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EDICIONES
COMPLUTENSE

# The care for oncologic patients undergoing pediatric palliative care and the griefs of a health team

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**Abstract.** Introduction: The health care offered to children and adolescents with cancer has been expanded, giving space to orthothanasia and palliative care, with a comprehensive look at the subject facing the threat to the continuity of life, as well as challenging professionals to access issues related to grief. Objectives: In order to explore this reality, this study intended to analyze how professionals experience grieving processes in the exercise of palliative care in pediatric oncology. Method: A qualitative research was conducted with the participation of 23 health professionals working in palliative oncology and pediatric care, who responded to a semi-structured interview script, whose analyses were performed with the support of the IRaMuTeQ (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) software. Results: The results were organized in four classes: in class 1, the specificities of the treatment of children with cancer and other aspects related to chronic illness are portrayed; class 2 shows that health trainings do not prepare professionals to deal with death and with patients with no possibility of cure, and these professionals have (pre-) concepts about palliative care; class 3 highlights the principles of palliative care and other factors of the work in this therapy; and class 4 deals with the bonds formed by professionals and their grieving experiences. Conclusions: Cure must not be a requirement for the provision of care in relation to children with cancer that can benefit from the adoption of palliative care therapy and the validation of the sensitivity of professionals.

**Keywords:** Health personnel, bereavement, childhood cancer, palliative care, pediatrics.

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# [es] Asistencias al paciente oncológico en cuidados paliativos pediátricos y los lutos de un equipo de salud

**Resumen.** Introducción: La asistencia en salud ofertada a los niños y jóvenes con cáncer han sido ampliada, dando espacio a la ortotanasia y a los cuidados paliativos, con una mirada integral sobre el sujeto delante de la amenaza de la continuidad de la vida, y desafiando profesionales accedan cuestiones relacionadas al luto. Objetivo: Para explorar esa realidad, el presente estudio tuvo como propósito analizar como los profesionales viven la experiencia de los procesos de luto en el ejercicio de los cuidados paliativos en oncología pediátrica. Método: Se llevó a cabo una pesquisa cualitativa que ha contado con la participación de 23 profesionales de salud que actúan en cuidados paliativos oncológicos y pediátricos, que contestaron una hoja de ruta de entrevista semiestructurada, cuyos análisis fueron realizadas con el apoyo del *software* IRaMuTeQ (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*). Resultados: Los resultados se organizaron en cuatro categorías: en la categoría 1 son retratadas las especificidades del tratamiento del niño con cáncer y otros aspectos relacionados a la enfermedad crónica; la categoría 2 muestra que las formaciones en salud no preparan los profesionales para hacer frente con la muerte y con pacientes fuera de la posibilidad de curación, que presentan prejuicios sobre cuidados paliativos; la categoría 3 señala los principios de los cuidados paliativos y otros factores del trabajo en esa terapéutica; y la categoría 4 aborda sobre los vínculos formados por los profesionales y sus experiencias de luto. Conclusiones: La cura no debe ser un requisito para la prestación de cuidados ,bien como los niños con cáncer que pueden beneficiarse con la terapéutica de los cuidados paliativos y validación de la sensibilidad de los profesionales.
**Palabras clave:** Profesionales de salud, luto, cáncer, cuidados paliativos, pediatria.

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## 1. Introduction

When situations in which the end of life is approaching or in which the outcome is death, the caring for the health and disease process can be a challenge for health professionals. Accordingly, it ends up being important to know the difficulties inherent in the exercise of care in chronic illness, as well as the capacities developed from the contact with suffering in the context of life and death(1).

Health actions in the process of a patient's death rely on references derived from the perspectives of care and cure. The curativist paradigm is based on the dedication to saving lives. Meanwhile, the care procedure is based on empathy, respect and trust; being mediated by factors such as time and intensity, and marked by aspects related to the anticipation of a loss with the advancement of a disease and considers death a component of the human condition. It also advocates quality of life in the processes of finitude based on the principles of quality of death(2-3).

Nevertheless, academic training in the health area is predominantly focused on curing the most diverse diseases and fighting death. There is no preparation to act at the end of life, leading professionals to focus their praxis on the objective of saving lives, dealing with the reality of those who will die under their responsibility in a distressing way(2-4).

As a reflection of the social environment, most health professionals are regulated by dysthanasia. They invest in therapeutic obstinacy, adhering to the practice in which one seeks to extend life, even if under intense suffering and when the possibilities of reversal and cure do not present themselves(5-6).

