Received: 23 October 2023 | Revised: 1 January 2024 | Accepted: 4 February 2024

DOI: 10.1002/pon.6304

ORIGINAL ARTICLE

WILEY

Exploring grandparents' psychosocial responses to childhood cancer: A qualitative study

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Funding information

Swiss National Science Foundation, Grant/Award Number: 10001C_182129/1

Abstract

Objective: A childhood cancer diagnosis is a traumatic experience for patients and their families. However, little is known about the effect on grandparents. We aimed to investigate the negative psychosocial impact, coping strategies, and positive outcomes of grandparents of childhood cancer patients in Switzerland.

Methods: We collected data using a semi-structured interview guide and applied qualitative content analysis.

Results: We conducted 20 interviews with 23 grandparents (57% female; mean age = 66.9 years; SD = 6.4; range = 57.0–82.4) of 13 affected children (69% female; mean age = 7.5 years; SD = 6.1; range = 1.0–18.9) between January 2022 and April 2023. The mean time since diagnosis was 1.0 years (SD = 0.5; range = 0.4–1.9). Grandparents were in shock and experienced strong feelings of fear and helplessness. They were particularly afraid of a relapse or late effects. The worst part for most was seeing their grandchild suffer. Many stated that their fear was always present which could lead to tension and sleep problems. To cope with these negative experiences, the grandparents used internal and external strategies, such as accepting the illness or talking to their spouse and friends. Some grandparents also

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reported positive outcomes, such as getting emotionally closer to family members and appreciating things that had previously been taken for granted.

Conclusions: Grandparents suffer greatly when their grandchild is diagnosed with cancer. Encouragingly, most grandparents also reported coping strategies and positive outcomes despite the challenges. Promoting coping strategies and providing appropriate resources could reduce the psychological burden of grandparents and strengthen the whole family system.

KEYWORDS
cancer, child, family, grandparents, humans, oncology, positive psychology, psychological adaptation, psychological stress, Switzerland

1 | BACKGROUND

Childhood cancer not only affects the sick child, his or her siblings, and parents but also the grandparents, who are often an important source of support for the entire family.

Grandparents of childhood cancer patients experience more distress, anxiety, depression, anger, sleep issues, and take more medication than grandparents of healthy children.[1–3] Their overall quality of life is lower than in comparison groups.[1–3] A recent study showed that grandparents experience many of the same stressors as the child's parents,[4] such as balancing work and childcare, underscoring their important role in the family and their emotional closeness to the child. Grandparents worry about their sick grandchild, but also about the parents and, if present, healthy siblings. This is referred to as *triple concern* in the literature.[5] However, they often hide their feelings and concerns from the family to avoid being an additional burden.[3]

In stressful situations, individuals often develop coping strategies to better deal with the circumstances.[6,7] They may use internal and external coping resources.[8] A recent systematic review on grandparents of children with a severe physical illness found that seeking information about the child's disease, helping the sick child's family, maintaining a positive attitude, believing in God, and talking to others helped grandparents to cope with the situation.[3] Overall, grandparents dealt with the situation themselves rather than seeking professional support. Their spouse was usually their main source of support. However, some grandparents reported that they were afraid of not having enough resources to cope with the situation. Difficulties in coping were mentioned particularly regarding uncertain prognosis and parental distress.[3]

Yet, grandparents also reported positive outcomes. These included pride of their own children and healthy grandchildren for handling the situation so well, experiencing good moments more intensely, and becoming emotionally closer to the sick child's family.[3]

However, research on the experiences of grandparents of children with cancer is limited. In this qualitative study, we aimed to explore (a) the *negative psychosocial impact* of a childhood cancer diagnosis on grandparents, (b) the *coping strategies* grandparents used to deal with the situation, and (c) the *positive outcomes* reported by grandparents. Understanding the specific psychosocial experiences of grandparents is critical for health care providers to effectively address their needs. Insights into coping strategies and positive outcomes have been neglected in the past and will help to improve future interventions to support grandparents.

