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DIGNITY OF LIFE AND DEATH: TERMINATION OF CÁNCER PATIENTS IN ORTHOTANASIA

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ABSTRACT. The objective was to understand the perception and meanings expressed by cancer patients undergoing exclusive palliative care in regard to death, cancer and their experience of the finitude process. Ten cancer patients participated: five in home care and five in hospital care. Different instruments and techniques were used at different stages. For the accomplishment of Stage 1, observations were made through systematic visits and open listening, guided by an observation script and recorded in a field diary. For Step 2, the Free Word Association Test (FWAT) was used, with the inducing verbal stimuli 'Cancer' and 'Death'. The data were understood through descriptive analysis (field diary) and categorization (FWAT). The results show that cancer and its treatment are associated with pain and fear. Participants experience dualities between hope for a cure and certainty of a poor prognosis, and also between acceptance and denial of death. The family has a fundamental role in welcoming and offering autonomy and dignity to the dying patient, although they can also suffer from corresponding illnesses. Spirituality / religiosity is a coping strategy used by patients, reducing spiritual distress, although it can also support hope for a cure and death denial, hindering the terminality process. Autonomy is also a factor that contributes to the patient's dignity. It is concluded that acceptance of death, family and spiritual/religious support, and respect for autonomy contribute to orthothanasia and allow for a death with more dignity.

Keywords: Neoplasms; palliative care; orthothanasia.

DIGNIDADE DE VIDA E MORTE: TERMINALIDADE DE PACIENTES COM CÂNCER EM ORTOTANÁSIA

RESUMO. Objetivou-se apreender a percepção e os significados expressos por pacientes oncológicos em cuidados paliativos exclusivos sobre a morte, o câncer e sua

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experiência do processo de finitude. Contou-se com a participação de dez pacientes com câncer: cinco em atendimento domiciliar e cinco em internação hospitalar. Utilizaram-se de diferentes instrumentos e técnicas, em etapas distintas. Para a realização da Etapa 1, realizaram-seobservações, por meio de visitas sistemáticas e escuta livre, guiadas por um roteiro de observação, com registro em diário de campo. Para a Etapa 2, utilizou-se o Teste de Associação Livre de Palavras (TALP), comestímulos indutores ‘Câncer’e ‘Morte’. Os dados foram compreendidos por meio de análise descritiva (Diário de campo) e categorização (TALP). Os resultados mostram que o câncer e o seu tratamento estão associados àdor eao medo. Os participantes apresentam dualidades entre a esperança de cura e a certeza de prognóstico reservado, e entre a aceitação e a negação da morte. A família tem papel fundamental no acolhimento e na oferta de autonomia e dignidade do paciente em processo de morte, embora também sofram com o coadoecimento. A espiritualidade/religiosidade é uma estratégia de enfrentamento utilizada pelos pacientes, reduzindo a angústia espiritual, apesar de também poder sustentar a esperança de cura e negação da morte, dificultando o processo de terminalidade. A autonomia também é um fator que contribui para a dignidade do paciente. Conclui-se que a aceitação da morte, suporte familiar e espiritual/religioso e respeito à autonomia contribuem para a ortotanásia e permitem a morte com mais dignidade.

Palavras-chave: Neoplasias; cuidados paliativos; ortotanásia.

DIGNIDAD DE VIDA Y MUERTE: TERMINALIDAD DE PACIENTES CON CÁNCER EN ORTOTANASIA

RESUMEN. El objetivo era comprender la percepción y los significados expresados por los pacientes con cáncer en cuidados paliativos exclusivos sobre la muerte, el cáncer y su experiencia del proceso de finitud. Asistieron 10 pacientes con cáncer. Se utilizaron diferentes instrumentos y técnicas, en diferentes etapas. Para la realización de la Etapa 1, se realizaron observaciones, mediante visitas sistemáticas y escucha libre, guiadas por un guión de observación, registrado en un diario de campo. Para el Paso 2, se utilizó la Prueba de asociación de palabras libres (TALP), con estímulos inductores ‘Cáncer’ y ‘Muerte’. Los datos se entendieron mediante análisis descriptivo y categorización. Los resultados muestran que el cáncer y su tratamiento están asociados con el dolor y el miedo. Los participantes tienen dualidades entre la esperanza de cura y la certeza de un pronóstico reservado, y entre la aceptación y la negación de la muerte. La familia tiene un papel fundamental en dar la bienvenida y ofrecer autonomía y dignidad al paciente moribundo, aunque también padecen una enfermedad conjunta. La espiritualidad/religiosidad es una estrategia de afrontamiento utilizada por los pacientes, que reduce la angustia espiritual, aunque también puede apoyar la esperanza de curación y la negación de la muerte, lo que dificulta el proceso de terminación. La autonomía también es un factor que contribuye a la dignidad del paciente. Se concluye que la aceptación de la muerte, el apoyo familiar y espiritual/religioso y el respeto por la autonomía contribuyen a la ortotanasia y permiten una muerte con más dignidad.

