

ORIGINAL PAPER

PARENTS' EXPERIENCE WITH A DYING CHILD WITH CANCER IN PALLIATIVE CARE

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Abstract

Aim: The aim of the descriptive qualitative study was to illuminate and analyze experience of parents with failed treatment and the death of their child suffering from cancer. The analysis was focused on how the parents perceived the treatment itself, the care of their child, the level to which they were informed as well as health care workers' attitudes during the treatment. **Design:** A descriptive qualitative study. **Methods:** A semi-structured in-depth interview was used for data collection. One married couple and three mothers whose children died from cancer were interviewed. The respondents' ages ranged between 37 and 46 years. The thematic analysis method was used to analyze the data. **Results:** Three basic themes were identified: Managing the treatment; The return of the disease; and Communication and support. Within the themes, eleven subthemes were identified: Activation and protection; Consequences of the treatment; Re-evaluation of decisions; Disappointment; Experimental treatment; Siblings and bone marrow donation; The conflict of perspectives; Inner Conflict; Being informed; The control of treatment; and Understanding from health care workers – emotional and instrumental aspects. **Conclusion:** The results of the descriptive qualitative study can help nurses and other health care workers better understand the issues from the parents' perspective and suggest options that are available to make the therapeutic communication and emotional support for suffering families better and more effective.

Key words: cancer, palliative care, thematic analysis, dying child, parents' perspective.

Introduction

Progressive, life-threatening cancer in a child has significant physical, psychological as well as financial impacts on the life of the whole family. Despite the advances in therapeutic options and prolonging life, pediatric cancer may be associated with death, incurability, loss and suffering (Malta et al., 2008). The failure of curative cancer treatment in a child and the progression of cancer are among the most traumatizing experiences of parents. Parents are confronted with long-term hospitalization, aggressive therapy, therapy side effects, and various losses, changes within families and habits that can negatively influence coping with the roles connected with their development process (Kohlsdorf et al., 2012, p. 119; McGrath, 2002). Managing incurable cancer in a child is particularly difficult for the parents. Not only because of the young age but also

because of the child's dependence and the feelings of blame, insecurity and guilt present in everything (Švecová, 2014). Dying and the death of a child represent one of the most tragic losses that is often perceived as the most unfair of all losses possible (Firth et al., 2007). A decade ago, McGrath et al. (2004) stated that the amount of clinical literature dealing with the treatment of cancer in children outnumbered the amount of literature about the psychosocial aspects of handling the disease and its treatment for families. The trend has continued until now. The scientific literature only offers a limited number of studies providing a detailed picture of needs of families with a child in whom curative treatment for cancer failed. Every child and every family are unique. Their needs change depending on the child's diagnosis, disease progression as well as individual characteristics of the family members and their emotional reserves. Experiences of families with a child dying from cancer are unique and thus bring a number of impulses on how to improve the quality of life of the child and the family, whether it is during the

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treatment itself or, in case of its failure, in the area of palliative care. Given the above reasons, we aimed our analysis at the parents' perspective and their individual experiences which could help nurses and other health care workers understand the issue better and bring new ways to make the psychosocial support of families more effective. Our goal was to find out how such situations are experienced and perceived by parents who lost their child due to cancer.

Aim

The goal of the qualitative study was to describe and analyze the experiences of parents following failure of cancer treatment and the death of their child suffering from cancer. In our work, the following main experiential question was formulated: How do parents describe the experiences with disease, treatment and dying of their child?

Methods

Design

The descriptive qualitative approach with in-depth interviews and thematic analysis was used.

Sample

The method of a convenience sample was applied. The connection of the respondents with a specific institution was used for searching and contacting them (Miovský, 2006, s. 138). A nonprofit organization called *Svetielko pomoci (Light of Help)* was approached. This organization provides comprehensive help and support to families with cancer patients in the Kosice Region. Respondents in the study were selected on the basis of the following criteria: the death of a child due to cancer, one year elapsed from the death, willingness to participate in the research, working age, and residency in Eastern Slovakia. The sample comprised three mothers and one married couple (Table 1). The parents' age ranged between 37 and 46 years. The data were collected between December 2013 and March 2014. The names of the respondents as well as their children were changed to keep their identity safe. Also included in the research was the mother of a twenty-year-old patient provided with care from a children's mobile hospice despite his age. The family was approved treatment at a pediatric oncology department as a result of previous treatment in the above institution.