2 | METHODS

2.1 | Study design

The present study was part of a larger mixed-methods project investigating the acute and long-term consequences for grandparents when their grandchild is diagnosed with cancer (GROKids).[9] Ethical approval was granted by the Ethics Committee Northwest and Central Switzerland (Study ID: EKNZ 2020-01409), and all participants provided written informed consent. This paper reports on the results of the qualitative sub-study, following the Standards for Reporting Qualitative Research reporting standards (see Supplemental Appendix A).[10]

2.2 | Sample and procedure

Grandparents of patients diagnosed with childhood cancer according to the International Classification of Childhood Cancer—Third Edition (ICCC-3) below the age of 18 years and undergoing treatment at a pediatric oncology center in Switzerland were eligible to participate in this study, provided they spoke German, French, or Italian. Recruitment for the qualitative study was done through a questionnaire item in the longitudinal questionnaires (3, 6, or 12 months after diagnosis).[9] Additionally, grandparents who were not eligible for the longitudinal study because they were recruited too late for the first questionnaire were invited by the study team to participate in an interview by mail. Interviews with grandparents were thus conducted at different time points after diagnosis. Participants received information and consent forms prior to the interviews and were asked where and when they would like the interview to take place.

They were informed that the interviews would last approximately 1 hour per person and would be audio-recorded. They were

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also informed that they could interrupt or stop the interview at any time without providing a reason. Interviews were conducted with one grandparent at a time, unless they specifically requested to be interviewed as a couple. Interviews were conducted by PH (German, French) and AI (Italian). PH has a background in psychology and AI in health communication science. Both interviewers are female, PhD students in the project, and had never seen the participants before the interviews. A psychotherapist specialized in psycho-oncology was part of the study team in case a grandparent needed psychological support.

2.3 | Data collection

Sociodemographic and cancer-related information were obtained through contact forms (parents, grandparents), consent forms (grandparents), and questionnaires of the longitudinal questionnaire study (grandparents that participated in the longitudinal study). The semi-structured interview guide covered grandparents' experiences, including their emotional and physical health; the impact on their work, daily life, and relationships; the support provided to the family; the information and support received and needed; coping strategies, advice to other grandparents and positive insights gained (see Supplemental Appendix B). We conducted the interviews between January 2022 and April 2023. The interview guide was based on previous literature.[1,2,11–15]

2.4 | Data analysis

We used descriptive statistics for sample characteristics. After verbatim transcription and anonymization of all personal information using *f4transkript.v7* (PH, NM, master student), we performed qualitative content analysis[16] in *ATLAS.ti.23*. We used an inductive-deductive categorization approach by first forming deductive categories based on previous study results[1,2,11–15] and the research aims of this study and then specifying and expanding these using our material, whenever the data did not seem to fit into a pre-existing (sub-)theme or code.[17] Thereby, we were able to gain new insights without losing sight of previous findings.

PH developed an initial coding scheme that considered the negative psychosocial impact, coping strategies, and positive outcomes found in the literature (concept-driven categories). All transcripts were then systematically and independently coded by two authors (PH, NM). During this process, new (data-driven) categories emerged from the interviews. The coding structure was discussed, revised, and refined until the final coding scheme was reached (see Supplemental Appendix C). Interviews were re-coded according to the final coding structure. Consensus coding[17] was ensured through discussion of each transcript (PH, NM). Once the data were fully coded, all categories and associated codes were individually reviewed and written up by PH. NM critically reviewed the report of findings to ensure they corresponded to the categories and associated codes.[17] Consensus on the final coding was reached through discussion. Like PH, NM is a female psychologist. She works on the project as a research assistant.

3 | RESULTS

3.1 | Sample characteristics

All 41 grandparents of the longitudinal study were invited to participate. Of these, 24 grandparents expressed interest in being interviewed, and 19 of them were eventually interviewed (46%). Additionally, we invited 11 grandparents who were recruited too late to participate in the longitudinal study, of whom 5 were interested in participating and 4 participated (36%). The final sample included 23 grandparents, of whom 13 were grandmothers and 10 were grandfathers (Table 1). Although saturation of themes had already been reached, we decided to interview all grandparents who expressed an interest in being interviewed to enrich the categories identified and to give them the opportunity to talk about their experiences. Based on previous literature, we viewed saturation as an ongoing process of conceptual depth rather than a fixed endpoint.[18]

Reasons for non-participation included no longer being interested in being interviewed, not being available to schedule an interview, or not being healthy enough to participate in an interview.

3.2 | Themes found in the qualitative analysis

Themes and subthemes identified through qualitative content analysis, along with sample quotes, are presented in Figure 1.