Guided by the logic of prolonging life, the qualification of care for children with cancer is marked by the lack of specialized services for this audience, due to inconsistencies in training courses and consequent delayed performance. The absence of specific knowledge and previous experiences can also compromise the care of children with cancer and specialized health care in the process of terminality during childhood, thus prolonging the dying process and not the opportunity to live(6-8).

In opposition to this logic, orthothanasia recognizes the need to adjust the therapeutic approach in view of the advancement of a disease and the impossibility of curing it. It represents the occurrence of death at the appropriate time, with treatments that alleviate pain and other inconveniences, without performing unnecessary invasive procedures(5).

The perspective of orthothanasia refers to palliative care therapy. This approach is operated by a multidisciplinary team that seeks to promote quality of life and maintenance of care with comfort and dignity for patients and their relatives in the face of a serious disease that entails limiting conditions. They are based on the prevention and relief of suffering, with early identification of its causes, impeccable assessment and treatment of pain and physical, social, psychological and spiritual symptoms; since it contemplates death as a natural process and advocates welcoming the grief of those involved(9-10).

Specifically in pediatrics, palliative care seeks to satisfactorily meet the individual needs of a child in the course of a life-threatening disease, reducing its impact and torment; regardless of whether or not it is curable. Despite being an important approach, it is poorly understood and associated with the end of life, thus contributing to many pediatric specialists not feeling comfortable in approaching the patient's family with conversations about palliative care(11-6).

Once in the condition of caregivers of children with cancer, professionals can develop significant bonds with these patients and their relatives, due to the long period of coexistence with them, also creating expectations about the treatment and suffering when the possibilities of cure are depleted. At this point, terminality-related work requires an empathetic and sensitive service and, therefore, professionals must have their human condition recognized, as they are not exempt from the commotion caused by the death of a patient, even though it is recurrent in their routine, due to the growing transfer of the place of death from homes to hospitals(1,2,9,12).

In health spaces in general, ambiguous conflicts emerge for the teams, ranging from avoidance in the face of the invincibility of death to the desire to be close to the patient who pass away in a sensitive and welcoming way, alleviating the psychological effects of the disease and its treatment. Therefore, it is considered that the distance observed between some professionals and their patients does not cancel out the feelings of failure and powerlessness derived from the experience with death, despite the silence about its occurrence and the triggered feelings(2,8,13).

Working in circumstances involving death makes health professionals have access to issues related to grief, which, in turn, is a state in response to the loss of a loved one, of something or someone important. It corresponds to a departure from the state of health and well-being, where a period is needed for the bereaved person to restore the psychological balance compromised in response to the loss, whether by death or by situations throughout life. In this process, several feelings and behaviors can appear in the course of grief, such as sadness, anger, guilt, fatigue, drowsiness, sleep and appetite disturbances, isolation, dreams, crying and agitation(14-16).

The experience of loss felt by the professional can start from the diagnosis of a disease that puts the patient's life at risk or with the proximity of death, in a process of anticipatory grief. The conscious perception of the imminence of death causes the anticipation of grief and the expression of associated reactions, which can vary among the components of a health team according to the bond, degree of involvement and meaning of the relationship established with the patient and his/her family(17).

It can also take place during the professional's grieving process, having to deal with the lack of social recognition of this condition, thus composing unrecognized grief or disenfranchised grief. This modality of grief qualifies the experiences of loss in which there is no authorization and social validation to be publicly mourned because of the lack of legitimization of human suffering, regardless of the plot in which the grief reactions manifest(2-18). Nevertheless, professionals are people who can form significant bonds with those they care for and end up losing, demanding an emotional and psychological organization(19-12).

With the reverberations of silence due to oppression and because of the representation of their role in society, professionals tend to deal with the feeling of ambivalence between the denial and the expression of their grief. Accordingly, the space for talking about working with terminally ill patients and their relatives can help in ordering emotions and in the grief trajectory, considering that the components of a health team are also vulnerable to mental illness(20,21).

The grief among those who make up the palliative care teams in pediatric oncology requires consistent studies that can contribute to the necessary qualifications and give visibility to their demands as subjects in the world, thus authorizing the exteriorization of the grief silenced for a long time. Therefore, the therapeutic function of strengthening the voice of the public in question must be considered, recognizing them as professionals to the extent that it validates them in their condition as a person. This can have positive repercussions on the quality of the provided service.

