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Health professionals in the memories of grieving mothers

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Abstract

Mourning the loss of a child can begin at the moment of diagnosis of a serious illness and be shaped by the quality of care received by the family and patient. This study aimed to describe and analyze the memories of grieving mothers regarding the communication and attitudes of health professionals over the course of the disease until death. This is a qualitative cross-sectional study based on semi-structured interviews with eight mothers of pediatric patients. Three thematic axes were found: health team's attitude toward the family; communication of bad news; and death. The study revealed that the attitudes and communication of healthcare professionals over the illness to death process remain vivid in the memories of mothers. Exposing healthcare professionals to these findings may contribute to the development of empathy, ethical values, and improved interdisciplinary care.

Keywords: Bereavement. Empathy. Terminal care.

Resumo

Profissionais de saúde nas memórias de mães em luto

O luto pela perda de um filho pode começar no momento do diagnóstico de doença grave e ser moldado pela qualidade da assistência recebida pela família e paciente. O estudo objetivou descrever e analisar as memórias de mães em luto relativas à comunicação e às atitudes dos profissionais de saúde durante a trajetória da doença até a morte. Trata-se de estudo transversal, de natureza qualitativa, que realizou entrevistas semiestruturadas com oito mães de pacientes pediátricos. Foram encontrados três eixos temáticos: atitude da equipe com a família, comunicação de más notícias e óbito. Conclui-se que as atitudes e a comunicação dos profissionais de saúde durante o processo da doença até o óbito permanecem vívidas na memória das mães. Expor os profissionais de saúde a tais achados pode colaborar com o desenvolvimento de empatia e valores éticos, bem como com a melhoria da assistência interdisciplinar.

Palavras-chave: Luto. Empatia. Assistência terminal.

Resumen

Profesionales de la salud en la memoria de madres en duelo

El duelo por la pérdida de un hijo puede empezar con el diagnóstico de una enfermedad grave y estar condicionado por la calidad de la asistencia recibida por la familia y el paciente. El estudio tuvo como objetivo describir y analizar los recuerdos de madres en duelo en relación con la comunicación y las actitudes de los profesionales de la salud durante el transcurso de la enfermedad hasta la muerte. Es un estudio transversal, de naturaleza cualitativa, basado en entrevistas semiestructuradas realizadas a ocho madres de pacientes pediátricos. Se identificaron tres ejes temáticos: actitud del equipo con la familia; comunicación de malas noticias; y la muerte. Concluimos que las actitudes y la comunicación de los profesionales de la salud durante la enfermedad hasta la muerte permanecen vívidas en la memoria de las madres. Exponer a los profesionales de la salud al conocimiento de estos hallazgos puede contribuir al desarrollo de la empatía, los valores éticos y la mejora de la asistencia interdisciplinaria.

Palabras clave: Duelo. Empatía. Cuidado terminal.

Research

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Child death can be considered a disruptive process in the natural order of life, both for society and for parents [1]. In addition to the loss of the child, commonly there are secondary losses, such as professional career, salary, personal motivation and planned family structure. In general, families have major difficulty in overcoming the loss of a child, since they have vivid memories of the experiences involved in the end of life [2-8].

Bereavement over the loss of a child may begin at the time of diagnosis of a serious disease and be informed by the quality of the care received by the family and patient during the process that culminated in death. In a review study, Vig and collaborators [9] evaluated risk and mitigation factors for the acute effects of loss concerning the relationship between the health care team and the family, concluding that the support of providers with whom the parents established a relationship of trust was mitigating. On the other hand, poor quality communication was considered a risk factor for acute effects of loss. Boven and collaborators [10] showed that families appreciate sensitive and clarifying communication when experiencing the imminence of the death of a loved one and consider receiving emotional support relevant. In addition to environmental measures and effective communication practices, the bond established between health care professionals and families can produce feelings of gratitude and form memory of the lost child [11,12].

This study aimed to describe and analyze the memories and feelings of bereaved mothers regarding the communication and attitudes of health care professionals during the course of the disease until the death of their children and in the bereavement period.