Table 1 Parents' characteristics

Parents	Age	Education	Child's disease	Child's age	End-of-life care
Maria	44	secondary	Acute lymphoblastic leukemia	16	hospital
Amelia	37	secondary	Medulloblastoma	9	hospital
Jakub and Greta (married couple)	41; 40	tertiary	Diffuse mediastinal large B-cell lymphoma	8	home
Jarmila	46	secondary	Acute lymphoblastic leukemia	20	home

Data collection

The in-depth semi-structured interview technique was used to collect the data. The questions in the interviews were based on the semi-structured interview used in a dissertation by Yorke (2007) which focused on the description of parents' experience with dying children and the care as well as environment at an intensive palliative care unit. In the present study, the questions were adapted to the context of palliative care in general. The first area deals with the actual stories of children – parents' experience description, perception of care and the relationship with health care workers. The second part covered additional personal notes and observations from parents. The interview protocol was created for field research. The interviews were audio-recorded and transcribed verbatim. Each interview was recorded using two voice recorders to prevent any loss of data. During the interview, we used the field notes to get additional aspects of the situational context such as the place and atmosphere of the interview or the parents' nonverbal expressions.

These notes also included the information on how the families had been contacted as well as their responses. All the records, field notes and transcriptions were assigned codes to ensure anonymity of the participants. Additional trustworthiness and credibility were achieved using data source triangulation. The empirical data were enhanced with documents such as the children's release reports and parents' diaries.

Data analysis

The interviews were analyzed using the method of thematic analysis (Braun, Clarke, 2006). The authors describe the approach as a method of pattern (theme) identification in data. The analysis is performed in six stages: introduction to data, generating the initial subthemes, looking for themes, examining themes, defining and naming themes, and summary of results. During the analysis, continuous connection of all the steps as well as transparent recording of the process were crucial. Before the actual analysis, the sound

records were transcribed verbatim using transcription symbols (Hendl, 2005). In the first stage of the analysis, the individual recordings were repeatedly read to get accustomed to the parents' language. During this stage, we tried to read the interviews actively, being aware of any patterns and importance in the data. Braun and Clarke (2006) recommend taking notes of any initial ideas related to the future coding; as a result, we took marginal notes in case of need. Later on, we marked the passages (excerpts, data illustrations) where we identified the important patterns. The excerpts were imported to MS Excel for better manipulation with the data, their naming, regrouping and pooling. At the same time, the application enabled us to keep logical sequencing of each step which we could refer back to at any time. Connecting the first excerpts, the preliminary subthemes were created. Those were reevaluated, that is, all the excerpts were reread and reexamined to see whether they were related to the specific subtheme. This step led to the correction of the preliminary subthemes, additions or even discovery of new aspects which we had not paid attention to earlier. Based on that, the final subthemes were discovered. Those subthemes were categorized based on their similarities or content connectedness. Once again, we went through each step of the analysis to ensure that the themes were categorized appropriately using subthemes and excerpts from the data that belonged there. The criteria for the evaluation were that the data in one theme were appropriately consistent when together (internal homogeneity) and, at the same time,

differed from the other themes (external heterogeneity). During the final stage, three critical themes reflecting the participants' responses in a very detailed way were identified. This was done by two researchers independently (investigator triangulation). In the following stage, a third person was invited in the process to discuss the themes and subthemes (peer debriefing). The analysis of the interviews was sent to all participants for further member checking. This process enabled the researchers to review the analysis. The participants' comments were used as feedback and included in the results.