In light of the foregoing, this research was intended to analyze how health professionals experience the grieving processes in the exercise of palliative care in pediatric oncology. Its specific objectives were to analyze how they understand the support they offer to the relatives of children with cancer undergoing palliative care, also identifying the specificities of the performed work.

## 2. Method

### 2.1. Type of study

A qualitative exploratory and descriptive research was carried out, seeking to promote greater ownership of the proposed theme.

## 2.2. Participants

It was attended by 23 health professionals, men and women from different health categories (physician, nurse, psychologist, social worker, dentist, physiotherapist and educator), based on the saturation criterion(22). All worked with pediatric oncologic patients undergoing palliative care.

As inclusion criteria, the following were considered: a) being a health professional who had graduated for at least one year; b) working in hospitals, public or private, which had a palliative care team; and c) working in pediatric palliative care for at least one year, considering that this can be a considerable period for the professional to adapt to the peculiarities of the service. As exclusion criteria, it was considered: a) not being available to participate in the research; b) not acting continuously in palliative care; and c) requesting to interrupt the interview.

## 2.3. Instrument and Techniques

In order to accomplish the research, a semi-structured interview script designed by the authors was used, developed from the interest of better understanding the experience of professionals with grief in the context of palliative care in pediatric oncology. It addressed the following categories: (1) Perception about death in pediatrics; (2) Support to the family of patients undergoing palliative care undergoing the process of finitude; (3) Knowledge and perception about the experience of anticipatory grief; and (4) Experience of the grieving process after the loss of a patient undergoing palliative care in pediatric oncology.

## 2.4. Ethical and Data Collection Procedures

The study was approved by the Research Ethics Committee, under opinion Nº 3.248.281. Subsequently, contact was made with the participants following the Snowball Technique. The interviews were conducted individually, at scheduled times, according to the convenience and availability of the participants, with the aid of an audio-recorder and an average duration of 40 minutes. All had access to the Free and Informed Consent Form, based on resolutions 466/2012, 510/2016 and 580/18 of the National Health Council (CNS, as per its Portuguese acronym).

# 3. Data analysis

The interviews were understood through the IRaMuTeQ (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) software, which seeks to apprehend the structure and organization of the discourse(23).

Analyses were performed in four steps. Initially, the Word Cloud grouped the words and organized them graphically according to their relevance, being that the largest ones had the highest frequency, disregarding those with a frequency lower than 8. Next, classical lexicographic analyses were performed to check the statistics of the number of text segments – TS (text clippings of approximately 3 lines), evocations and shapes. Then, the Descending Hierarchical Classification (DHC) allowed the recognition of the dendrogram with the classes that emerged, from which the higher the $\chi^2$, the more associated is the word with the class; and disregarding the words with $x^2 < 3.80$ ($p < 0.05$), the understanding of the material and the denomination of the classes were performed by two judges. Based on the material emerged in each class, content analysis by Bardin (2016) was performed, in order to achieve a greater depth in the analysis of the material. Finally, a Correspondence Factor Analysis (CFA) was performed to check the differences in the speeches of different groups, comparing the reports by age group and professional categories, with demonstration in the Cartesian plane.