3.3 | Negative psychosocial impact

Grandparents described many negative aspects that were summarized as decreased emotional well-being, decreased physical health, strained relationships, and particularities about their role as grandparents (Figure 1).

3.3.1 | Decreased emotional well-being

Grandparents experienced a variety of negative emotions related to their grandchild's cancer diagnosis. Upon being informed of the diagnosis, many experienced *shock and disbelief*.[1] They described it as “the world collapsing”, “a thunderclap”, “the worst-case scenario”. Reactions included silence, crying, shouting, falling on the floor, or having pessimistic thoughts. The shock, lasting from a brief moment to a continuous state, was often accompanied by disbelief. Grandparents could not believe that their grandchild, of all people, would receive such a terrible diagnosis. Some participants had to keep

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TABLE 1 Sample characteristics of the 23 grandparents interviewed in the study.

Characteristics	*N*	%	Mean (SD)	Range
Grandparent information				
Total	23	100		
Sex				
Female	13	57		
Male	10	43		
Relationship to child				
Maternal grandmother	5	22		
Maternal grandfather	6	26		
Paternal grandmother	8	35		
Paternal grandfather	4	17		
Age at interview (years)			66.9 (6.4)	57.0–82.4
Child information				
Total	13	100		
Sex				
Female	9	69		
Male	4	31		
Diagnosis				
Hematological malignancies	5	38		
Brain tumors	2	15		
Other solid tumors	4	31		
No information	2	15		
Age at diagnosis (years)			6.5 (5.8)	0.3–17.3
Time since diagnosis (years)			1.0 (0.5)	0.4–1.9
Age at time of interview (years)			7.5 (6.1)	1.0–18.9
Interview characteristics				
Interview language				
German	18	78		
French	3	13		
Italian	2	9		
Interview setting				
University of Lucerne	9	39		
Grandparents' home	7	30		
Grandparents' work place	2	9		
Phone or video call	3	13		
Other	2	9		
Interview length (hours:minutes)			01:11 (00:19)	00:37-01:49

reminding themselves that their grandchild was sick or could not remember the state of shock at all because they suppressed reality.

A sense of *injustice* as a result of the child's disease was also experienced by some. This feeling was sometimes intensified if the child had been very lively or healthy before or had a special position in the family, such as being the only girl in the family. Many found it profoundly unfair that such a life-threatening disease had to hit a young child of all people, or in the case of difficult family situations,

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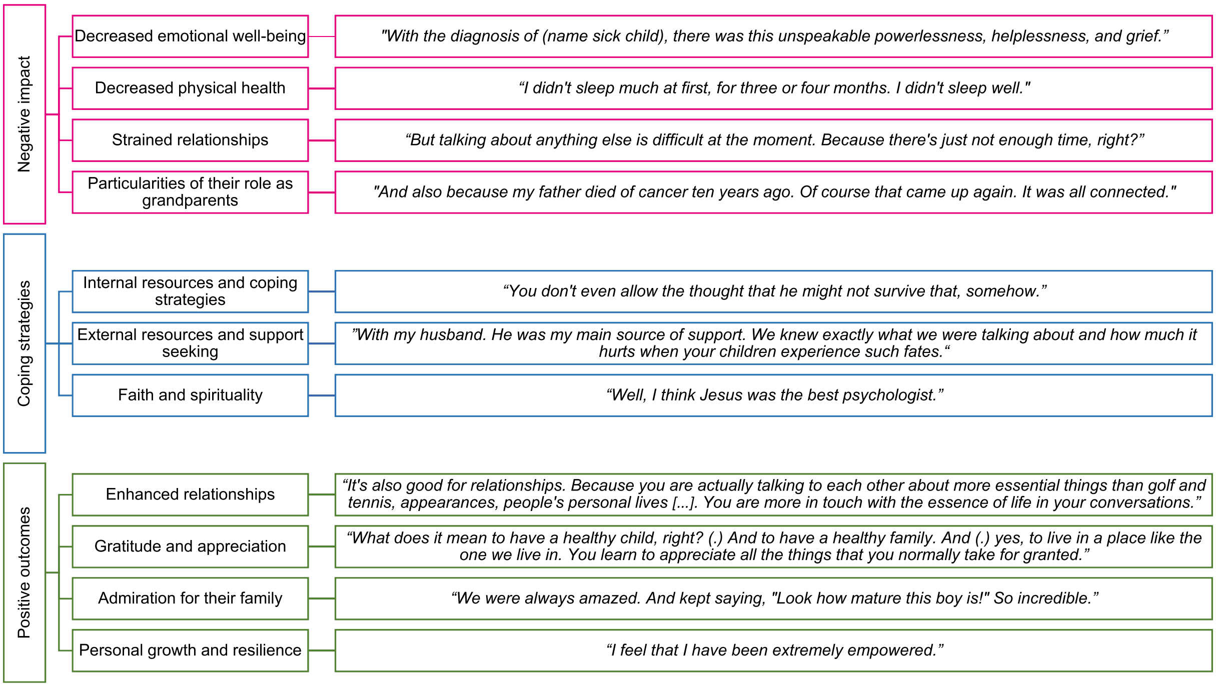