Results

Based on the results of the thematic analysis, we identified three major themes, namely *Managing the treatment*, *Relapse* and *Communication and social support*. As a part of the themes, we uncovered other subthemes specifying their meaning in a greater detail (Table 2). To give a more detailed picture of the meaning of the individual subthemes, we have used selected responses of the participants.

Managing the treatment

In the theme named *Managing the treatment*, we identified three subthemes: *Activation and protection*, *Consequences of the treatment* and *Re-evaluation of decisions*.

These subthemes mirror the treatment trajectory as they appear in a chronological order and show the content of the whole theme at the same time.

Table 2 Identified themes and subthemes

Managing the treatment	The return of the disease	Communication and support
<ul style="list-style-type: none"> ▪ Activation and protection ▪ Consequences of the treatment ▪ Re-evaluation of decisions 	<ul style="list-style-type: none"> ▪ Disappointment ▪ Experimental treatment ▪ Siblings and bone marrow donation ▪ The conflict of perspectives ▪ Inner conflict 	<ul style="list-style-type: none"> ▪ Being informed ▪ The control of treatment ▪ Understanding from health care workers <ul style="list-style-type: none"> ▫ Emotional aspect ▫ Instrumental aspect

Activation and protection

After being informed about the diagnosis of their child as well as its severity, the parents tried to accept the situation and invest the energy in the most effective help and protection of their child possible. Greta accepted the protective aspect of her activity: *"I tried to protect Samko from all those negative things, so that he wouldn't see them... but the situation there, as it was... just horrible. I tried to protect Samko at all costs all the time so that he wouldn't be aware of his surroundings."* Maria, on the other hand, describes her intensive personal activation: *"I had so many problems that I just didn't have time to deal with*

myself over those four years. I just had to function and in the last six months, I didn't even sleep properly. I guess it is because when you are under such stress, you are somehow energized and just go, go... I was asked to go back home and have a proper sleep many times." Amelia expressed something very similar: *"I worked like a robot, 200%. All my energy was focused on Peter."*

Consequences of the treatment

The participants described their own experience in relation to the consequences of their children's treatment. Maria described it as follows: *"She experienced all kinds of side effects. I'll never forget*

one doctor telling us: We have two types of children – easier ones, more difficult ones and then... those like Ema. She was joking because Ema had all infections she could possibly have. It was like that. But she was recovering even though her hip joints started to fall apart. She had one leg 9 cm shorter than the other after those two years. It was such an incredible difference indeed.” Greta described the problems with the loss of appetite: “A week before the last radiation, his esophagus was completely burnt, he had problems taking in any food and it started basically overnight.” Jarmila talked about pain as a common and very challenging factor: “And it was also very bad when his knee started to die. We just didn’t know what to do with him at that time, he was screaming from pain. Nothing worked, only the strongest dosage of morphine suppressed the pain – just that.”

Re-evaluation of decisions

The parents re-evaluated doctors’ decisions regarding their children’s examination, treatment and transplantation. Jakub expressed himself as follows: “The clinical condition was not good but it was slowly improving. However, then – and it might not be a very nice thing to say – doctor P. got a great idea how to get rid of him and sent him for a PET scan. And there it was actually visible how it grew, how it had already overgrown so much. So we try to convince ourselves even now that after all, it was all good because if he had been sent to transplantation, he might not have survived it.”

Maria said that she had been sort of pushed into some decisions, for example: “I had a feeling that we had been shipped to transplantation and I can honestly say that it was all different there. They had lowered her CRP artificially under 50 just to make sure she could undergo the surgery. That’s my opinion.”

The return of disease

Within the theme named *The return of disease (Relapse)*, we identified the following subthemes: *Disappointment*, *Experimental treatment*, *Siblings and bone marrow donation*, *The conflict of perspectives* and *Inner conflict*.