Palabras clave: Neoplasias; cuidados paliativos; ortotanásia.

Introduction

The perception and meanings expressed about the illness experience can be perceived by the ways in which individuals show, interpret and communicate their experiences of distress, but also by the way people behave towards treatment, presenting behaviors and ways of dealing with the situation. These are intersubjective processes under construction, continuously experienced by the patient and their family. During this moment, the suffering produced by the disease can lead the individual to limitation, fragility and impotence, presenting the idea of finitude. On the other hand, the development and use of coping devices can be mobilized, which can have a mediating role between subject, health and disease (Ravagnani, Domingos, & Miyazaki, 2007).

Coping, according to the interactive model of stress, refers to a set of cognitive and behavioral strategies, which undergo frequent changes and are used to manage internal and/or external conditions, considered threatening to the individual and evaluated as a burden on their personal resources (Lazarus & Folkman, 1984). Everything will depend on the perception and meaning attributed by the individual to the context of illness and the family/social support they have during this journey (Machado, Soares, & Oliveira, 2017).

Among the many pathologies that bring subjects closer to death and that challenge them, neoplasms are highlighted for their aspects that configure terminal health factors throughout the process, which may weaken the patient's emotional states. Due to the stigma it carries, cancer represents a disorder-producing element, as it is almost always associated with painful illness and death (Almeida & Melo, 2018, 2019). Thus, cancer represents much more than physical pain. Within it, the experience of illness implies the risk of suffering total pain – physical, psychological, social and spiritual (Saunders, 1996). This is because it interferes with the individual's goals, changing their routine, lifestyle, work dynamics and family structure; and also, their mobility, autonomy and body image; it can generate low mood, subjection, pain, loss of dignity and fear of intense suffering (Manso, Lopes, Fonseca, Rei, & Santos, 2017; Muñoz, 2016).

In this context, as important as the correct diagnosis of the disease and other symptoms is the offer of quality of life to the patients, both during curative treatment and in cases where there is no longer any indication of cure, there being a poor prognosis - when there is a small chance of survival and the greatest probability is to progress to death (Leite, Amorim, Castro, & Primo, 2012). As this presents a long journey of excessively threatening, offensive and hostile clinical procedures, which are a source of intense anguish and assumptions for patients and families, there is a need for greater care to ensure not only adherence to treatment, but also an autonomy which is conscious and realistic about the diagnosis, treatment and prognosis.

Respect for autonomy is understood as the manifestation of the will directed towards a situation that is well understood by the decision maker. In the health context, respect for autonomy is effected through the validation, listening and recognition of interests and desires for the patient's way of life and the opportunity for shared decisions between patients and health professionals about clinical approaches, discussing all information, risks and benefits (Van Bruchem-Visser, Beaufort, Mattace-Raso, & Kuipers, 2020; Poletto, Bettinelli, & Santin, 2016). Autonomy is also expressed in the right to experience the death process with dignity.

To adapt to this treatment and seek to maintain their quality of life, dignity and autonomy, cancer patients need to use different resources. At this moment, the perception and meanings expressed about the disease, the way of coping and the tendency to seek social support depend on certain factors, such as the stage of the subject's life cycle, sociodemographic characteristics, personal beliefs, information about the disease and the treatment, social support, and bonding with professionals, among others (Leite et al., 2012).

The adaptation and adjustment to this new situation and the need to look for ways to face the diagnosis and treatment of cancer requires enormous personal, emotional and social mobilization. This is because, in addition to the neoplastic pathology and the difficulties inherent to this, is its negative social valuation, a situation that is almost always unfavorable to treatments, which demand high levels of tolerance (Santos et al., 2017; Pérez, González, Mieles, & Uribe, 2017). Adequacy, which is especially required in the face of a crucial moment in the progression of the disease, can occur when/if the patient, professionals and family members are faced with a poor prognosis, with no prospect of a cure.

Depending on the stage of cancer and the responses to treatments already offered, including, for example, surgery, radiotherapy and chemotherapy, there will be a need to make a decision about the care approach. If the disease presents regression with the treatments, the care of the team will remain focused on the cure or on controlling the progress of the disease. However, if the patient no longer responds to therapeutic measures and does not present conditions for recovery or prolongation of survival, the main objective of care should no longer be the cure and the attempt to maintain life, and become the offer of a possible dignified and comfortable life (World Health Organization [WHO], 2018).