Method

This is a cross-sectional, qualitative, descriptive-interpretative study based on semi-structured interviews with mothers of pediatric patients who died. According to Turato [13], the qualitative research method in the health field does not allude to intuitions about the issue of interest or free interpretation of data based on the research author's beliefs and convictions, but takes into consideration that researcher view and attitude are integral parts of the research and favor the validity of the research process, since the researcher's attentive observation provides in-depth insights into and clarification of information with participants.

Participants were initially recruited from a list of contacts of the bereavement support program of the pediatric intensive care unit at the Emergency Unit of the University of São Paulo School of Medicine of Ribeirão Preto Teaching Hospital, with mothers of pediatric patients who died in the last eight years. Subsequently, the group of researchers made individual telephone contact with five mothers, who refused to participate. In addition, 30 participants in a virtual maternal bereavement support group in the WhatsApp application also received invitations to participate in the research by message in the group; the confidentiality of those who voluntarily accepted or refused the invitation was respected. Of this group, the present study had on the collaboration of eight mothers in a situation of parental bereavement.

It is important to note that the study included mothers aged 18 years or older of patients who died in the age group between 0 and 18 incomplete years. The sample was defined by convenience, with voluntary acceptance of the participating mothers, and respected the order of consent to participation in the research for scheduling the online interviews.

Table 1 presents the description of the sociodemographic characteristics of the families in the study. Information was obtained using a questionnaire applied during interviews.

The average interview time was 65 minutes. The time between the child's death and the interview ranged from four months to seven years. Five deaths occurred in the context of the COVID-19 pandemic. In the case of 100% of the respondents, the main caregiver of the deceased child was the mother. The families were mostly composed of married parents, with an average of five members per family, with a predominance of Catholic religion and an average family income of R$ 5.762,50. Of the eight mothers who participated in the interview, three were health care professionals: a physician, a physical therapist and a nursing technician. With the exception of one patient, who was treated and died in another state, all others were treated in the same hospital complex.

Table 1. Sociodemographic characterization of the population under study

Mother	Age at death	Diagnosis	Time from interview to death	Ethnicity	Sex	Number of hospitalizations	Place of death
M1	3 months	Innate error of metabolism	9 months	Brown	M	3	ICU
M2	5 years	Oncologic disease	7 years	White	M	>10	Ward
M3	11 years	Severe dengue	2 years	White	M	1	ICU
M4	1 year and 8 months	Neuromuscular disease	4 months	White	F	3	Home
M5	8 years	Oncologic disease	1 year and 2 months	White	F	2	Ward
M6	14 years	Oncologic disease	2 years and 5 months	Brown	M	>10	Ward
M7	15 years	Oncologic disease	1 year and 8 months	White	M	>10	Ward
M8	9 months	Central nervous system malformation	4 months	White	M	5	ICU
	6 years	Central nervous system malformation	6 months	White	F	6	ICU

M: male; F: female; ICU: intensive care unit

Each volunteer participant was submitted to a recorded online interview via the Google Meet platform between her and one of the researchers, who was never involved in the care of the patient who died, with an average estimated duration of one hour, with the time necessary to report the facts. No interview was interrupted or had to be repeated. The interviews followed a semi-structured questionnaire with open questions (Annex 1), which encouraged mothers to verbally communicate the experiences and memories of the phases of experiencing the disease, death and grief for their children, in addition to providing space for suggestions to health care professionals. One of the researchers, an intensive care pediatrician with 16 years experience and aged 42 years at the time, conducted two interviews. The other researcher, a resident physician in the third year of pediatrics and aged 28 years at the time, conducted six interviews. The interviews were held from March to August 2021. The first interview was a pilot conducted by the resident medical researcher with the other researcher.

After the interviews, the family members' accounts were transcribed *ipsis litteris* for analysis of generated data by pairs of researchers, in order to categorize the mothers' feelings and memories related to the communication and attitudes of the health care professionals throughout the process of death of the children. A third researcher, a psychologist in pediatric oncology, reviewed the codes obtained from the analysis of the interviews. The interviewed mothers did not receive the transcript of the interviews for comments or corrections.