Negative impact	Decreased emotional well-being	"With the diagnosis of (name sick child), there was this unspeakable powerlessness, helplessness, and grief."
	Decreased physical health	"I didn't sleep much at first, for three or four months. I didn't sleep well."
	Strained relationships	"But talking about anything else is difficult at the moment. Because there's just not enough time, right?"
	Particularities of their role as grandparents	"And also because my father died of cancer ten years ago. Of course that came up again. It was all connected."
Coping strategies	Internal resources and coping strategies	"You don't even allow the thought that he might not survive that, somehow."
	External resources and support seeking	"With my husband. He was my main source of support. We knew exactly what we were talking about and how much it hurts when your children experience such fates."
	Faith and spirituality	"Well, I think Jesus was the best psychologist."
Positive outcomes	Enhanced relationships	"It's also good for relationships. Because you are actually talking to each other about more essential things than golf and tennis, appearances, people's personal lives [...]. You are more in touch with the essence of life in your conversations."
	Gratitude and appreciation	"What does it mean to have a healthy child, right? (.) And to have a healthy family. And (.) yes, to live in a place like the one we live in. You learn to appreciate all the things that you normally take for granted."
	Admiration for their family	"We were always amazed. And kept saying, "Look how mature this boy is!" So incredible."
	Personal growth and resilience	"I feel that I have been extremely empowered."

FIGURE 1 Themes and subthemes of the qualitative content analysis and sample quotes from the interviews.

add to the already existing family burden. One grandfather said it would have been much easier for him if he had received the diagnosis himself.

Fear and concern were the most prominent emotions experienced after the initial shock, mostly related to the child's health. The worst-case scenario imagined was that the child might experience a relapse or not survive. Even grandparents who were optimistic about the chances of a cure were concerned about the child's long-term development and possible late effects. Additionally, they were afraid of infecting the child with pathogens because of the weakened immune system, or of doing something wrong when they spent time alone with the child. Furthermore, some grandparents were concerned about the environment to which the child would return after inpatient treatment if the social situation in the family was difficult. Beyond their concern for the child, many grandparents experienced fear and concern for the child's family: the well-being and relationship of the parents, who were often strained by the situation, and about healthy siblings, because of their suffering, their psychosocial development, and the reduced attention they received compared to the sick child. On top, some grandparents were concerned about their own parents, the child's great-grandparents. They concealed that the child had medical setbacks because they were afraid it would upset the great-grandparents too much. Finally, some grandparents were worried about their spouses or their own well-being and feared that they would eventually no longer be able to manage the situation.

This feeling of *overwhelm* was mainly attributed to emotional stress. Although they were generally happy to help, grandparents were at times overwhelmed by the amount of support they were providing. Few grandparents felt that the child's parents expected too much of them. Some also felt that no matter how much they supported, it could never be enough. Many felt *powerless*, as the child's fate was beyond their control. Some also shared that they felt very *sad* or experienced *grief*.

Grandparents *suffered* greatly when they saw their grandchildren suffer or observed severe physical changes. They suffered especially from witnessing pain, side effects of the treatment, medical complications, the fact that the child did not like the medication, weight gain due to cortisone, and hair loss.

Another aspect that often weighed heavily on grandparents was a general feeling of *uncertainty*. Grandparents felt unsettled because there were many questions that could not be answered, but only the future could tell (e.g., best treatment choice, prognosis, late effects). Adding to the uncertainty was the knowledge that the situation could quickly deteriorate. Some grandparents *doubted* treatment plans, but always kept their doubts to themselves. They wondered whether the decisions made were good for the child and whether other decisions or second opinions would have been more appropriate.

