2 Major themes of regret

Regret theme	Definition	Representative quotes
Dealing with the child	Regrettable actions concerning parenting, interaction and communication with the child	"My son was very sociable and easy to care for, so I did not realize how sensitive he was."
Shift of appraisal	Reflection concerning existing values, attitudes and set priorities	"It is perhaps regrettable, that before the illness everything was taken for granted and the gratitude for the 'normality' was not there. I considered many things as important, that were not important at all."
Dealing with the disease	Regret concerning influence on the diagnosis, medical decisions and coping with the situation	"Our whole endeavor was that our child does not have to suffer! And yet I always asked myself the question: Did I fight too little for him? Which is nonsense, because I think everything was done for him."
Siblings	Regret about neglecting the remaining siblings	"That I neglected the siblings in that time, that I did not pay enough attention to them."
No regret	Contentment about the time lived together	"No, with the knowledge that time will be limited with him, we have enjoyed every single moment. In all times, good or hard. We lived very consciously and gratefully with him."

The mean age of the participants was 48 (range: 25–59 years) and most parents had a high school diploma ($n = 14$). The average age of the child when he/she became sick was 8.9 years old (range: 4 months to 20 years). The duration from diagnosis to death varied from 1 week to 15 years. An equal number of children died at the hospital ($n = 13$) as at home ($n = 13$). The average interval between death and the study participation was 4.4 years (range: 8 months to 12 years).

3.1 | Major themes of regret

Asked whether parents would have acted differently, almost every participant expressed regret concerning the time before and starting once their child became sick. Four major regret themes were identified: "dealing with the child," "shift of appraisal," "dealing with the illness," and "siblings." Only very few parents stated "no regret" (see Table 2).

3.1.1 | Regret theme: dealing with the child

For most parents, remembering how they dealt with the child *before* the cancer diagnosis was a major regret topic. This topic included regrettable actions and thoughts concerning parenting, and both interaction and communication with their child before it became ill. Parents judged themselves as having failed: either to adapt their parenting style to their child's personality or to react constantly in a sensitive and understanding manner to their child:

I regret that I wanted to educate him as a model child and had brought him up very strictly.

Everyday requirements caused difficulties responding appropriately to the child's needs and personality. Consequently, negative interactions arose (e.g., dissension, impatience with the child), which parents regretted severely. Memories of treating their child unfairly and causing disharmony due to their own perceived inability were intense and painful. Many parents rated themselves as strict, projecting their wishes and putting too much pressure on the child to perform. They felt sorry for not seeing their children's true personality or needs. Ret-

rospectively, parents wished to emphasize family life and spend more time with their child.

Considering *the time following the diagnosis*, parents focused on fulfilling all of their child's wishes to contribute actively to his/her comfort. If wishes were unfulfilled, parents felt regret:

He always wanted to join me at football Schalke 04. Unfortunately, I took him only three times. That still hurts me a lot.

Some parents revealed their inhibition about speaking honestly with their child about the terminal situation. They sensed the importance of talking about it when there was no longer a chance to do so. Another regret was the need for more information about the disease's status and prognosis. In some cases, they lacked clear communication from the physician about the terminal situation and would have made more consciously choices had they known:

If I would have known that my child would die, it had been better to have had more courage to be home more often.

3.1.2 | Regret theme: shift of appraisal

A *shift of appraisal* occurred retrospectively. This second regret theme covered the critical reflection of existing values and set priorities.

Before their child was diagnosed, parents invested too much time and effort in the job, instead of being there for their children. Focusing on their careers became less important, while taking care of an ill child. Parents considered themselves blind for not perceiving the high value of everyday life. They agreed about the preciousness of carefree time as a family *before* cancer and repented not having appreciated it. If they had known about upcoming events, they would have disregarded irrelevant concerns and been more thankful for the normality they had:

Looking back, I would like to spend more time with her. More pictures, more videos made and more memories created. You probably would have experienced things with more awareness. As long as everything is good, so much is lost in everyday life.

3.1.3 | Regret theme: dealing with the disease

A third regret theme affected *dealing with the disease* and described regret concerning parents' influence on the diagnosis, medical decisions, and coping with the situation. Some parents considered their move to another location as a possible cancer-triggering situation, linking the move with increased stress and change for the child. Most parents blamed themselves for their influence on cancer progression, like not recognizing symptoms earlier, not choosing the right physician, or not being persistent enough with the examining physician. They wondered about their contribution to the course of illness and the amount of suffering:

Yes, I am very sorry that I did not believe him when the pain began (at least at the beginning) and that I was not more persistent with the internist. Everyone has portrayed my son as faking an illness, so valuable time has been lost.