Disappointment

The relapse or the return of health complications connected with the disease comes into play after unspecified length of time after the stabilization or even improvement of the child’s health condition. Jakub expressed it like that: “And then, after we had finished the treatment in May, we thought: Great, we won! Because no one expected the relapse. Statistically, Samuel was identified as cured.” The parents remembered the time when they had been waiting for the examination results confirming the

relapse. Maria said: “I will never forget how we were waiting for the results and from that room with a microscope, a doctor came out. I will never forget that. When I saw her I knew it was not good. And so we ended up there again... we were back.”

Experimental treatment

The participants described that in case of the failure of conventional treatment, neither the parents nor the doctors hesitated to try experimental treatment. Jamila: “The treatment didn’t work; it didn’t work as we expected so we started trying... we tried different dosages, different combinations and finally even experimental medicine. With experimental medicine, we knew the maximum was done for him.” Jakub talked about experimental treatment as of some sort of hope: “During that time it was like we had to try something, even though the treatment failed, there was always an alternative. OK, one thing didn’t work so we would try everything there was to try. Naturally, we didn’t tell Samko anything about the bad news. We just told him we wouldn’t leave and so we got engaged more in the treatment itself. We searched into the options that were available and we even got into contact with America (USA).” Besides hope, however, experimental treatment caused parents more stress due to a lack of research and severe side effects. Maria: “But it was such a shock; I was so scared because no one really knew about possible side effects. She got five doses, and then she was recovering from it for three weeks and then another five. And after that, she didn’t actually recover. For a month, she had suppression of bone marrow, all kinds of infections, CRP 200, 150 and all around again.”

Siblings and bone marrow donation

Healthy siblings in our experimental group were affected not only at a psychological level but also at a physical one connected with preparations for as well as the actual bone marrow donation. Greta and Jakub described how their healthy son Lukas interpreted the process of bone marrow donation: “When we were preparing Lukas for transplantation, he asked if it was about changing the bone marrow. He accepted that his healthy marrow would be given to Samko and Samko’s unhealthy marrow would be given to him. But he didn’t say it right away, maybe after two weeks: So you will give mine to Samko and I will get his bone marrow. We said yes and explained that we needed to save Samko but we didn’t fully understand what he meant until later. Lukas thought that after the procedure he would get sick while Samko would get healthy again.” Jarmila also talked about the fear from the donation her healthy daughter experienced: “She was given a dialysis catheter – it hurt and she had to bear with it for a week... but she understood it

differently already. And then, when we told her that Michal couldn't be saved anymore, she claimed to give him everything he needed just to stay alive. So the second time she thought of it differently despite her big fear of injections. So that was the biggest problem – to convince her. The problem was actually just her fear of injections."

The conflict of perspectives

Amelia described her conflict with a doctor regarding the aforementioned experimental treatment: *"I thought I would faint there... I started crying and I begged her – after all, it took us a month and a half to get that medicine. Moreover, the company paid for it so the hospital didn't have to spend a cent on it. I begged her to give it to him! But her response was still the same, saying that it wouldn't change our situation. We didn't get it and she didn't want to give it to us either. All our effort, telephones, writing, errands and she would just keep it to herself. And it was worth 200 000 euro. I didn't let it happen! At that point, the doctor completely failed in my eyes."* Greta talked about the conflict connected with her son being informed and the attitude of a doctor: *"On Saturday morning, an unknown doctor came to us saying that we should start packing as there was nothing else they could do for us. She suggested she would bring a report from hospital. Samko looked at her... and turned green because we had not told him anything about leaving before that. He didn't know we would go home. I remember how I stood up, I don't know if I gave her an evil look, but I pushed her out of the door and she was completely quiet. Finally, I played it safe for Samko saying she was just being silly."* Greta followed describing her experience: *"When the doctor saw him in his condition it was obvious from her look that the first thing she wanted to do was to get rid of him. Right from the beginning, it was clear she would do anything to avoid transplantation and not looking for ways to do it."* Amelia described the conflict in a similar way: *"I told her I knew what stage of cancer my son was in, I didn't have to be reminded of that. We had been undergoing the treatment for the last six years. I asked her for one thing only and that was to send him to a children's department. She gave in finally but added that in case the child stopped breathing while being transported she wouldn't try to save him. I said alright, took the equipment and told her I would do it myself in case anything happened on the way."*¹ Amelia was also talking about how she had insisted on continuing the treatment: *"So we went to see the doctor again – he agreed but told us that he had already went against his belief. Were the circumstances different, he would not agree and continue with radiation."*