In some cases, grandparents expressed *incomprehension and anger* toward family members or third parties, such as others staring at their grandchild or avoiding them because of physical differences, parents not wanting to accept help, parents expecting too much from them, or family members not behaving supportively. Regarding the health care system, they expressed a lack of understanding and anger about the fact that in the acute phase of the COVID-19 pandemic, only one parent was allowed in the hospital at a time, that preventive measures for fertility were not covered by health insurance in Switzerland, and that in one case they did not feel understood and supported by the hospital staff in the difficult process of giving the child medication.

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3.3.2 | Decreased physical health

The strongest *psychosomatic effect* reported was sleep problems, especially early after diagnosis. Grandparents also reported mood swings, adrenaline rushes from unexpected phone calls, digestive problems, and weight gain. Interestingly, one grandfather reported that he was so afraid of infecting the child that he developed fever blisters, which he attributed to his anxiety and nervousness.

3.3.3 | Strained relationships

The situation affected the grandparents' *relationships* with various individuals. The psychological burden and the huge amount of support provided sometimes strained the romantic and intimate relationship between grandparents and their spouse. Some grandparents reported that their lives were centered around the child, leaving little space for romance. Others reported that their children, the child's parents, were so stressed and tense that they withdrew from everyone or were easily hurt or hurtful. One grandmother, however, also stated that she withdrew from her friends because she needed to deal with the situation herself.

Many grandparents felt *left out*. This was often because of COVID-19 measures that did not allow grandparents to come to the hospital. Not being able to provide support at the hospital and see the child was difficult for them. However, sometimes their children or their sick grandchild did not want them to help. Some grandparents would have liked to be more involved in the medical conversations, which was impossible because of legal reasons.

Some participants felt *left alone* or *disappointed* by others, mostly by friends and acquaintances. Grandparents were disappointed when they did not feel supported or thought of by them, or if they felt that the "interest" of others was mainly nosiness. In a few cases, disappointment also related to family members, and in one case, to a grandmother's general practitioner not responding to her need to talk about the situation.

3.3.4 | Particularities about their role as grandparents

While grandparents were *concerned about many people around them* (see above), they often *put themselves in the background*. Some saw it as their duty to be on call and would cancel their personal activities to be available at all times. The child's increased risk of infection also led many grandparents to avoid seeing friends or to drop out of social club activities to minimize social interactions. Despite wanting to have information and updates on their grandchild's diagnosis and treatment, some grandparents put their information needs aside to not burden parents with questions. Similarly, they often hid their emotions in the presence of the child's family to not burden them. Some grandparents relativized their suffering by saying that it was not as bad as that of their children because they were more distant from the sick child.

Another peculiarity related to their age is that almost all grandparents had *previous experiences with cancer*. Some had had cancer themselves, others had friends or family members with cancer. Although one grandparent had a rather positive experience with the course of the disease, for most grandparents, cancer was a terrifying experience that had a negative impact on the evaluation of the current situation, especially, if they lost a loved one to the disease.

3.4 | Coping strategies

Grandparents used both internal and external coping resources. In addition, some grandparents coped through faith and spirituality (Figure 1).

3.4.1 | Internal resources and coping strategies

Some grandparents drew on *pre-existing resilience and strength* to cope with fate. One grandmother said that her advanced age was the reason for her resilience.

For many grandparents, *acceptance* was a way to come to terms with the situation and a first step toward focusing on the future. In conjunction with this, it was essential to maintain *hope*, *trust*, *and optimism*, despite their great fears and concerns. This was mainly related to the child's health, but also that the family would recover from the difficult circumstances. Some said it was important to simply trust the doctors.

An important aspect for many was to *take care of themselves* or *distract themselves* from the situation. The mechanisms that helped them were manifold: doing sports, working in the garden, exploring nature, meeting friends, visiting art exhibitions or the theater, going out for a coffee, socially isolating, playing games, cooking and eating well, hosting a birthday party. Some mentioned that it was helpful to maintain their daily routine despite the circumstances. Many interviewees gave rational reasons for being in a good mood, as it would not benefit anyone to be sad all the time.