Regrets about medical decisions were expressed on two levels; some parents questioned whether they had done everything to prevent their child from dying, such as searching more actively for healing or asking more physicians to help or simply believing in a cure. Other parents regretted they did not let go earlier and became overactive in finding a curative treatment, as they could not accept the reality of the palliative situation. Further, they projected this belief on their child without considering the child's position:

Today I think, for example that I should rather have let go... That I should not have urged my daughter to fight, not to give up.

Further treatment regrets concerned using either (sometimes harmful) alternative and complementary therapies, or following only conventional methods. Some had regret about another round of chemotherapy, which led to suffering. However other participants regretted not pushing physicians harder to give further chemotherapy to improve the survival rate. Parents shared feelings of helplessness at not being able to influence the progression of their child's illness:

and of course to be unable to protect my child from the disease and death. This is pure powerlessness, anger, despair and profound regret.

3.1.4 | Regret theme: siblings

As a fourth theme, parents with several children agreed that after the cancer diagnosis and until the child died, the remaining *siblings* were neglected and did not receive enough attention:

The worst thing for me was, and is, that our two girls came too short during the time.

Siblings sometimes became dysfunctional, for example withdrawn, developed issues at school (regarding achievement and social interaction), or displayed behavioral problems.

Although the parents understood they needed to take better care of the remaining children, they were too absorbed in the sick child's care and felt torn. They regretted being unable to give appropriate and sufficient support to their other children during the time of treatment and grief.

3.1.5 | No regret

Very few parents answered, that there was *no regret* at all because they had experienced a perceived fulfilled time:

We had a wonderful time together. There is nothing to regret or to feel sorry for, we would have done everything the same way. If we would have come earlier to the "right" doctor... yes, what would be? Unfortunately, we cannot turn back time.

Respondents underlined their stable, close, and loving relationship with their child. This relationship enabled them to consider the time spent together a gift. They focused more on positive aspects and memories and looked at the entire life of the child, not only the last portion. Little things could have been different, but overall they accepted the course of illness and the impossibility to change the past. Being confronted with the diagnosis was a radical learning experience concerning finiteness, which led to a future daily life with more awareness and gratitude about the available time.

3.2 | Effects of regret experience

The experience of regret had multiple effects on personal, interpersonal, and attitudinal levels. Most often, parents mentioned that their *handling of the remaining children* changed (see Table 3). After their ill child's death, they directed their attention to the other children, being grateful for them and considered them their main priority. Further, they believed their interaction with their children was more conscious, intense, and relaxed than before:

It has effects that I experience with my other children. I try to be there for them better and more intensely in everyday life. Life can be short, and you have to try to enjoy every day.

Facing a general *changed perception of life* included conscious choices according to personal values. Through the impact of loss, parents questioned their previous lifestyle and their desired nature of their future life. They were more strongly aware of which people and activities were beneficial to them.

Parents were less willing to compromise and focused on personal freedom and choice rather than external demands. For most parents, family became their highest priority, while job, career, and money became less relevant. Because they learned they had limited time, they now unhesitatingly take opportunities.

Concerning their social surrounding, parents stated they did not receive the support and understanding they needed and expected. Consequently, they determined whom in their social networks they

TABLE 3 Effects of regret experience

Effects	Description	Representative quotes
Handling of the remaining children	Directing the attention to the remaining children	"I live more consciously with my remaining child. I let go a lot." "I now communicate family needs better with my employer. When in doubt, the children are always there [...] a successful career is less important to me than before."
Changed perception of life	Questioning the previous lifestyle and making conscious choices according to personal values.	"I feel very clearly what's good for me and I am less willing to compromise with people or things that are an effort. Maybe a little more selfish and generous at the same time." "One lives more consciously and is grateful for things that used to be taken for granted. Personally, I know who I can rely on even in difficult times and have separated myself from things and people who have put a strain on or disappointed me."
Attitude toward medicine and physicians	Developing a different approach to health and sickness	"You value health more and realize that it can be over from one day to the next." "I do everything differently when it comes to doctors. I now determine what needs to be done. I do not trust any doctor anymore." "One is more open (more sensitive) to the illnesses of other people. You now take the time and let go of other plans to look after these people."

could rely on. The time of illness, death, and bereavement became a lesson in expressing their personal needs and learning to set limits. Although parents were aware of tremendous fatigue, they learned their strength and endurance levels.

Due to the cancer experience, parents developed a different approach to health and sickness. For some parents, time of treatment and death had an influence on their *attitude towards medicine and physicians*: they lost their trust in, and were critical of medicine. Others appreciated their health, had an understanding of the impact of disease, and tried to be supportive of sick people nearby.

3.3 | Advice to other parents

Asked about required help or advice for other parents in similar situations, parents discussed in detail reflections about the child's last weeks and an appeal to medical and psychosocial hospital staff.

One of the strongest challenges was to cope with their child's dying. They recommended parents make decisions according to their sense of what is right. Parents suggested keeping a balance between hope and desperation, between encouraging the child and accepting his/her death, and between not losing courage and enduring when facing powerlessness:

It is difficult to switch from 'combat mode' to 'let go'. Immediately at the time of the diagnosis, I have included death in my mind and prepared to let go. That later benefited me.