Inner conflict

Maria described how, deep down, both she and her daughter knew her daughter's transplantation would be useless. *"I knew that even if we went there it would be useless. She knew that too. Maybe if she hadn't gone for that transplantation, she would have lived, maybe a year or two, maybe she would have been in long-term remission. I was forced into that decision. And I haven't told anyone that I can't live with that now. It wasn't just my decision to do that. Actually, we didn't want to go there. We were literally pushed into that. It felt as if Ema was just another number for the statistics... and that has not changed!"* The parents had strong feelings that the responsibility for their children's treatment was in their hands. Greta: *"That was also one of those decisions... to resuscitate or not; to go home or not. Those were the hardest decisions we had to make. And no one else could do that for us."*

Communication and support

The last theme we identified among the participants was *Communication and support*. Regarding the content, three subthemes characterized this theme, *Being informed*, *The control of treatment* and *Understanding from health care workers*.

Being informed

All participants agreed on the problems regarding this subtheme – being informed. Greta explained how she had to insist on being informed: *"Way too often it was like this: I was waiting in the hall trying to catch the doctor to get some information. I never got any space to get some information; rarely was I given any by the doctor."* Jakub pointed to the passivity of health workers as well: *"We didn't get the information in a way that they would approach us, we always had to chase them to get some."* Greta missed any kind of educational information concerning the care of her child as well: *"Because until you find out what the neutropenia regimen actually is... it was the hospital staff who should have informed me that I didn't do it right, that I had to do this or that because it threatened the child. It was quite the opposite though. In fact, if I hadn't learned it by myself, I wouldn't have known."* Nevertheless, there were also positive reactions regarding health care workers and giving the information to parents. Amelia remembered a doctor who answered her questions honestly: *"Firstly, I was in a shock that he talked to us so honestly but I was very grateful later. He was grounded, not trying to appeal to our fantasies, he was always honest."* The problem of unanswered questions resonated with many parents. We give Maria's response as an example: *"The transplantation was in September but I still don't know if the bone marrow has actually been accepted. No one has told me that at all. I knew my*

child had a donor, I knew it would be very demanding but no one told us anything about the costs, nothing at all. That might not have been the most crucial information at the moment but when I asked... they just looked at me as if I was bothering them."

The control of treatment

In a group of three parents (Jakub, Greta, Amelia), we recognized the need to control the treatment of their children. Jakub explained: *"When someone told us that at 6 pm my child would be given a medicine or something, or that we would start with the treatment, and it was 5:15 pm and nothing was happening, of course we tried to find out where the problem was. If they had just told us that everything was alright but there was just a minor change in the plan, we wouldn't have bothered them so much."*

Greta added: *"But this kind of information was missing. Some mothers didn't even know what was dripping in their children's IV. But we tried to follow everything, to be informed. And so when I knew that something was supposed to be taken at 10 am, it should have been taken at that time."* Amelia described how she had checked her son also in the home environment: *"We sat in the living room where I had a picture from a video camera and could see Peter; I also watched a monitor so I could check his breathing and have it all under control."*

Understanding from health care workers

There were two aspects identified within this theme: *emotional and instrumental.*

Emotional aspect

The participants expressed their need to share their suffering; however, oftentimes they didn't get the support from health care workers. Maria described it as follows: *"One doctor just completely shut me down. But I didn't mean anything bad when I approached her. I understood that many children there were in a serious condition. After all, everybody there was in a serious condition. But I just expressed my feelings and frustrations saying that it was our fourth year of treatment and we were tired of it all. But I honestly didn't mean to be negative or confrontational. And she replied saying: Do you think that other children have not been treated here for a long time? And then she just left. Ema's [daughter] reaction to that was: Mom, does she think I am an idiot, that I am faking it, the pain or what? I really didn't expect such a reaction. It would have been much better if she had not said anything at all. I know that all children were in a serious condition there, I understand that. I guess I just needed to hear that it would be better and that there was no need to worry, basically any words of understanding and encouragement. But she almost*

told me off for saying anything. She was really mean." Greta appreciated the support she had from health workers: *"We had such an incredible doctor there, we perceived the whole situation differently, all those negative things. There were far more positive situations than negative."* Jamila said: *"We were really encouraged to fight again when the leukemia returned."*