The study design and the informed consent form (ICF) were submitted to assessment by the research ethics committee (REC) of the Teaching Hospital of the School of Medicine of Ribeirão Preto – University of São Paulo (HCFMRP/USP).

For analysis and systematization of interview results, we adopted the content analysis principles of Bardin [14], which, based on a systematized set of procedures and techniques, enable the detection of variations in meanings expressed in communication, thus providing methodological conditions for establishing inferences and interpretations about the phenomenon under study [15].

According to the assumptions of Minayo [16] for the analysis of interviews, we adopted the following steps:

a. Pre-exploration of the interviews: several readings of the interviews, with an interested attitude and fluctuating attention, to globally apprehend the main ideas presented in each account and in the set of accounts. This type of analysis enables identifying general meanings and transcend what is explicit in the accounts.

b. Selection of units of meaning: taking as a starting point the key ideas identified in the

Research

previous step and the objective of the study, we built utterances (phrases, words, quotes) to illustrate memories and feelings of the bereaved mothers in relation to the health care providers. Subsequently, excerpts from the accounts were selected to illustrate the units of meaning.

c. Categorization process: based on the researcher's view, supported by the objective of the study, the previously established units of meaning were grouped into thematic axes according to the familiarity of the subjects, which would be fundamental aspects in the construction of the meanings attributed by the collaborators to the phenomenon under study.

Results

According to the adopted analytical strategy, after peer review of the interviews, the data were classified into three categories, with the corresponding descriptors: team attitude toward the family, communication of bad news, and experience of death.

As for team attitude toward the family: in the care subcategory, the memory and gratitude for positive involvement with different health care providers and the team's caring attitudes were perceived in the recorded accounts, both as to professional practice (listening, guidance, occupational therapy, provision of free access to the hospital, room reservation) and attitudes outside the professional scope (gifts, food, hugs and other expressions of affection) in the course of the diagnosis and the disease that culminated in the death of the children. All mothers expressed memories of care. Two mothers referred to the providers as "angels," which refers to guarding and protecting. Two mothers said their child was treated "as if they were family" by the professional.

Below are excerpts from the interviews:

"There was that doctor there, Dr. [physician's name], *wow, he had a love for* [patient's name], *it seemed like he was his family and that's very good. They treated us very well, they cared about me, they didn't just care about him"* (W1).

"Dr. [physician's name] *talked with me and said: 'No, you will not leave, you can rest assured, I already talked there and we will secure the bed of* [patient's name], *you will stay. So even with* [patient's name] *in the ICU, I was allowed to stay in the room"* (M1).

"She [the physician] *gave me a pink paper that is free access. So, anything he felt at any time, he would have free access to* [hospital name]. *That's why I tell you, like, I feel that, to me, we were special there"* (M2).

"And the work of occupational therapy, because there was a period that we were hospitalized for more than 1 month and then we did a lot of crafts and we had like an exhibition in the room and we gave people things as gifts. (...) *It makes a lot of difference to have the brushes and paints there for us to express ourselves"* (M2).

"When we were not well, me, my mother, Dr. [physician's name] *called me in another room, then I cried, she hugged me, asked how I was feeling* (...) *It was a relationship with a lot of friendship, of people who are really interested in that contact. It was like a family. If today I'm strong, it's because I had their support"* (M5).

"There [in the hospital] *I was cared for very well. I got there like a shy country bumpkin, scared to death of everything. I had never gone to a city further away* (...) *I didn't even know where* [city name] *was.* (...) *And the nurses* [nurse's name] *is very dear to me. She would bring me food. She was everything to me"* (M6).

The subcategory called negative experiences with health care providers contains negative memories of attitudes of different professionals that marked the mothers, expressed in lack of empathy or sensitivity to the situation and also in contempt for the patient's symptoms. The poor experiences aroused feelings such as anger, sadness, revolt and hatred. Three mothers recommended more empathy to the team. The following are interview excerpts that fit into this category.