Thus, what may be an appropriate treatment for an individual with an accelerated-stage disease, with a high degree of staging, is inadequate for a patient in the terminal process, in other words, the individual who has an irreversible disease, who does not react to any known therapy and who is in a circumstance in which the outcome will be death, and which may occur in days, months or years. For these patients, curative care is no longer effective, and orthothanasia is indicated, which is consistent with a perspective that understands the patient's right to die with dignity, respecting the manifestation of death at the right time, without delaying or postponing, and offering humanized care to the patient during the entire process. There is a refusal to invest in obstinate therapeutic actions, performing unnecessary and inhumane procedures that, despite aiming to prolong life, only extend the process of death and imply greater suffering for the patient (Almeida & Melo, 2018; Bomtempo, 2011).

Within this proposal of respect for life and dignity in the process of death, palliative care emerges as an approach that improves the quality of life of patients and their families who face problems related to life-threatening diseases, through the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems (WHO, 2018). This is indicated from diagnosis onwards and, given a poor prognosis, it should work exclusively (Oliveira, Viana, Soares, & Andrade, 2017; Támara, 2014).

In view of the vulnerability and fragility involved in the terminally ill patient, different care proposals are suggested, demarcating goals that must be achieved. At this stage, teaching and training of new strategies to control stress and pain are carried out; family members are encouraged to administer self-care, benefiting the grieving process; and incentive is offered, according to the possibilities, of assistance in the modality of home care. Measures that aim to identify and meet the specific needs of patients who experience the terminal process are carried out, so that their quality of life and dignity in the process of death are preserved (Silva, Cota, Vieira, Arrazão, & Cyrino, 2017).

This patient, afflicted with what they perceive, accepting or not their clinical condition, generally craves information and looks around themselves for confirmation of their impressions, and sometimes for magical solutions. Even if facts such as the diagnosis and prognosis, their clinical condition or the possibility of death are hidden through a conspiracy of silence by the family or health professionals, often maintained by a futile attempt at protectionism, or even amidst the very denial of the patient, they know and feel their prognosis and the progress of the disease. As a result of this collusion of silence, sometimes, even if there are many people around them, an enormous feeling of abandonment can be experienced by the patient (Kovács, 2009; Muñoz, 2016).

Faced with these silent perceptions, the patient may be much more afraid of dying and of all the suffering involved in this process than of death itself. During this journey, with or without acceptance of death, feelings of despondency, helplessness, abandonment and hopelessness still arise. Furthermore, fear of the death process involves the unpleasant condemnation of suffering, that is, there is the possibility of experiencing physical and psychological distress that makes dying such a repellent event, and fear is the most frequent psychological response (Aquino et al., 2017, Almeida & Melo, 2019; Vassbakk-Brovold, Antonsen, Berntsen, Kersten, & Fegran, 2018).

At this time, patients use different coping and support strategies to go through the process of death with more dignity, and religious coping constitutes strategies that employ belief, faith, religiosity and spirituality to face complex situations of illness. For some patients, faith can provide tranquility in the face of the disease, facilitating the acceptance of the prognosis, and generating more relief. On the other hand, when used in an inactive way, it can create a desperate attachment to a cure that can only come from something miraculous and not from technical-scientific means, thus maintaining hope (Evangelista et al., 2016; Sousa, Meneguin, Silva, & Miot, 2017).

Therefore, accepting terminality is a very complex process, however, when the patient is able to understand the situation they are experiencing and its consequences, they can develop ways to deal with this new reality. In this context, exclusive palliative care aims to ensure death as a natural cycle of life and provide care that reduces and contains the unpleasant symptoms resulting from the disease, through prevention. The individual is also guided in re-evaluating the behaviors and values that command their existence and preparations for death. In addition, this type of care seeks to alleviate physical, psychological, social and spiritual suffering, including support for the family and attention to anticipatory grief (Visentin, Mantovani, Kalinke, Boller, & Sarquis, 2018).

Envisioning care with respect to the wishes and autonomy of the patient in the terminal process and aiming to regulate the treatments to be applied, the Living Will Advance Directives appeared in California legislation in 1976, through the *California Natural Death Act*. They assured patients undergoing the terminality process clarifications about the effective possibility of rejecting specific treatments, in view of the likely end of their disease. The instrument for this manifestation was called the Living Will, and is known in Brazil as *Testamento Vital*. Through this document, a conscious and legally capable individual can record which treatments they accept or reject if they suffer from a terminal-stage disease, and their will must be obeyed in future situations in which their explicit manifestation is not possible, as in the case of coma or loss of consciousness (Dadalto, Tupinambás, & Greco, 2013; Godinho, 2012; Mabtum & Marchetto, 2015).