## 4. Results

### 4.1 Word cloud

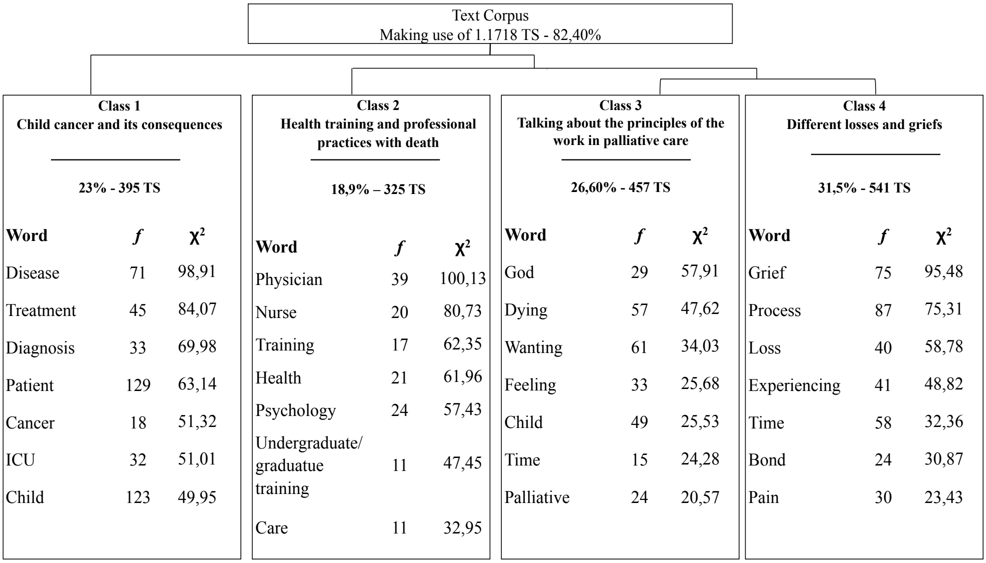
Firstly, the word cloud generated from the participants' reports was obtained, in order to have an overview of the data. It was found that the most frequently mentioned words were: "Child" (*f* = 489), "Patient" (*f* = 427), "Family" (*f* = 375), "Speaking" (*f* = 298), "Understanding" (*f* = 246), "Death" (*f* = 209), "Process" (*f* = 190), "Moment" (*f* = 194) and "Mother" (*f* = 176) (Figure 1).

Figure 1. Word Cloud formed by the most frequent evocations among the participants

### 4.2 Textual statistics and descending hierarchical classification

The general corpus consisted of 23 texts, separated into 2,085 text segments (TS), making use of 1,718 TSs (82.40%). The analyzed content was categorized into four classes: class 1, with 395 TS (22.99%); class 2, with 325 TS (18.92%); class 3, with 457 TS (26.60%); and class 4, with 541 TS (31.49%). Seeking to achieve a more accurate view of the classes, an organizational chart was designed "Class diagram with words and descriptive variables", with evocations that had similarities in their vocabulary and differences among classes (Figure 2). Below, there are descriptions of the classes built in the Descending Hierarchical Classification and their subcategories apprehended from Bardin's Content Analysis (Table 1).

Figure 2. Class diagram with descriptive words and variables.



Text Corpus
Making use of 1.1718 TS - 82,40%

**Class 1**
**Child cancer and its consequences**

**23% - 395 TS**

| **Word** | *f* | $\chi^2$ |
|---|---|---|
| Disease | 71 | 98,91 |
| Treatment | 45 | 84,07 |
| Diagnosis | 33 | 69,98 |
| Patient | 129 | 63,14 |
| Cancer | 18 | 51,32 |
| ICU | 32 | 51,01 |
| Child | 123 | 49,95 |

**Class 2**
**Health training and professional practices with death**

**18,9% – 325 TS**

| **Word** | *f* | $\chi^2$ |
|---|---|---|
| Physician | 39 | 100,13 |
| Nurse | 20 | 80,73 |
| Training | 17 | 62,35 |
| Health | 21 | 61,96 |
| Psychology | 24 | 57,43 |
| Undergraduate/ graduatue training | 11 | 47,45 |
| Care | 11 | 32,95 |

**Class 3**
**Talking about the principles of the work in palliative care**

**26,60% - 457 TS**

| **Word** | *f* | $\chi^2$ |
|---|---|---|
| God | 29 | 57,91 |
| Dying | 57 | 47,62 |
| Wanting | 61 | 34,03 |
| Feeling | 33 | 25,68 |
| Child | 49 | 25,53 |
| Time | 15 | 24,28 |
| Palliative | 24 | 20,57 |

**Class 4**
**Different losses and griefs**

**31,5% - 541 TS**

| **Word** | *f* | $\chi^2$ |
|---|---|---|
| Grief | 75 | 95,48 |
| Process | 87 | 75,31 |
| Loss | 40 | 58,78 |
| Experiencing | 41 | 48,82 |
| Time | 58 | 32,36 |
| Bond | 24 | 30,87 |
| Pain | 30 | 23,43 |

Table 1. Synthesis of presentation of the classes with the main covered aspects

| Classes | Subcategories |
|---|---|
| Class 1 – Child cancer and its consequences | The context of chronic diseases in children and its repercussions |
| | Aspects related to the diagnosis of cancer in children |
| | |
| Class 2 – Health training and professional practices with death | The professional training for death |
| | Working with patients with no possibility of cure |
| | (Pre-)concepts about palliative care |
| Class 3 – Talking about the principles of the work in palliative care | The principles of palliative care |
| | Support tools |
| | Work experiences with death |
| Class 4 – Different losses and grifes | Bonds formed and losses experienced |
| | Anticipatory grief |
| | The grieving experience of professionals |
| | |