Instrumental aspect

Handling ordinary daily needs of their children was among the problems the parents had to deal with. Conflict in this area was expressed in Maria's response: *"She just couldn't get into that shower. And the doctor came to tell us that she had to take a shower. I knew she had to! I cleaned her with wet wipes every day. I asked him to show me how to get there, in the shower. So he took out the door, literally pulled it off the hinges. But even then she couldn't get in with her wheelchair."*

Greta considered the presence of a psychologist at the department as very beneficial although unused due to a lack of privacy: *"When Samko was depressed we dealt with it in the hall where there were no conditions for that. And even when you just wanted to talk to Samko, there were always other children around. He wouldn't say anything. There was no space for that there. So it was nice that the psychologist was there but it was useless anyway. A quiet room as a space for discussion would have been such a help."*

Discussion

A cancer diagnosis in a child leads to an existential shock to the parents and overall disruption to normal life. Experiencing such a period was the subject of many qualitative studies (McGrath, 2002; Kars et al., 2008). In a longitudinal study (Earle et al., 2006), where the data sourcing was done in three time periods (3-4 months after being diagnosed, after 15 months and finally after 27 months), the authors confirmed that leading a normal life is incredibly important yet immensely difficult to actually accomplish for parents. Uncertain future, the child's reactions to treatment, undesirable side effects, changes in the child's behavior, suspension from work, and focusing on the care of the child are among the factors which strongly affect the quality of life of the involved families. It is a change which affects all family members (parents, siblings, etc.) as well as the diagnosed child. Some studies (Stewart, 2003) have proved that despite all the uncertainties, children are able to build the feeling of "being normal". They can get used to a new life which eventually helps their parents adapt to such a life change as well. After the initial shock of their children being diagnosed with cancer, parents focus all their

energy on the care and protection of their children (theme: *Managing the treatment*). They get to know the procedures and respect them, fully adjust to the new reality of their lives (theme: *Re-evaluation of decisions*). They try to protect their children and accompany them through the whole new challenging period of their life (subtheme: *Activation and protection*). The above efforts are typical for the concept of parenting a child suffering from acute lymphoblastic leukemia which was created by Kars et al. (2008) in their qualitative study based on the grounded theory. This concept covers the parents' answer to perceiving the child's vulnerability. It means: "I am here for you. I will never leave you." Parents not only protect their children from the negative aspects of their disease and treatment but also try to influence the way their children perceive the disease itself and motivate them to willingly undergo the treatment and thus increase their chances for recovery and survival (Kars et al., 2008). This attitude was present in our research as well. Parents accompanied their children from the very beginning until the end. They actively sought experimental treatment (subtheme: *Experimental treatment*), communicated with pediatric oncology centers abroad, protected their children from insensitive care of health care workers even if that meant coming into conflict with doctors (subtheme: *The conflict of perspectives*). The conflict of parents'/doctors' perspectives often led to the parents re-evaluating their decisions, which was followed by disappointment and helplessness (subtheme: *Inner conflict*). During their remission, children are able to do the activities with their parents and siblings that have been impossible for a long time; the children return back home, their contacts with friends are restored and overall wellbeing improves. The previous complications are quickly forgotten and children enjoy good health. Such situation is disrupted by relapse of the disease which means not only general worsening of their health condition but also disappointment, sadness, depression and hopelessness. It is important how the family as well as the child cope with this deterioration of their health condition because giving up signifies a loss in the psychological area which is crucial for the next progress of the disease (Démuthová, 2010). In our work, we have captured how parents experienced the failure of curative anticancer therapy and relapse of the disease in their children (theme: *The return of disease*). The care for children dying from cancer as well as their families is complex. The vision of palliative care is to offer an integrated approach which includes symptom management, emotional and psychological support for a child and family, help with the practical aspects of care, understanding the