In this regard, in Brazil, the Federal Council of Medicine [CFM], through Resolution No. 1,995/2012, establishes that “[…] the physician shall record, in the medical record, the Advance Directives Will (ADWs) that were directly communicated to them by the patient” (Resolução n° 1.995, 2012). This resolution appears in addition to Resolution No. 1805/2006, which states that “[…] in the terminal phase of serious or incurable illnesses, the physician is allowed to limit or suspend treatments that prolong the patient's life, guaranteeing them the necessary care to alleviate the symptoms that lead to suffering […]”, practicing orthothanasia and changing the therapeutic approach, using exclusive palliative care (Resolução n° 1.995, 2012, p. 169).

From this perspective, for some patients the experience of the disease at an advanced stage makes them recognize themselves as finite beings, appropriating the possibility of death as part of their existence. This does not necessarily mean that they have given up on life itself, but that they have learned to live with the life-death duality. For others, the fear of death can cause suffering as intense as the physical pain of a degenerating body. On the other hand, it is considered that if they can accept their final death, they may be able to learn to face and react productively to all the changes that arise in their life (Kübler-Ross, 1989).

From this reflection, it is observed that death is far from being an easy topic to focus on, especially from the perspective of those in the process of death, which is why studies that analyze the situations of death from the patients themselves are recent and still very scarce. However, it is necessary to talk of the unspeakable and break the silence that permeates death. With ethical and moral care, it is possible to research the phenomena involved in death from individuals diagnosed with illnesses that lead to an immediate end, giving them a voice (Silva et al., 2017). Given the above, this study aimed to understand the perception and meanings expressed by cancer patients undergoing exclusive palliative care in regard to death, cancer and their experience of the finite process.

Methods

Type of study

This is descriptive and exploratory, cross-sectional study with a qualitative approach that intends to delve deeper into this little-studied theme (Gomes, 2014).

Participants

Using the criterion of saturation (Fontanella, Ricas, & Turato, 2008), 10 patients with cancer, in the process of terminality, undergoing exclusive palliative care participated, five patients in home care and five patients in hospital (see Table 1).

Table 1. Characterization of research participants

Participants	Gender	Age	Pathology	N. of visits	Home Care (HC) Hospital Assistance (HA)
1	F	54	Lung cancer with metastasis in the central nervous system	03	HC
2	M	71	Lungcancer	06	HC
3	F	86	Vulva cancer	03	HC
4	F	74	Colon cancer with adenocarcinoma	01	HA
5	M	60	Stomach cancer	01	HA
6	F	71	Breast cancer withbone metastasis	03	HC
7	F	49	Lung cancer	03	HC
8	F	51	Spinal cell câncer with cervical lesion	01	HA
9	M	67	Lungcancer	01	HA
10	F	49	Ovarycancer	01	HA

Source: The authors.

The decision to limit the sample to cancer patients is due to the need to avoid the type of disease that could be a variable which biases the data - since the type of pathology implies different therapies and, consequently, a variation in perception and meanings of the death process. Furthermore, cancer is the second leading cause of death in the country and has the largest investment in palliative care (WHO, 2018). The decision to approach patients in home and hospital care was made because they are the two main locus of palliative care (Almeida & Melo, 2019).

As inclusion criteria, the following were considered: adult patients (over 18 years old) with a poor prognosis declared in their medical records and followed up by a palliative care service (hospital and/or home). As an exclusion criterion, we did not consider patients who were very debilitated due to the progression of the disease or intubated and who, therefore, were unable to respond to the instruments. It is considered that the saturation of data from Step 1 occurred in participant 10 and in Step 2 in participant 9.

Instruments and techniques

Different instruments were used in two distinct stages. To carry out Step 1, which sought to capture the patients' perception of their experience of the death process, observations were made through systematic visits and open listening. These were guided by an observation script, consisting of four themes: (1) the patient's social support network, (2) ways of coping used by patients, (3) the patient's perception and reactions to the death process, and (4) the patient's autonomy. The data were registered in the Field Diary.

For Step 2, which sought to understand the meanings that patients attribute to cancer and death, another instrument was applied - the Free Word Association Test - FWAT. This is a projective technique that is organized through the evocation of participants' responses (words or ideas), from inductive stimuli previously defined by the researcher, whether verbal (word, expression, idea, phrase, proverb), image (figure, photography), video (film, advertising) or sound (a song or a sound). From this, it is possible to identify semantic universes related to an object or social phenomenon (Coutinho & Do Bú, 2017). For its application in the present study, when listening to the inducing stimuli ‘Cancer’ and ‘Death’, participants should immediately express related words or expressions. It is considered that the use of ideas was chosen, rather than words (as is more commonly requested in FWAT), due to the difficulty of this form of expression in patients with low educational level and poor physical conditions.