"I made an appointment with a hematologist (...) *I even ask God to one day take the pain out of my heart because I don't forgive this doctor at all. So,* [patient's name] *was playing there on the doctor's floor and he said:* [patient's name].

Research

Then [patient's name] *stood up and shouted: 'That's me.' Then he said: 'I see that he has nothing, huh, mom? Because children with blood problems don't run like that"* (M2).

"The father said that, when he came in, he heard a phrase from the nurse. She said like: 'This is fussiness of this child! He's not feeling all that'. And less than two minutes after that he was intubated. So that left a deep mark on my husband, you know? He felt a lot of hatred for that girl" (M3).

"You know, I think her [the psychologist's] *conversation, even my friends don't talk to me like that, you know, very like, you know, very hard, I don't know if that's her way, but unfortunately it didn't help me.* (...) *I left there indignant, I never came back"* (M4).

"The nutritionist too, I almost threw her out the window, because she found him eating a pastry, she took it out of his hand and threw it in the trash. He turned on his side and went to sleep. We knew it wasn't allowed and that it was wrong, but she was dealing with a teenager with cancer, who might not get out of there alive. So I think there has to be more love" (M7).

Regarding the communication of bad news: in the subcategory called communication with the patient, we note to the anguish that mothers of cancer patients expressed when thinking about or witnessing the patient receiving the diagnosis of a disease that involves risk of death.

"I remember well when the psychologist helped me tell the diagnosis. He came and told me that [patient's name] *was more desperate for seeing us crying and not knowing what was going on. I asked what I should tell her. He asked me for permission to talk to her* (...) *Oh* [psychologist's name], *don't tell her that she has cancer, that she can die. He told me to be calm, to trust him" (M5).*

"And the doctor just came in and said that he had to be referred to [hospital name] because he had a huge mediastinal lymphoma, that it was cancer. Well, then for one I thought it was unethical that she said that near him. I immediately got (...) *But then my world fell apart and I straight hit rock bottom, and haven't been able to recover to this day"* (M7).

In the subcategory called communication of diagnosis or prognosis for parents, some mothers reported in detail the moment they received the news, including details such as the accent of the professional, the characteristics of the settings and the choice of words.

"And then she called us and it was like this: today I laugh, but it was very interesting, poor thing, because it was the first diagnosis she gave. Then she picked up momentum and went on [laughs]. [Imitating the physician with a regional accent] [Patient's name] *test was positive for leukemia, leukemia is a cancer that affects the blood, and whatnot. But she picked up speed... poor thing. I think she prepared herself, you know, memorized all that. And I, of course, at the time I was nervous and I said: 'Stop, stop. My son has leukemia, what do you mean?'. I fell into a deep despair and then they said: 'Look, don't worry, he has it and the chances of recovery are very good, we work here with 94% cure', something like that. A very high number and I said: but there's still 6%. Right? And that's how I got the news"* (M2).

"The only negative thing that impacted me was the day Dr. [physician's name] *gave me the news... And he came one day and said there was a room, which is called comfort room. This room, for me, has no comfort at all.* (...) *'I'm Dr.* [name of resident physician], *I'm a resident in oncopediatrics, I'm going to treat [patient name], and I wanted to know what you know.' But I wanted to cut the conversation short, you know? I said I knew everything. 'Look,* [patient's name] *has a* [tumor name], *it is in the brainstem, it is a place of difficult access, there is no treatment, chemotherapy does not reach the place we need, because of the blood-brain barrier. We will apply radiotherapy to* [patient's name], *but I'll advise you already. For this type of cancer, we apply radio... sometimes it diminishes, sometimes it does not diminish, sometimes it disappears. But after about three, two months, it comes back, and it comes back in full force. And then there is nothing to be done.'* (...) *Hearing it like that, that your seven-year-old daughter, who was in school, who was playing, who was in a normal life, that she had six months to live, was a bomb. I sat down, started crying and he then left me in the room"* (M5).

In the subcategory called non-verbal communication, some mothers reported team attitudes that already foreshadowed imminent bad news.