***Note.*** The classes emerged from DHC in IRaMuTeQ, while subcategories emerged from Bardin's Content Analysis.

### *4.2.1. Class 1 – Child cancer and its consequences*

Class 1 corresponds to 23% of the text segments (*f* = 395 TS). The content of this class addresses aspects of the reality of a child with cancer. That is, it discusses the context of chronic diseases and their consequences, as well as some aspects related to the experiences of the small patient affected by cancer.

#### *The context of chronic diseases and its repercussions*

Professionals highlight nuances of treatments for chronic diseases, which sometimes generate demands that lead some relatives to abdicate their daily tasks and other commitments, in addition to social and family life, to dedicate themselves exclusively to the care of the sick child. According to the participants, this can lead to economic problems and withdrawal of the child's treatment. In order to avoid these problems, they highlight the importance of the financial benefit provided by the government and the risks of forgoing treatment.

> Patients belonging to SUS, who drop their lives, leaving everything there, in order to spend a year and a half in treatment. Therefore, the treatment became much heavier [...]. The benefit, which is a right of these children, is sometimes the only income these parents have. All the money can go to the child, but it's the only income that family will have. (Participant 12)

In addition, caveats were made about the possible differences in experiencing a chronic disease at different stages of development; especially between the child and elderly audiences.

> In all these years of practice, I have followed-up patients of all ages, from infants to 117-year-olds, and I could see the difference at each stage of development. I could see my differences dealing with this. (Participant 9)

#### *Aspects related to the diagnosis of cancer in children*

It was found that the study participants are also aware of the particularities of child care. There are changes in attitudes towards the child, information omitted due to taboos about the disease and the impact of diagnosis and relapses.

> It's always thought that the child will not understand, that they will get depressed, that they will give up. (Participant 13)

> Dealing with children in cases where we already know the diagnosis, that diagnosis that does not have a disease-modifying treatment, is heavier than treating a child, for example, who has an acute problem. (Participant 5)

### *4.2.2. Class 2 – Health training and professional practices with death*

Corresponding to 18.9% of the text segments (*f* = 325 TS), this class addresses content about the training process of professionals working in palliative care. It is divided into three subcategories that talk about the professional training courses, the work with patients with no possibility of cure and the team's role in palliative care.

### *The professional training for death*

Participants highlighted that there were no significant discussions about the death of patients in their undergraduate and graduate courses, as well as in other training processes, including those aimed at empowering them for this occurrence in their work routines. Accordingly, they pointed out a gap in the structuring of their courses and highlighted the importance of such a debate for the humanization of health services.

> I think we are really not prepared for this. I even think that this issue of having now palliation in hospitals is something that helps us a lot, because it gives us support and we are not alone in this very difficult time. But in terms of preparation, neither in college, nor in undergraduate, nor in graduate studies, at any time. (Participant 4)
>
> Nowadays, I take a training course in palliative care. Nevertheless, it took place long after my practice. (Professional 15)

### *Working with patients with no possibility of cure*

Regarding the work with patients with diseases that do not respond to curative treatments and are beyond the possibility of cure, the professionals highlighted the importance of palliative care therapy in health services, with early appointment.

> It happens that the palliative care opinion is requested only at the moment close to death. So, the palliative care team here acts as an inter-consultant. It will only meet the patient if it is requested by the assistant doctor. And it happens that doctors don’t realize that the patient in palliative care is not only the one who is close to dying. It’s also since he has a diagnosis of a threatening disease, but it happens that we can only follow-up from that moment when he is already close to death, and then it’s much more difficult for this family too, including the process of grieving. (Participant 10)

Psychology and its skills were highlighted in the professionals’ speeches, who highlighted how essential the presence of the psychologist as a member of the team is, especially in the management of crisis situations, fluidity of relationships, and communication.

> Psychology and the medical team have to be very close to these parents, clarifying what the disease is, what the evolution of this disease is, that is, what the father and mother can expect from this disease. (Participant 14)

### *(Pre-) concepts about palliative care*

Palliative care and its care proposals are addressed in a wrong way, according to the participants’ speech. The consequences of distortions on this therapy reinforce the reduction of its application only to end-of-life care, thus associating it with a death sentence.