Ethical and data collection procedures

The research was developed through a partnership made between the University of Fortaleza and the largest reference hospital in cancer care in the city and was approved by the Research Ethics Committee, under ruling nº 2.036.680. Before starting the collection of research data, a selection was made of the hospital's patients who met the inclusion criteria by analyzing their medical records and collecting additional information from the professionals of the interdisciplinary team of continuous care who accompany the patients. Then, an invitation was made by the researcher, explaining the research procedures and offering full autonomy to accept or refuse the invitation. After acceptance, patients received systematic visits (one to six meetings), from their entry into exclusive palliative care until terminality. It is emphasized that these visits were always carried out in pairs - by the palliative care psychologist for the patients, who was an employee of the hospital, and by one of the researchers in the present study, without a connection to the hospital.

In these meetings, in the form of a relaxed dialogue, and respecting the moment, the desire and the physical and emotional limitations of the patients, information was collected through the research instruments and techniques, in two distinct stages. Depending on the patient's receptivity, physical conditions, availability and stage of end of life, between one and six visits were made. Stage 1, observation, started from the initial contact with the patient on the first visit and extended until his/her dismissal (due to hospital discharge or death). In this step, only the field diary was used for recording. The recorder was not used to record the therapeutic encounter between the patient and their psychologist, as these were long meetings (between 2 to 5 hours in duration) in which the expressions went beyond the verbal, with the use of gestures, looks and silence, and because of the place occupied by the researcher in certain moments of the visits, as a more distant spectator. Stage 2 was carried out at the end of the first meeting. It is considered that all ethical aspects proposed by Resolutions 466/12 and 510/16 for research with human beings were respected and the data collection process throughout the visits took place during 8 months, between April and December 2017.

Data analysis

The reports heard and observations made about the participants collected in the visits, recorded in the field diary, were understood through descriptive analysis and organized into categories. For the organization by categories, the proximity of the reports and themes addressed by the participants was taken into account. For the analysis of the

FWAT, all the ideas evoked and emerged from the inducing stimuli 'Cancer' and 'Death' were considered. Initially, the contents of the most frequent answers were verified, which were established as categories and the answers with semantic and content similarity were grouped for the categorization of the evoked ideas (Coutinho & Do Bú, 2017). Then, a frequency count of each category of meaning was made and the participants that formed them were verified.

Results and discussion

This topic refers to the analyzes carried out with the aim of understanding the perception and meanings expressed by cancer patients undergoing exclusive palliative care in regard to death, cancer and their experience of the finite process. The data obtained were presented in two parts: (1) Field diary and (2) Free Word Association Test (FWAT).

1. Categories emerged in the analysis of observations recorded in a field diary

In the diary, we sought to record everything that was seen, heard and experienced in the visits. Some annotations were recorded in the context of the research activity, others were carried out in a suitable space a few hours after the field activity, as only a few details remained for later recording. To present the records, a table was created containing the synthetic descriptive aspects of the diary entries (see Tables 2 and 3). The extensive material of what was observed and heard was organized into three categories, analyzed below: (1) Support network: the emotional and instrumental support of the family; (2) Ways of coping: spirituality/religiosity; and (3) The terminality process: the relationship with death and the desire for autonomy.

Table 2. Descriptive aspects of field diary notes

Participants	Description
Participant 1	**1st visit:** Weak voice and headaches. **2nd visit:** Very fragile and saying little. **3rd visit:** Very debilitated and did not respond to calls and already presented an advanced terminal state. Passedawaythefollowingweek.
Participant 2	**1st visit:** Stable and bedridden, using probe and concentrator. **2nd visit:** No probes, already carrying out activities and in a good mood. **3rd visit:** No probe and no constant use of concentrator. **4th visit:** Sad mood and talking about a disturbance in the head; with anguish, using the concentrator a little and with bed restriction. **5th visit:** Improved depressive traits. **6th visit:** Appeared in good spirits. Remains alive with a 6-month prognosis.
Participant 3	**1st visit:** Stable and lying in the bed, very quiet and sad. **2nd visit:** Passive posture and waiting for death. **3rd visit:** Changed residence, however, continued with the same talk of waiting for death. Passedawaythefollowingweek.
Participant 4	**1st visit:** Stable. Was aware of the seriousness of the illness

	and appeared at ease about the prognosis. Dischargedthefollowingweek, breakingtieswiththeresearch.
Participant 5	**1st visit:** Post-surgical moment of total removal of the stomach; carried a colostomy bag and used a nasogastric tube with parenteral feeding. Had difficulty speaking and had severe back pain. Passed away the following week.