"Then started that thing of serving one, serving another one, and we were left to the end, and then my heart was already growing heavy, 'there is something going on'" (M2).

"Dr. [physician's name] would only call me to the little room to tell me that there was no way. When he called me, I already knew it" (M7).

"When we got there, two [physicians] came to talk to us. My husband said that that was not a good thing, that they had not allowed us to go see him, that they came to talk first—'Get ready, that's not a good thing'" (M8).

As for the experience of death: in the subcategory called witnessed deaths, mothers reported in detail the hour, day of the week, weather, people present and last hours of life. These are accounts full of intense pain, some mothers needed a break to cry.

"And then when it was Friday he was calmer, more listless, [psychologist name] *was with me at lunchtime, then he woke up, called me, asked for his little pillow, asked for the pacifier and said he missed* [brother's name], *said he missed the pool, but that everything was fine and then he didn't wake up anymore, he stayed there, his heart was beating because the last that stops is the heart drum. On Saturday, at 4 p.m., he died. That's it. It was very hard, I was not in much condition to go to the wake"* (M2).

"And that day I kissed her little forehead and said, 'I love you,' and turned her aside. (...) That's it, the hours passed, I went there, turned off the milk, used water, kissed her forehead, but she was cold, but I don't know if at that moment she hadn't already passed away. I went back to the room, talked to my mother, when it was about 11:30 I went and started preparing the medicines, the midday medications and the milk I would already have prepared, I went there on the table and took everything I had prepared and went there to change her. (...) And then, when I turned around, I put my hand under her, I turned her to the side, I already saw it, she with the purple mouth, I started screaming" (M4).

"Until it was 1:30 in the morning, I looked out the window, the weather was so calm, so calm... and I looked to the side, I saw the two nurses (...) I didn't have the strength to get out of bed... and I got up from the chair I was sleeping in... and I asked if he had died. They said they didn't know, that they were waiting for the doctor to come. The doctor came, examined him [crying] *and I asked if he had died, and she only answered me with a yes. And at the same time my tears fell* [intense crying]. *And my world ended and to this day I don't live anymore* [cry]. *I can't live (...) I asked her to take his tee shirt off for me (...) I still have this tee shirt to this day (...)"* (M6).

"It was the worst day of my life, it was the day I regretted having beenborn and I would rather have gone with him. It was horrible, a mother watching her son stop breathing. There's no explanation for that, nothing takes it out of your mind, out of the rest of your life. Unless we have Alzheimer's, which is the disease I want to have if I reach this stage of old age, so I don't even remember that I had a child. That scene was the worst of my life. They could have mutilated me, my arms, my legs, it would have hurt a lot less [cries for a while]. *But he wanted to live it* [dying in palliative care without being intubated], *and I wanted to live it with him"* (M7).

Of the mothers who did not witness the death, in the subcategory called deaths not witnessed, we note the right to farewell promoted by the health care providers.

"When he was already going, they went up there to inform it and the doctor sent for me, I went down. When I got there, they were already removing the devices from him and I was able to pick him up and hold him. The nurse asked me. I thought it was very important. She asked if I wanted to hold him for the last time. (...) And I did want to hold him and it was important" (M1).

"So, like, the ICU doctors, when they came to inform us that he was not responding, called us to say goodbye to him, let us stay with him for a while, one on each side, so, like, they allowed us the opportunity to say goodbye to our son. And then they asked us to leave and we stayed there waiting for them to resuscitate him and I

think he went into cardiac arrest, they kept trying to resuscitate him and I remember that I was hugging his father and I said, like (...) *I felt. I can't explain it, guys. He had a normal birth and I felt the same pain as in normal birth, but it was a physical pain, that from inside I was short of breath. So, I screamed and said like this, I screamed and said: '*[father's name]*...', then I said: 'Our son is gone!'. I felt him passing away"* (M3).