> In the current days, there are still these professionals, there are still many of these professionals who open their mouths and say: I have nothing more to do for you.

> I'll refer you to the palliative care team. It's as if the palliative care team was the death sentence, right? (Participant 14)

> Usually, the professional who communicates best within the team is the Psychology professional. (Participant 13).

### *4.2.3. Class 3 – Talking about the principles of the work in palliative care*

Equivalent to 26.60% of the text segments (*f* = 457 TS), the content of this class highlights factors on the principles of palliative care, the support tools that act as help devices for those involved in the patients' processes, also containing reports about the work experiences of professionals in the context of death.

#### *The principles of palliative care*

Participants recall that palliative care therapy is not directly related to death. The work in this approach proposes to take care of the patient in the course of his/her disease, offering support to his/her family, even after death.

> Personally, as I've already said, I don't like to think about the issue of palliative care, if he's going to die tomorrow or in an hour. Then, I try to work, be present, thinking about what I can do today. (Participant 23)

The validation of the wishes of cancer patients undergoing palliative care is something recommended in the guidelines of this health care and was also underlined in the statements of professionals who work in the scenario in question and who seek to respect the positions of those they care for.

> I don't want to know what the other is seeing; or, for me, what matters is him. There, I always ask questions. Or how I respect it too. Not, I don't want to do anything today (...) Not, I'm not in the mood, I don't want to talk to anyone, I don't want. Anyway, it always happens. I come up and ask, so like this. In this sense, it's this bias that I seek to work. (Participant 23)

#### *Support tools*

The study participants recalled that the context of a chronic disease, such as cancer, in clinical conditions in which the patient has no possibility of cure, requires not only a careful attitude, but also resources that help to cope with difficulties. Among the strategies most used by patients and professionals, one can mention spirituality and good communication among those involved.

> When the family has a religious basis, it has an acceptance, right? When it has that base, it's different from when it doesn't (...) whether it wants it or not, the process of religion is very present, right? I'm really talking about what I see, what I've experienced. (Participant 23)

> I don't like to say that, because I think it belongs to God, it doesn't belong to us. We're all going to die, I don't know which day I'm going to die. I may pass away

> before them. Therefore, that's one of the things that makes me never give up on them before their time. (Participant 4)

> We even learn to communicate, because, anyway, we have to communicate somehow (...) not that this is such a correct way of transmitting information. Therefore, we learn to communicate in a way that plays out, so that you take it on with you, the child is yours, and you should go on. And then you say: gosh! I must have done so much wrong because I didn't know, I didn't have a communication strategy. (Participant 6)

### *Work experiences with death*

The coexistence with cancer patients who are undergoing palliative care makes the team deal with issues related to death on a daily basis, since the impossibility of cure and the advancement of some diseases refer to terminality. In this sense, the participants emphasized nuances of their practices, such as the stigma of death and the feelings triggered by this occurrence.

> Even today, this is still a big problem. Our colleagues, when we talk about loss, about death (...) it's like something like that. The word "death" disturbs people a lot. (Participant 22)

The follow-up of terminally ill children allows us to observe that these patients are also able to perceive their own finitude and express their awareness. Given this and the losses experienced, professionals highlight the suffering experienced in this context.

> I used to cry a lot with the families, it made me feel bad, sometimes I couldn't sleep, I came home and said: "Gosh". I questioned myself about some details, not about behavior, but I questioned why so much suffering from that family, and everything. (Participant 6)

### *4.2.4. Class 4 – Different losses and griefs*

Referencing 31.5% (*f*= 541 TS) of the total analyzed corpus, the content introduced in this class deals with the losses experienced from the worsening of the patient's cancer and their grief as professionals, due to the bond formed during the long period of contact imposed by disease and treatment. It talks about the anticipatory grief felt with the prelude to death and the grief itself, experienced after the loss of the patient.

### *Bonds formed and losses experienced*

The study participants paid attention to the formation of bonds with the children and their relatives, recognizing their own griefs due to the losses experienced with the advance of the disease and the importance of being together with the family, caring for its components and the patient in this process, providing a space for everyone to speak and the possible well-being, thus validating the griefs of those involved.

> I'm really linked to this patient, and I'm already in mourning, because I know she'll be getting worse and worse, the disease advancing and everything, but I understand that a lot. (Participant 8)

According to the health professionals' statements, the approach of death ends up being something perceived, felt and experienced by everyone. Their acceptance and acceptance of the family favors the patient care process, even without overcoming the suffering generated by the loss.