Source: The authors.

Table 3. Descriptive aspects of field diary notes

Participants	Description
Participant 6	**1st visit:** Good mood and concentrator off. However, could not stand the fact of approaching death. **2nd visit:** Bedridden and presenting significant breathing and eating difficulties. Also had difficulties in expressing themself verbally. **3rd visit:** Bedridden and using an oxygen tank. Had respiratory arrest and medications were intensified. Passedawaythefollowingweek.
Participant 7	**1st visit:** Stable and without using the concentrator. **2nd visit:** Emaciated and despite being fully aware of their condition, spoke of hope in finding a way to a cure. Showed tiredness and tenderness in the feet. **3rd visit:** Bedridden and weakened, using a concentrator. Passed away the following week.
Participant 8	**1st visit:** Used a fixed nasoenteral feeding tube and after radiotherapy the skin was burned (radiodermatitis). Was discharged from hospital and returned to their town, breaking ties with the research.
Participant 9	**1st visit:** Did not appear to be frail, but knew the seriousness of their condition. Received good family support. Was discharged from hospital and returned to their town, breaking ties with the research.
Participant 10	**1st visit:** Appeared to be very emotionally fragile. Was very distressed and disgusted with their condition. Was discharged from hospital and returned to their town, breaking ties with the research.

Source: The authors.

Category 1 - Support network: the emotional and instrumental support of the family

Based on the reports and context of death observed in participants 2, 3, 5, 9 and 10, the family involvement was intense during this process and there was satisfaction from the participants with this acceptance. This is because the family, due to its bonds of affection, has special characteristics of proximity and coexistence that provide the conditions to accompany the illness process of its members. In cases of serious illnesses, the family reacts internally and interacts in a social context to care for and support their loved one. This behavior is a way of assistance that the family develops to guarantee protection to the sick family member and favor the practice of orthothanasia and thus offer dignity in the death process.

For Oliveira et al. (2017), the family context presents itself as an important foundation in the face of palliative care interventions, being a fundamental strategy for the development of a more comprehensive treatment, focusing on the patient's health. The family environment can provide the perception and sense of protection and belonging, integrating the set of affective bonds built throughout the life of its members.

On the other hand, the absence or lack of commitment of someone important in the family, as in the case of participants 1 and 4, generates the feeling of abandonment, reducing the social support network, making the patient feel more fragile. It is recognized, therefore, that family support is essential for the terminally ill patient to experience death and dying in a calm way, making it less stressful and without worrying so much about those who will remain after their death (Silva et al., 2017).

It was also recognized, from the complaints and behavior observed in participant 2's wife, that, in addition to being central figures in patient care, family members also suffer from corresponding illness, and are subjects who lack attention and monitoring by the health professionals, as they deal with their life routine, associated with the care routine, permeated by the close experience of the patient's death process (Almeida & Melo, 2019; Oliveira et al., 2017).

This context is also addressed in the research by Oliveira et al. (2017), which points to the need to observe that the family's coping with the disease may depend on some aspects, such as: the moment of life at which this family unit finds itself; the role each member plays in the patient's life; the role played by the patients themselves; and the consequences that the impact of the illness causes on each of these members, as well as the way it presents itself in the family structure.

Category 2 – Ways of coping: spirituality/religiosity

Faced with serious illness, people use different coping strategies, among them, beliefs stand out in a predominant role and are related to tools of confrontation and emotional reinterpretation. Thus, in the case of participant 1, spirituality and religiosity are configured into cognitive or behavioral adaptive strategies that use faith to face stressful events. As portrayed by Evangelista et al. (2016), spirituality and religiosity are presented as important resources for coping with the most frequent physical and psychological symptoms of patients undergoing palliative care. We may consider that during treatment spirituality can favor positive redefinition processes, promoting better quality of life, dignity in the process of dying and acceptance of imminent death, by reducing spiritual anguish.

On the other hand, participant 5's observations show that spirituality can hinder the process of accepting the process of dying, as the patient expects the miracle of a cure, denying death. In this case, faith supports an expectation of healing, making the process of terminality difficult (Leite et al., 2012).

Category 3 - The terminality process: the relationship with death and the desire for autonomy

Critically ill patients who are facing the process of death are aware of the seriousness of their condition, whether they have been informed or not, but sometimes they prefer not to tell others who, in turn, may also resort to a conspiracy of silence (Kovács, 2009; Muñoz, 2016). This is because it is painful to talk about death. Family members believe that they protect the patient by hiding the prognosis and the patient takes advantage of any message, explicit or implicit, so that it is not necessary to talk about the subject.