spiritual needs and, finally, support to families after the loss of their child (theme: *Communication and support*). The results of our study prove that social support from health care workers was meaningful (its emotional and instrumental aspects) (subtheme: *Understanding from health care workers*). The importance of social support from health care workers was also shown in a longitudinal qualitative study (McGrath, 2001) where parents appreciated the sensitive approach of health professionals, advice concerning the care for their children in the home environment, and 24-hour phone consultation in case they needed help or advice. In this study, the importance of social workers who significantly help parents, especially with official matters, is mentioned as well. We have also concluded that for departments, clinics or pediatric oncology centers, a social worker is an important member of the team. Another important team member is a psychologist. However, parents were dissatisfied with literally absent conditions needed for a proper therapeutic discussion (subtheme: *Understanding from health care workers*). In the parents' recollections and memories of the time of treatment, the area of awareness and being informed was highly stressed (subtheme: *Being informed*). In relation to being informed about the diagnosis, parents need time and space for the initial handling of the information. The way how they are informed influences their coping with the situation and it also affects the quality of cooperation with doctors and search for the best procedures (Záhorec et al., 2009). Parents were actively interested in methods and practices in the treatment of their children. They were eager to participate in the care of their children as well as control it (subtheme: *The control of treatment*). The most problematic area was awareness and being informed as stated by parents. The whole process of experiencing the situation – from making the diagnosis, through treatment, relapse, experimental treatment, to the last moments in the life of the child – could subsequently influence the way parents have handled the loss of their children.

Methodological notes

During the research, we aimed for the highest level of rigor possible as well as the reduction of bias. We used several strategies to increase credibility such as data and researcher triangulation. The limitation of the work is rather narrow selection of study participants who could be characterized as actively participating in the process of treatment. Further research could be done using a larger sample of participants and axial coding which would bring more plastic description of relationships between the themes and their subthemes.

Conclusion

Three main themes were identified using the thematic analysis: *Managing the treatment*, *The return of disease* and *Communication and support*. Eleven subthemes were identified within those themes: *Activation and protection*, *Consequences of the treatment*, *Re/evaluation of decisions*, *Disappointment*, *Experimental treatment*, *Siblings and bone marrow donation*, *The conflict of perspectives*, *Inner conflict*, *Being informed*, *The control of treatment* and *Understanding from health care workers – emotional and instrumental aspects*. The identified themes and subthemes chronologically reflect the long term impact of their child's treatment on the life of parents, with important implications for clinical practice. Regarding the care, parents highly stressed the area of awareness and being informed by health care workers. The results of the descriptive qualitative study point to the need to improve this area throughout the whole duration of treatment. The reflection of parents' experience can help nurses and other hospital staff make the therapeutic communication more effective (space and time aspects, setting consulting hours) and offer families much needed emotional support (acceptance of parents' decisions, identification and verbalization of emotions related to care). Seeking the specific possibilities can be done by individual or team supervision meetings with workers.

Ethical aspects and conflict of interest

Each participant was informed about the research nature of the study, ensuring the anonymity, the way of publishing the results and the possibility to refuse the participation in the study at any time. Subsequently, informed consent from each participant was obtained. The authors declare that there is no conflict of interests in the study.

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Author contribution

Conception and design (EG, JC), data analysis and interpretation (IA, EG), manuscript draft (IA, EG, JC), critical revision of the manuscript (EG, JC), final approval of the manuscript (EG).

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Notes:

- ¹ Amelia could not accept the fact that her child was dying. In one of Peter's reports, there was a note: "*The child is repeatedly given life-sustaining treatment as requested by the parents despite complications such as severe pancytopenia.*"