> When patients and their relatives manage to absorb the idea, then I think it's more about acceptance, that that person can die, that's where I start to realize the processes, I don't know if it's mourning, or it's really a farewell time. From starting to think about what the funeral will be like, from starting to organize life. (Participant 12)

*Anticipatory grief*

The continuous care in oncology provided to children who are undergoing palliative care leads to follow-up the sequence of losses experienced by the patient and observed by those around him/her during the disease's worsening process. Thus, there is the anticipatory grief process, which starts before the actual loss, and which can contribute to the preparation for death and the elaboration of grief after the death occurs, without being related to the idea of abandonment of the person who is passing away.

> But most of them will experience and have different grieving processes throughout the illness, right? They experience a series of losses, they experience the possibility of losing at any moment that subject, that child that was so desired. Therefore, they experience anticipatory grief. (Participant 13)

*The grieving experience of professionals*

With the inevitable losses and the feelings triggered by them, acting in palliative care offered to children with cancer helps professionals to validate their own grieving processes in the face of a patient's death. They become aware of how these griefs reflect on the whole team.

> I think the first step is for us to recognize this, that there is a grieving process. So, of course, there are some cases that capture us more, which we end up dedicating even more time to, because they demand a lot more from us. Then, when there's that final departure, when there's really death in fact, there's some grief. (Participant 11)

### 4.3. Correspondence Factor Analysis (CFA)

By means of CFA, comparisons of evocation differences among the groups were made, considering age and professional category. In the comparison by age group (Table 2), participants aged between 25 and 30 years evoked words more associated with the awareness of professionals and difficulties in working with children with cancer undergoing palliative care ("example" -8.640-, "perspective" -5.449-, "absorbing" -5.652-, "perceiving" -5.294- and "rethinking" -4.486-). The evocations among the components aged 31 and 38 correspond to gaps in training courses and bonds ("speaking" -11.028-, "defense" -4.066-, "thanatology"- 3.565-, "bond" -3.226- and "priority" -3.131). Those aged 39 to 60 years were more focused on palliative care and end-of-life therapy ("treatment" -16.838-, "palliation" -10.022-, "context" -6.453-, "support" -4.103- and "pass away" -4.613).

Table 2. Presentation of the Correspondence Factor Analysis according to the age group of the participants.

| Age group | Characteristics of evocations |
|---|---|
| 25-30 years | Sensitization and difficulties in palliative care with children |
| 31-38 years | Formation of bonds |
| 39-60 years | Palliative care and end of life |

In the comparisons by professional category (Table 3), the contents evoked by the surveyed physicians address well-being and anguishes ("suffering" -14.723-, "mother" -9.215-, "dying" -5.007-, "better" -5.847- and "party" -11.547-). Nurses were more focused on the difficulties and management of emotions ("trying" -8.929-, "understanding" -4.884-, "complicated" -6.999-, "absorbing" -5.761- and "bandage" -3.582-). Psychologists, on the other hand, addressed emotional support to those involved in comprehensive care ("Psychology" -8.282-, "being" -7.146-, "caring for" -3.867-, "dealing" -3.366- and "support" -3.426-). Meanwhile, the social workers' speeches were more focused on families ("patient" -4.177-, "family" -5.321-, "father" -10.957-, "context" -7.141- and "health" -5.940-). The dentists' responses highlight their experiences in working with children with cancer ("way" -3.595-, "seeing" -4.084-, "love" -3.053-, "acceptance" -5.772- and "professional" -2.467-). Physiotherapists evoked words associated with sensitivity in the face of death ("involving" -5.041-, "passing away" -2.207-, "terminality" -9.012-, "final" -2.655-, "difficult" -4.281- and "love" -5.230-), while educators evoked terms referring to the emotions triggered by the patient's health condition ("crying" -3.577, "wanting" -4.163-, "feeling" -5.329-, "thinking" -3.7628- and "status" -3.768-).