Thus, avoidance behaviors were noticed in participants 2, 6, 7 and 10 when talking about their health condition, as there is difficulty in starting a conversation that can make them aware of the end of their life. As a result, the desire to try all the possibilities in search of a cure for the disease may arise, including non-conventional treatments (healers or medicines and treatments with the promise of a miraculous cure), as was the case with participant 7. In this regard, the literature indicates that the denial about the terminality process indicates a kind of anesthetic against reality that serves to keep a terrible and threatening event at bay, a source of anguish and sadness. Denying death implies avoiding the confrontation with the anxiety caused by the perception of separation. Such behavior can be configured as a maintainer or enhancer of stressful events, as it hinders the adaptive coping of the patient and/or family members to the context considered adverse (Aquino et al., 2017; Silva et al., 2017), and this, in turn, can reduce dignity in the death process.

In the reports of participants 4 and 8, at certain moments, they expressed themselves in an accepting way, demonstrating the certainty of their own death, accepting themselves as finite beings. However, these comments of naturalness and acceptance can reveal an impersonal way of dealing with the disease. Furthermore, this behavior can be an attempt to cover up the suffering and their own dying (Silva et al., 2017).

Another factor that can help the patient's terminal process with dignity is respect for their autonomy, as reported by participant 6. In this regard, it is understood that the patient should be considered as the subject and protagonist of their own history and destiny and that their wishes should be respected whenever possible. Thus, in the concept of bioethics, during the final stage of life, the patient's autonomy must be seen as a central and guiding point, a predominant characteristic of orthothanasia. Likewise, the role of health professionals must always be that of conductors and administrators of therapeutic procedures, and not that of determining the fate of their patients (Mabtum & Marchetto, 2015; Polettoet al., 2016).

2. Free Word Association Test (FWAT)

From the FWAT, participants were able to express ideas that referred to the meaning of ‘Cancer’ and ‘Death’. Tables 4 and 5 show the structure and organization of the content that emerged from the participants' statements.

Table 4. Free Word Association Test (FWAT) for the word ‘cancer’

Ideas represented by ‘cancer’	
Partic.	**Ideas evoked by participants**
1	*“I'll be fine. Very cruel disease. Everything comes to mind. Pain in the pit of my stomach. Pain in my hips. So many things. I think I’m going to die".*
2	*“Nothing crosses my mind. I only think about the treatment”.*
3	*“Disgust. Sadness. I feel so much. Too much pain. I wonder why this happened to me.”*
4	*“A democratic disease. The word democratic says it all. Anyone can catch it. There is no cure. There is no miracle”.*
5	*“Sadness in life. Having God, everything will continue. I’m happy to have my wife by my side”.*
6	*"I don’t know what to say. I'm afraid. Tiredness. A lot of shortness of breath”.*
7	*"Treatment. Family. Seeing death up close. Becoming incapable. I don't see it as an end. I see it differently”.*
8	There was no declaration.
9	*“Very little goes through my mind. I’ve always clung to God. I put it in God's hands. May the Lord let me live until my day comes. Every one has their day .*

10	*“I was very shaken when I found out about the disease. It was horrible. I was shocked. Someone in my family has already had cancer. I believe in healing and medicine”.*

Source: The authors.

Table 5. Free Word Association Test (FWAT) for the word ‘death’

Ideas represented by ‘death’.	
Partic.	**Ideas evoked by participants**
1	*“Don’t even say that. I’m scared. I see my eyes popping out. What gives strength is God, it’s Jesus”.*
2	*“Something that there is in the world. Everyone will die. I don't think about it. I'm not afraid to die. Everyone was born to die”.*
3	*"That’s the way. It's God's will. I wonder how my family will be. I think about the people who will miss me. I think about God. Who thinksit'sgoodto die?”.*
4	*“I feel peace. Quiet. I feel good. Acceptance. Waiting for my moment”.*
5	*“I'm not afraid and neither is my wife. I have God. I have no problem here on Earth”.*
6	*"I'm not afraid to die. Sooner or later everyone will go through this. Many people are cured of cancer. I'm not afraid of death”.*
7	*"It’s not the end. The end is to stay vegetating. I rest. God will take you to the next place”.*
8	*“Everything I'm suffering here I will take through to death. Meet with God. I'm not afraid to die. I feel for the people I'm going to leave suffering here”.*
9	*“Separation from the family. I'm not afraid of death. I’m trying to get used to when the time comes. What hurts me most is knowing that I'm going to be separated from the Family”.*
10	*“I don't think about death. God is with me. I have to trust God. People are never prepared to die. If God wants to take me then I can do nothing. He knowseverything”.*

Source: The authors.