Some grandparents *protected themselves* and actively tried to *keep their distance*. For example, by not allowing negative thoughts, such as about the child's possible death, by not searching the Internet to avoid reading negative material, or by not talking about the sick child with their spouse or others. In some cases, they also set clear boundaries for the parents by refusing to do certain things, especially in terms of support, to protect their own interests. Some grandparents reported that they kept their distance to avoid being too emotionally involved. Two grandfathers deliberately imagined worst-case scenarios to be prepared, or so that things could only get better.

Many grandparents *searched for information material* to cope with their concerns and uncertainties. In addition, grandparents sometimes

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actively asked others for information. The information source were often their children, the child's parents. One grandmother also turned to a childhood cancer association for information.

3.4.2 | External resources/support seeking

For many, it was good to be able to *talk to others* and receive *emotional support*, often with their spouse, but also with other family members, friends or acquaintances. In some cases, maternal and paternal grandparents supported each other. Neighbors or strangers, such as clients at work, and pets were also perceived as providing emotional support.

To cope with the psychosocial and psychosomatic stress, some grandparents sought *professional help*. Professionals that they turned to included psychotherapists, primary care physicians, coaches, and a childhood cancer association. In general, however, they rather used internal and non-professional resources.

Many grandparents have found great strength in *actively supporting* the child's family. Being close to the child and the child's family and actively supporting them reduced their sense of powerlessness. Some grandparents said that this was the only way they could bear the situation.

3.4.3 | Faith and spirituality

For some grandparents, *faith and spirituality* were important coping strategies. Some believed in God in the Christian sense, others felt more distant from the Church and had their own beliefs or prayers. Several grandparents had spiritual rituals that helped them (e.g., power stones, music, art).

3.5 | Positive psychosocial outcomes

We found four subthemes of positive outcomes: enhanced relationships; gratitude and appreciation; admiration for their family; and personal growth and resilience (Figure 1).

3.5.1 | Enhanced relationships

Many grandparents reported that certain relationships had become closer. This was particularly felt for the *sick child and their parents and siblings*. Many grandparents also reported feeling closer to their *spouse* as a result of sharing care and concerns. On a more general level, some reported that they had *strengthened relationships with third parties* (e.g., neighbors) because they often asked how the child was doing. One grandfather also emphasized that the situation helped him to have more meaningful conversations with others.

3.5.2 | Gratitude and appreciation

Grandparents appreciated multiple things they had previously taken for granted or paid less attention to. The value of *being healthy and having a healthy family* was reflected by many in a general way. Any improvement or positive phase experienced by the sick child was highly appreciated. Even minor improvements, such as the child having enough energy to play, were observed and highly valued. Many grandparents realized their fortunate position in Switzerland, granting them access to the *local healthcare system*. The hospitals were appreciated for their high-quality medical care, reliable and transparent doctors, and the friendly and helpful demeanor of the doctors, nurses, and cleaning staff. The fact that childhood cancer associations and sometimes hospitals made it possible for the family to go on medically supervised vacations with other affected families was also much appreciated. Grandparents appreciated *understanding, helpful and friendly behavior toward the child's family* from those around the family (e.g., employers, other children, grandparents on the other side of the family). They were especially grateful to witness the child being treated 'normally' by other children and making new friends. Grandparents who were still working themselves were grateful if their own employer treated them with kindness and understanding (e.g., if they could take flexible time off). Some grandparents were grateful for their *spouse*, especially for not having to go through the situation alone. Many grandparents were especially happy that, despite the difficult time, they were able to *spend beautiful moments with their family*. Many of them realized that there was nothing more important in life than family and that no matter what happened to them, they would always stick together.

3.5.3 | Admiration for their family

Most grandparents felt a deep *admiration for their sick grandchild* for being so positive despite the circumstances, for being a fighter, mature, motivated, independent, cheerful, active, and brave. This admiration varied according to the age of the child. For younger children, they were appreciative when they cried little and played happily; for older children, when they accepted their fate or kept a positive attitude. Some grandparents were also *proud of other family members*. For example, one grandfather described how proud he was of his son for taking such good care of the child's siblings, and one grandmother described how proud she was of the child's sister for being so supportive.

3.5.4 | Personal growth and resilience

Many grandparents felt *empowered* by the situation and realized they were more *resilient* than they ever thought. Some said they became

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more *humble and grateful*. One grandfather reported *taking his own problems less seriously*. Many participants reported *living in the moment* and trying to *live each day to the fullest*.

4 | DISCUSSION

In our qualitative study, we found that grandparents of recently diagnosed childhood cancer patients experienced various negative emotions. However, they used internal and external resources to cope with the situation and frequently reported positive outcomes.