Parents encouraged talking openly with the child about death and dying, as he/she should be informed about the ongoing situation to make his/her own choices.

For most, learning and accepting was a process, and a social network made it easier to cope with this situation. Therefore, parents recommended calling on support from others. However, there was a clear appeal to psychosocial staff, chaplains, and employers to offer more and active support. Regarding physicians, participants requested more honest, clear, empathetic, and open communication:

I would have wished that someone had told me really clearly it's his last days. Do what he wants, he will not be there soon.

Parents felt they were not being perceived as competent experts on their child, nor were they being treated as an individual and unique family with its own specific needs.

4 | CONCLUSIONS

Our findings demonstrate that bereaved parents share regret experiences. Parents felt sorry when they perceived that their child had to suffer. These disease-related regret themes all centered on parents' inability to contribute actively to a resolution. With respect to parents' duty to protect their child from harm, such experiences lead to feelings of failure, helplessness, and blame. Regret emerged when parental behavior caused common, negative interactions with their child. Further painful experiences and sources of regret were derived from parents being unable to give the remaining siblings the attention they needed.

Parental descriptions clarified that parents' intense regret sensations were caused by a great amount of grief paired with the irreversibility of their perceived wrong decisions and actions. That some parents felt responsible for the cancer underlines the close connection between regret and guilt. Parents reported that frequency and intensity of regret lessened with time. This is in line with findings that state upsetting thoughts decreased with time, while the frequency of positive memories does not change over time.²⁹ Parents who did not experience any kind of regret were characterized by a fuller acceptance of the situation, a positive appraisal, and gratefulness for shared time with their child, which was not limited to the time of his/her illness. Their focus on positive memories is a positive adjustment to the loss of their child.³⁰ Such cognitive strategies point to a direct link between regret issues and effects of regret. Regret seems to release an impulse to change, to avoid the highly negative state, and to try to make the future positive. Overcoming regret had an essential impact on the future:

TABLE 4 Recommendations for the clinic

- Enquire the family repeatedly and actively about their wishes and needs.
- Involve siblings, actively ask about their condition and show that you care about them.
- Initiate and enable the fulfillment of last wishes.
- Realize that empathetic and clear communication is essential for the families to make conscious decisions.
- Show respect for the way parents take care of their child.
- Integrate the palliative care team early and remain connected to the family.
- Stay in contact with the family after the child has died.
- Be aware, that your actions depend on your own personal attitude toward dying and death.

Parents questioned existing values and framed change. Family became the main priority and an attitude to take opportunities developed.

There are several limitations of this study. Bereaved parents' willingness to participate in research is generally low³¹ and possibly even more so if it concerns a painful aspect of their relationship with their child. The low participation rate might indicate a selection bias in a way: that only those parents who were ready to reflect on this painful topic might have participated in the study. Nevertheless, the analysis of the questionnaires led to a theoretically saturated understanding of the research topic. Face-to-face contact was avoided in favor of low-level threshold participation in order to explore the topic more fully. We hold on to the recommendation, that research in Grounded Theory should be judged on the credibility and trustworthiness of the findings and the contextualization and saturation of data,²⁷ which is the case here.

Although the present study identified regret themes and gained an understanding of how dealing with regret affects future life, these explorative results cannot be generalized for all bereaved parents who lost their child to cancer. Further research should focus on the examination function of regret and determine which variables (e.g., personality traits, coping style, cultural and socioeconomic background, etc.) might influence content and impact. Identified characteristics of parents without regret experience will help to better understand protective factors. Because death and grief are challenges for a partnership and family, future studies should investigate how regret affects the partnership, and consider the siblings' perspective of regret, as well.

Relevant aspects of regret can be strongly influenced through the way the treating team is in contact with the family.

Based on our findings, we have derived clinical implications (see Table 4): It all comes down to being and staying in contact with the family, acknowledging how the family takes care of the child, and inquiring them actively about their needs. This involves the sibling's perspective in particular. A clear and empathetic communication enables an open reflection on the process of dying and supports the family in making conscious decisions. Encouraging them to articulate, what is important to them and how they want to spend their last time together.

Another aspect is to integrate the palliative care team early in the process and remain connected to the family, even after the child has passed. We—as their treatment team—have been part of their

everyday life for a long time and an abrupt break of contact is experienced as leaving. Bereavement follow-up care is much appreciated and helps clarify open questions and facilitates making sense of the situation.^{22,32,33}

We should be aware that our actions depend on our own personal attitude toward dying and death. Along the lines of this responsibility we are learning to deal with it and train ourselves where we feel insecure or uncomfortable.

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CONFLICT OF INTEREST STATEMENT

The authors have declared that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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