The content was categorized and the frequencies (*f*) of evoked responses were counted. It was found that the participants evoked statements about the disease and its treatment which were marked by suffering such as pain, fear, fatigue and sadness (Individuals 1, 3, 5 and 6; *f* = 4). The duality between hope about a cure (Individuals 1, 6, 7 and 10; *f* = 4) and the certainty of non-cure (Individual 4; *f* = 1) were also presented. Consequently, in the expressions about death, contrasting ideas emerged among those who ‘do not fear death’ or ‘are not afraid of dying’ (Individuals 2, 5, 6, 8 and 9; *f* = 5), those who ‘see with neutrality and/or acceptance of death’ (Individual 4; *f* = 1) and those who ‘do not naturalize it’ (Individuals 1 and 10; *f* = 2).

These evocations corroborate the field diary data presented in category 3 (The terminality process: the relationship with death and the desire for autonomy), which highlights the varied perceptions and feelings about the context of death and the health-illness process. In the study by Poletto et al. (2016) it is shown that death can be perceived and shared among the population as something dreadful, in which most try to ignore or avoid talking about the subject, as well as making efforts in an attempt to deny the mortal condition. In this sense, the authors address the issue of the fear of death being necessary, as it is configured as a manifestation of the instinct of self-preservation, of overcoming destructive instincts. However, psychic damages are enhanced when one lives constantly under the presence of death. From this, it is noted that it is important to closely look at the finite process for the development of an education for and in the face of death. It is possible that this way can favor effective personal resources during life to face the condition of living as finite beings.

Ideas of attachment to faith/religiousness appear as a survival mechanism in the face of incurable disease (Individuals 1, 5, 7, 8, 9 and 10; *f* = 6) demonstrating the field diary data presented in category 2 (Ways of coping: spirituality/religiosity), which emphasizes this form of coping as fundamental and significant in the process of illness and death. In addition, statements emerge about the concern with those who will remain after their death (Individuals 3, 8 and 9; *f* = 3), evidencing the field diary data found in category 1 (Support network: emotional and instrumental support of the family), which refer to the roles and importance of family members in the constitution of the patient, being the main individuals affected by a possible separation anxiety due to death.

The data presented in the FWAT corroborate the records of the Field Diary, and show how the participants live with the suffering related to cancer treatment, expressing their weaknesses and difficulties. The psychological aspects, when associated with this disease, are intensely affected, resulting in different feelings at different intensities, which include: fear, doubt, anguish, anxiety, tiredness, and sadness, among others. These are all symptoms that affect one's quality of life, and social, family and work relationships, due to the lack of care (Vassbakk-Brovold et al., 2018).

Final considerations

Talking about death and the process of dying for terminally ill patients is not easy, especially in today's society, in which there is little clarification of the problematizations in regard to this theme and which still shows enormous fragility with regard to the awareness of finitude. These characteristics mean that most individuals have difficulties in dealing with death, making it infeasible or limiting, in some cases, the practices of orthothanasia and palliative care.

The results obtained demonstrate that, throughout treatment, patients use strategies to cope with daily losses and the disease, and these are sometimes used to deny reality and reject the disease. There is the use of spirituality, as a device for coping with pain and fear, as well as for denial, through which healing is expected through a miraculous solution. Some participants said they were not afraid of dying, however, they had difficulties in accepting and dealing with their own death.

The results also pointed to the significant role of the family in the illness-death process, in that they are active care agents. The need for their attention to balance care actions was perceived, in order to avoid family work overload and the patient's feeling of uselessness. Thus, it is remembered that the patient is the protagonist of their story and that the family has a double role – care agents and subjects to be cared for. In addition, concern was noted from patients who had individuals who would remain after their death.

In regard to the limitations of the research, the small number of participants should be considered and the unique profile of patients with low socioeconomic status and assisted by SUS (the national health service); the realization of cross-sectional data collection, with it not being possible to carry out a longitudinal research, due to the early death of patients as well as those that moved to another city; and not using a recorder. Therefore, it is suggested to carry out other studies, with varied samples, including patients from private health services; and the use of diverse methods and techniques, such as surveys and longitudinal studies.

As a contribution to scientific production, the relevance of the theme is highlighted in the sense that it proposes as the focus of the research the individual in the process of approaching terminality, as well as the approach of the theme through different research instruments, in relation to what is found in the scientific literature. Furthermore, the reflections addressed in this study found a voice in current discussions about dignified death and orthothanasia. Therefore, it is essential to expand the knowledge of ideas and conceptions about death and dying, so that this process can be seen as something that belongs to the natural process of the life cycle.

It is hoped that this research will contribute to promote the investment of public policies to train professionals and educate the population about the themes that permeate orthothanasia and palliative care. Only from an education about death can the essence around the dignity and quality of death for cancer patients undergoing the terminal process be reinforced.

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