The negative impact on grandparents was broadly consistent with the literature on grandparents of children with severe illnesses.[3] Grandparents in our sample suffered greatly, especially in the first few months after diagnosis. Consistent with previous findings,[4] their great suffering underscores the emotional closeness of grandparents to the sick child and the whole family.

Other studies have shown that many reported higher levels of clinically relevant distress (32.9%), anxiety (48.8%), depression (24.4%), and anger (23.5%) than grandparents of children without a serious illness.[1] With the high survival rate,[19] and overall good quality of survival,[20] it is to be hoped that most symptoms will diminish over time. Yet, some fears and worries, for example, those about late effects and cancer recurrence, might continue. This assumption is consistent with findings on parents of childhood cancer survivors.[21,22]

Because our data collection partly took place during the COVID-19 pandemic, there were unique negative feelings. Grandparents often felt excluded, because they were not allowed to go to the hospital to see the child. In similar situations, it might be worth considering who falls under the category of immediate family, and whether grandparents should be included. Apart from the positive emotional impact it could have on grandparents, the whole family could benefit from this recognition. A recent Australian study found that parents appreciated support that did not require "supervision" and was offered without them having to ask for it.[23] Being able to rely on grandparents in the hospital could ease the burden on parents, especially if they are working or have other children to care for. Recognizing grandparents as part of the immediate family would provide families with more organizational flexibility.

We were able to identify several aspects exclusive to grandparents' experiences. In the literature, grandparents' concern was sometimes referred to as "double concern/whammy'[4,15,24], "triple concern/pain",[5,8] or "multiple concern/suffering".[13] Our findings support the term 'multiple concern', because grandparents were concerned about many people around them (sick grandchild, healthy grandchildren, children, own parents, spouse, and also themselves). It was particularly interesting that several grandparents still had living parents, who were very old, and therefore grandparents wanted to protect them from bad news. In a recent study, grandparents described the same phenomenon ('Sandwich generation'), mentioning that fulfilling the various caregiving roles can be emotionally and physically exhausting.[4]

Similar to previous studies,[25] grandparents often reported putting themselves in the background. Either because they considered their suffering to be inferior, or because they did not want to be an additional burden on the child's family. This might make it difficult to offer adequate help as their reluctance to share their feelings might lead others to underestimate their struggles and support needs. The fact that grandparents provided extensive support, often sacrificing their own needs, underscores how important they are to the family. Grandparents' emotional closeness and mutual trust may make it easier for parents to accept their help. Research should explore the exact nature of the support grandparents provide and the support they may need to set boundaries and defend their own needs.

Fortunately, grandparents were able to draw on various internal and external coping resources and, in some cases, faith and spirituality. However, most grandparents coped with the situation on their own or sought help from their close social circle rather than to seek professional help.[3] Most grandparents reported using familiar coping strategies rather than developing new ones, suggesting pre-existing resilience. Although many grandparents found it rewarding to provide extensive support to the family, many also highlighted the importance of having time to themselves and, in some cases, distance themselves from the situation. This might help increasing resilience. Most grandparents reported positive outcomes that were consistent with the literature on grandparents of childhood cancer patients and survivors.[3,8]

Overall, most experiences of grandparents were not exclusively "negative", "coping strategies", or "positive". All grandparents reported the coexistence of negative and positive experiences. Their ability to cope with the situation shows that there is more to the psychosocial spectrum than just negative emotions. Actively supporting the family, for example, was mentioned as a coping strategy but also as a source of overwhelm. Individual experiences can thus be quite different and ambivalent experiences may occur. This is not surprising, as the role of grandparents has many influencing factors, including grandparent characteristics, role identity, expectations, social norms, and cultural aspects.[26] Future research should explore the associations among these facets, particularly how coping strategies and positive experiences may serve as protective factors against distress.

4.1 | Clinical implications

Our findings highlight the need to support grandparents, especially during the phase of treatment. For most grandparents, practical advice from social workers or medical education from hospital staff might be most important.[25] Professionally delivered information may help alleviate the uncertainty of grandparents and avoid misinformation, especially among those not seeking information themselves. Because many grandparents have had traumatic experiences with adult cancer in the past, they could benefit from childhood cancer-specific education, highlighting the treatment success in this age group.