"Then we went, on Friday, then we already saw her (...) *They explained that she was going to undergo the tests. Then, on Saturday, they called me that they had done the tests and that she had suffered brain death. That if we wanted to go say goodbye to her. And see if we were going to donate her organs. Then we went there, said goodbye to her, accepted her donation* (...) *and then that was it.* (...) *We stayed with her, kissed her, hugged her. Caressed her. I took a little of her hair to keep. That's what we did"* (M8).

Discussion

This study provided as a singularity the interview of families in various clinical contexts for not restricting the target public as other studies [12,17,18]. Consistently with the data found in the literature, similar results were found in studies with similar methodology regarding the benefits/harms of the measures adopted by health care professionals in the care of patients and families [2,3,11,19,20]. The quality of the care provided at the end of a patient's life is fundamental for the family and can directly affect how they cope with death, as described by different authors [3,6,21].

The empathic attitudes of health care professionals were recalled by all mothers in the interviews and ranged from listening and gestures of affection to offering gifts and food. Some mothers name the professionals as "angels," for their care and protection at that time of extreme vulnerability. There were also comments that the patient was treated "*as if they were family*." The connection and gestures of the team can remain in the memory of families even years after the death and provide relief for the bereavement-related feelings of loneliness and despair [3,19]. According to the reports, we infer that families want to be well informed and that their loved ones receive the best possible care, in terms of both technical quality and care for affective needs [21]. This issue is little discussed and taught in professional training, as it is not part of the predominant biomedical model.

The situation of serious illness and end of life is already, in itself, stressful for the professional. Are we, as a health care team, technically, ethically and humanly prepared to meet the broad needs of caregivers? All health care-related professional categories should be aware of the impact of their gestures and of the importance of empathic, ethical, sensitive and individualized connection. While for one mother it was the paper for free access to the hospital that made her feel special, for another it was the company in the elevator, and for another it was staying in the same room in the ward while the patient was in the ICU. Hence the enormous importance of listening to and learning from family members' accounts.

There were comments on disregard for the symptoms expressed by the patient and lack of sensitivity in different situations. All mothers described in detail the negative experiences, regardless of the time of bereavement, and expressed feelings of hurt. Many of them recommended that professionals receive training in empathy, a subject that is not a priority in undergraduate medical schools, despite the 2001 National Curriculum Guidelines, and faces barriers such as unattractive methodologies, inconsistency between theory and practice, and undertrained teachers [22-24]. In addition to improving care for patients and their families, the development of empathy may correlate with less burnout among professionals [23,25]. One of the means to awake empathy in the team is precisely to listen to the accounts. The stories we hear from the human beings we care for or are involved with professionally, or even personally, inform our ability to feel and our ethical values. This is another justification for the dissemination of studies like this.

Communication is one of the most widely used tools in health care, and high-quality care for patients with serious diseases necessarily requires high-quality communication [26]. Good-quality communication is associated with a higher sense of peace and trust in the physician [4].

In our study, in the communication category, it was notable the anguish of mothers for the receipt of the diagnosis by the child or adolescent. Brower and collaborators [27], in 2021, observed the concern of parents of children with serious diseases regarding how and how much they should know about the disease. Another issue raised by the cited study is the subliminal messages of bad news and the effect that the indication of bad news in a context other than a conversation can have on the family. In the present study, three families mentioned the perception that they would receive bad news even before receiving it, just because of the context: being last in the outpatient clinic, being called to a meeting in a specific room, or not being allowed to visit without talking first. Health care professionals need to have some sensitivity and more attention to their actions. It is known that guidelines on good practices for communicating bad news, such as the established SPIKES protocol [28], can improve the performance of health care professionals [29].

It is already known that bereaved families vividly remember the moments leading up to the death of their child [4,5]. Dissatisfaction with communication or the feeling of insensitive communication can increase the stress of the end-of-life period and generate an additional emotional cost for parents that could be avoided [4,26].

Other studies have shown that the account of death is an absolutely marked scene in the memory of mothers [5,7]. The responsibility of witnesses is enormous. Barrett and collaborators [6], in 2023, described in a systematic review that the final stage of life of pediatric patients can represent an opportunity to resume parenting, sometimes absolutely weakened after the trajectory of serious diseases. The chance of unrestricted access, or discharge to the home, the reduction in invasive devices and privacy represent the transition from a process of the team "doing" to a process of return of the responsibility of parents, now more in the sense of "being" present at the end of life.