Table 3. Presentation of the Correspondence Factor Analysis according to the professional category of the participants.

| Professional category | Characteristics of evocations |
|---|---|
| Physicians | Anguishes and well-being |
| Nurses | Difficulties and emotions in the context |
| Psychologists | Comprehensive care and sensitivity |
| Social workers | Family |
| Dentists | Work in oncology |
| Physiotherapists | Death |
| Educators | Patient health |

## 5. Discussion

In class 1, the current study signalizes that the context of pediatric palliative care requires a different management of therapy, because the diagnosis of child cancer and its repercussions mark the continuous participation of the family in coping with situations experienced with the advance of the disease and the long periods of hospitalization. Moreover, they advocate individual care, which preserves the patient's autonomy and values the expression of feelings experienced during the disease and after death, as the actions of this team must also minimize the family's suffering in the process of grieving and resuming life(13-24).

Class 2 points out the importance of professionals taking ownership of palliative care to mitigate the problems caused by the lack of discussions about death during health training. This is because an academic education encompassing health interfaces must take into account patients with no possibility of cure and the psychosocial factors that may interfere with adherence to treatment and delivery of humanized care(25).

In sequence, the elements that resulted in class 3 show that the participants of this study prioritize palliative care from the diagnosis of the disease to the quality of life of the patient, and not just the deathbed, a fact that is corroborated by the palliative care guidelines, when advocating its continuity with early identification, correct assessment and treatment of pain and other symptoms. In addition to being important in health work, communication is essential for the well-being of patients undergoing palliative care, as well as spirituality, which presents itself as a form of resilience in the face of experiences of loss, death and the elaboration of grief(3,25,26).

Class 4 of this study addresses the various losses and griefs experienced by health professionals with the advancement of a patient's disease, as well as in function of the continuous losses of the formed bonds. From this perspective, the many adjustments and losses imposed by the worsening of a disease lead to anticipatory grief of health professionals as a response to the imminent possibility of losing someone with whom a bond has been built during long periods of interaction with health services and to the very notion of disruption. Nonetheless, the lack of social authorization regarding the adoption of grief by these professionals prevents them from expressing their feelings, not being accepted as the bereaved, thus configuring unrecognized grief(12-17).

The differences introduced by the Correspondence Factor Analysis in the evocations of different age groups are due to the fact that the elaboration of loss experiences is influenced by the personality and the cognitive and emotional development of each one. Accordingly, the attribution of meaning and adaptation to the possibility of death must be understood according to the stage of social, emotional and cognitive development, since it is something unique(16).

With regard to the specificities by professional category, there is a caveat to unpreparedness; in general, due to biases in training on issues of death and dying, which can lead to an impersonal and purely biological view of death. This justifies the absence of evocations specifically focused on the grieving process, as this does not have primary care in the professionals' work routine(17).

## 6. Conclusions

The exercise of work with oncologic children undergoing palliative care requires that professionals take an interest in the comprehensiveness of the sick subject and in the needs of the most diverse factors that constitute him/her and that affect his/her relatives, showing that much can be done, and deconstructing the tragic idea that the possibilities for intervention have been depleted. It is wise to always think about patient's relatives, since they generally devote themselves energetically to the care of their children and undergo changes in the dynamics of their daily lives.

Similarly, the validation of the health professional's grief is a way of legitimizing the investment relationships, not only scientific, but also affective, due to the bond that is formed in the long time of coexistence. Each one who offers his/her knowledge through care procedures, goes down the path of a child marked by cancer and treated by means of palliative care, lives together with the losses and different moments of this experience, the symptoms of the disease, the effects of the treatment, the frustrations with the progress of the disease and the anxiety with the announcement and arrival of death. They share the uniqueness of these griefs with what is broken in life and the consolidation of departure.

It is believed that the research carried out may help to better understand how palliative care in pediatric oncology is configured in its guidelines and practices. In addition, it contributes by giving visibility to the professionals' feelings and affective repercussions, since the validation of their griefs is a way of legitimizing the investment relationships, not only scientific, but also affective, due to the bond that is formed in the long time of coexistence.

Like any scientific endeavor, the current study has limitations. Part of the data collection took place during the COVID-19 pandemic, thus restricting face-to-face access to some participants and imposing remote interviews. Moreover, the sample number of participants in the municipality of Mossoró was smaller than in Fortaleza, as it is a city in the hinterland of the state of Rio Grande do Norte with only one oncology service that serves children in the form of palliative care.

It is relevant to carry out future studies on the topic discussed here, suggesting an emphasis on the effects of the COVID-19 pandemic for the recognition of the grief experienced by health teams dealing with death, considering the contemporary discussion about this phenomenon that, until then, was a great taboo.

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