Recognizing that this group often suffers in silence, resources should be made available to proactively inquire about grandparents'

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psychological support needs and provide appropriate care and support. This is critical for the entire family: grandparents who receive the support they need are better able to support the family, which ultimately benefits the child's well-being. While resources in the clinical setting are often limited, parent/family organizations might be able to offer specific support for grandparents. Promoting coping strategies that address their psychological suffering and account for positive experiences (e.g., through peer-support), could help improve the well-being of grandparents. Further research on specific information and support needs is essential and may help to provide targeted support in the future.

4.2 | Limitations

Results may be influenced by the subjective interpretation of researchers and participants. Although we tried to limit the results to quotes in which the grandparents explicitly talked about the cancer journey, it is difficult to distinguish this from their general experience. For example, their relationship with the grandchild may have evolved even without cancer, just as the child was getting older. Given that we recruited mostly through parents, it is possible that parents, who have a difficult relationship with their parents did not share study materials. This might have positively biased our results. Additionally, the interviews were conducted at different time points after diagnosis. However, the variety of time points provides multifaceted insight. Self-reported positive outcomes might be a result of social desirability. Though, this is unlikely when negative and positive experiences are reported simultaneously.[27]

Strengths of our study are that we included all language regions in Switzerland. The sample size surpasses previous qualitative research on this topic,[11–15] enhancing the variety of themes and subthemes. Furthermore, the high participation of grandfathers contributes to a broader and more diverse understanding of the topic. The in-depth exploration of negative and positive impacts on grandparents allowed for a comprehensive understanding of their psychosocial experiences. Finally, the unexpected emergence of themes like the impact of COVID-19 added valuable insights to the study.

5 | CONCLUSIONS

In conclusion, this study highlights the negative experiences of grandparents of children with recently diagnosed cancer. The findings underscore the importance of acknowledging their suffering and recognizing their important role in the core family. Encouragingly, most grandparents reported coping strategies and positive outcomes despite the challenges they faced. By promoting coping strategies and providing appropriate resources, grandparents' psychological burden could be reduced and their well-being and resilience ultimately improved throughout the cancer journey.

AUTHOR CONTRIBUTIONS

Gisela Michel and Katrin Scheinemann conceptualized the study design and secured funding for the study, Pauline Holmer and Anica Ilic collected the data, Pauline Holmer, Nadja Muehlebach, and Elena Bertolini transcribed the interviews, Pauline Holmer and Nadja Muehlebach analyzed the data, Pauline Holmer wrote the first draft of the manuscript, Nadja Muehlebach, Anica Ilic, Cristina Priboi, Katharina Roser, Peter Francis Raguindin, Eva Maria Tinner, Rebecca Baechtold, Marc Ansari, Manuel Diezi, Eléna Lemmel, Freimut Schilling, Ahmed Farrag, Katrin Scheinemann, Gisela Michel provided critical comments and revisions, Pauline Holmer revised the manuscript, all authors read and approved the final manuscript.

ACKNOWLEDGMENTS

First and foremost, we would like to express our deep gratitude to the grandparents who generously shared their time and personal experiences with us. We would also like to thank the dedicated hospital staff, namely Jannic Zeller, Prof. Dr. med. Nicolas von der Weid, Dr. med. Bettina Blank, Dr. med. Christina Schindera, Dr. med. Pierluigi Brazzola, Pamela Balestra, Prof. Dr. med. Jochen Rössler, Maryline Bovero, Rodolfo Lo Piccolo, Prof. Dr. med. Maja Beck Popovic, Barbara Gantner, Katja Bannenberg, Dr. med. Jeanette Greiner, Dr. med Heinz Hengartner, and Karin Hollenstein for recruiting study participants. Furthermore, we would like to thank Elena Bertolini for transcribing the Italian interviews and Dr. Daniela Dyntar, Salome Christen, Luana Marbot, Yara Sievers, and Lea Imbach for their support in the project. This study was funded by the Swiss National Science Foundation (10001C_182129/1).

Open access funding provided by Universität Luzern/Universitaet Luzern.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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ENDNOTE

[1] The codes of the individual sub-themes are italicized

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How to cite this article: Holmer P, Muehlebach N, Ilic A, et al. Exploring grandparents' psychosocial responses to childhood cancer: a qualitative study. *Psychooncology*. 2024;e6304. https://doi.org/10.1002/pon.6304

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