On the professional side, the experience of the patient's death with or without the family can mobilize many affections. Health care services should also offer support to professionals, in addition to education and training in end-of-life care. Expertise in end-of-life care comes from palliative care (PC), which, in pediatrics, is still present in few services in Brazil [30], albeit with good prospects after the approval of the National Palliative Care Policy within the scope of the Unified Health System (SUS) [31]. In medical schools, since 2022, the teaching of PC has been mandatory, according to Resolution of the National Council of Education [32]. Resolutions of this nature are expected to multiply to regulate the teaching of PC to all health care professionals.

It should also be noted the references to the right to farewell and production of memories. Allowing farewell rituals within the hospital facilitates the re-signification of the loss [1,6,33,34]. Johnston and collaborators [35], as bereaved physician mothers, wrote an article recommending good practices shortly after the death of a pediatric patient, in which one of the main topics is the family's right to spend time with the child's body and produce memories. The team can play a key role in supporting, collecting and suggesting to families the production of meaningful memories, such as hand and foot stamps, photographs, locks of hair [35]. The production of memories is both appreciated by families and impactful in the processing of bereavement and in maintaining the connection with the child who died [6,35,36].

The construction of the relationship between health care professionals and parents throughout the disease-death process has a relevant effect on coping with bereavement, either as a facilitating or aggravating factor. Our results corroborate the results found in the literature, which describe the participation of the multidisciplinary team as an active part of the memory of the deceased loved one [1,2,21,34].

Listening to the voices of bereaved mothers helps us understand important issues in pediatric patient care and what should be improved in order to build public policies and guidelines for the training and functioning of health care teams [8]. Providing quality care to patients and their families is is our ethical duty, and, to achieve this goal, we must meet the multidimensional needs of these people.

The study was limited to describing the reports of few families served in the context of end-of-life health care for children. Other limitations of the study include the theme itself, the responder's need for internet access, and the time of the

bereavement process. Mobilizing oneself to (re)expose oneself to the feelings generated by bereavement is not an easy procedure. However, it is worth mentioning that, despite being a vulnerable group, bereaved mothers may consider participation in research valuable and therapeutic for the opportunity to share their family history [37,38]. A strength of this study is the ambition to expose health care professionals to such findings and contribute toward the development of empathy and ethical values and the improvement of interdisciplinary and holistic care for families of pediatric patients with potentially life-limiting diseases.

Final considerations

We found that the health care providers' attitudes and communication during the process from disease to death remain vivid in the mothers' memories, with an effect on the positive and negative feelings generated during the bereavement phase. Therefore, the humanistic training of health care providers requires improvement in order to take into consideration the multidimensional needs of patients and caregivers in the context of serious diseases, in addition to training and research in the communication of bad news.

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Isabela S. Costa participated in the design of the study, elaboration of the methodology, interviews, formal analysis and writing of the manuscript. Nichollas Martins Areco, in the elaboration of the methodology, formal analysis of the results and review of the manuscript. Leila Volpon, in the design of the study, elaboration of the methodology, interviews, formal analysis and writing of the manuscript.

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Research

Appendix

Interview questionnaire

1. How did you feel after your child's death?
2. How was the health care providers' communication about the condition that led to your child's death?
3. How was the communication of the news of the death? (in case you were not present)
4. After the death, did you have the opportunity for a farewell moment with your child?
5. Do you have any positive memories regarding contact with the health care providers throughout the process of your child's disease?
6. Do you have any negative memories regarding contact with the health care providers throughout the process of your child's disease?
7. After the death, did you voluntarily seek any kind of help to cope with the loss?
8. After the death, did the hospital or health care team contact you to offer support or condolences? If yes, what was that like for you? If no, did you miss this contact?
9. Finally, would you have any suggestions on initiatives that health care providers can adopt to help parents in the severe stages of the disease and in bereavement?