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The Private Cemetery: Healthcare Professionals and Death of Patients in Palliative Care

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ABSTRACT

Palliative Care (PC) is an approach to health that promotes quality of life, prevention and relief of suffering. It sees the patients as holistic beings and seeks to provide them a dignified death. However, death remains strange to humanity, especially to health professionals, due to, among other factors, death's hospitalization and intellectualization. This vision invaded the health system, educational institutions and family nuclei. Health professionals are at high risk for depression and suicide due to emotional exhaustion and, therefore, this article aims to discuss their coping with death and dying. A qualitative and descriptive research was conducted, and the thematic analysis was carried out according to the principles of dialectical hermeneutics, in a capital of Northeast Brazil, with a multidisciplinary Palliative Care team. Good communication between the team and the family, decrepitude of the elderly patient, and the opportunity to assist in closing patients' life issues were associated with the best coping with death among professionals. The preparation time for death, when artificially and disproportionately prolonged, did not lessen the trauma of dying. Because Palliative Care aims to avoid these circumstances, the team reported to deal better with death at work after its implementation within the institution. Despite this, there was an inaccuracy regarding the concept of good death, highlighting the deficit of academic training of the team in the area. It is concluded, then, that Palliative Care alleviated the process of dying through the resignification of the end of life.

INTRODUCTION

The purpose of this article is to discuss the meanings of death and the process of dying for a multidisciplinary team in a Palliative Care (PC) service. We used the expression "the private cemetery" as the title of the article in order to summarize the question of this study: how do professionals face death and dying in their daily palliative care assistance?

We understand that work in the field of PC requires some practices and experiences and brings psychological, spiritual and existential issues that not every professional has the aptitude to deal with. Coping with this problem – the ability to experience so many losses and deaths, real and symbolic – finds metaphorical representation in the private cemetery of each professional, and it is up to each one to experience and symbolize these losses.

Palliative Care was developed from the 1960s onwards and its concept has been built and revised since then[1]. In 2017, the World Health Organization defined it as:

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO, 2017).

In 2019, the International Association for Hospice & Palliative Care (IAHPC), which already had its own concept of Palliative Care, made an update:

"Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers" (IAHPC, 2019).

The philosophy and principals of palliative care aim to avoid all forms of mysthanasia – which, conceptually, is the precocious, preventable and miserable social death, due to the maintenance of poverty, lack of infrastructure and minimum conditions for a dignified life[2].

PC is characterized by avoiding euthanasia – the action of shortening the life of an incurable patient, without pain and suffering – and dysthanasia, or therapeutic obstinacy– the act of extending the patient's life in a disproportionate and artificial way, implying pain and suffering[3].

PC is the method of practicing orthothanasia – or dignified death –, respecting the well-being of all involved – patient, family and team –, guaranteeing dignity and presenting dying as a natural stage of living, without abbreviating nor prolonging it[1].

This assistance requires humanization and acceptance and must include the family in the care process. Its objectives are to promote quality of life, establish good communication between patient, staff and family, resolve doubts, regard for hygiene and comfort and honor bioethical principles - autonomy, beneficence, non-maleficence and justice[1,4].

The Hospice Movement began in the 1960s in England. The Hospice can represent both a philosophy of care and a location. As a philosophy, it emerges as a holistic approach to being, aiming to rescue the essence of care. As a location, the institution receives and cares for patients applying the Hospice philosophy approach[5].

The translation of the term "Hospice" into Latin languages did not find a corresponding word, therefore, the term "Pallium" was chosen, as it alludes to the same meaning of user embracement and protection to human beings. Thus, the term “Palliative Care” emerged.

It is worth mentioning that the integration of PC is indicated as soon as life-threatening disease is diagnosed and it must be provided on a continuous basis, along with the disease-modifying therapies, either for cure or terminality.

This approach comprises three phases. In the first stage, in which there is a greater chance of recovery, the focus is on curative treatment, but PC must also be provided through symptom control and good communication between patient, family and team[6].

Subsequently, in the second stage, with the evolution of the disease to irreversibility/chronicity, curative treatment must be proportional to the demand of the disease while palliative care must be proportional to the patient's quality of life. These first two stages constitute the so-called primary palliative care, and every health professional must practice it[6,7].

In the third stage, or terminal phase, when the disease becomes irreversible and death becomes imminent, treatment is exclusively palliative. The needs of the patient and the family become more complex and, therefore, require the so-called specialized palliative care[7].

The Hospice movement revolves around these holistic health ideals. Cicely Saunders was the great founder of the movement, and dedicated herself to the control of pain and symptoms, based on humanitarian care for terminally ill patients. She brought the concept of total pain, showing that pain is not only physical but interacts with psychological, family, social and spiritual dimensions[8]. The movement also arrived in the United States in the 1960s and after the 2000s in Brazil and has become an assistance practice worldwide[9].

The introduction of these new concepts made the health team see the terminal patient from another perspective[8]. The patient was no longer just an incurable disease, but a total being, with dreams, fears, anxieties, purposes, family and friends. Principles such as promoting quality of life, humanization and user embracement were increasingly highlighted, and this new way of caring required almost revolutionary changes in the conduct and training of health professionals and health institutions as places of care[10].

Ariès[11] (p. 6), European, Western and Christian medievalist historian, while analyzing the period between the 5th and 18th century, affirmed that the common death was the one that “did not treacherously seize the person” and “gave time to be perceived” – in contrast to the sudden death, seen as divine punishment. The common death of the old days, on which Ariès discourses, is the procedural death of nowadays.

The author[11] reinforces how this form of dying - common procedural death - led the patient to resolve pending issues and complete unfinished tasks, as he felt that his life span was ending. People died admitting death in a more passive and peaceful way.

The division of property among the heirs was prepared in advance; forgiveness was requested and companions were forgiven, recommending them to God in prayer; through letters, loved ones and distant colleagues were asked to visit the tombs; the burial place was carefully chosen[11].

Death presented itself as more present in everyday life, producing a hiatus of preparation and goodbyes to slowly start the process of definitive removal. People died in a naturalized way, like someone who moved from one plane to another, equally predictable[11].

However, “death management” grew and became more complex, through the technical advances of medicine, especially in the 20th century. This situation brought the patient into hospital institutions, socially hiding death, which became regulated, disciplined, routinized and rationalized[11].

The patient began to die silently, hygienically and in a hidden way, in a hospital environment and in the midst of heavy loneliness. No longer at home, among family members, but moved to the hospital, surrounded by machines[12].

Death, previously a public event, was made private, becoming secretive and even pornographic, bringing with it modesty for exposure and debate, similar to the morally forbidden discussion about sex in the Victorian era. Today's urban and industrialized society fakes a life without death[11,13].

According to Foucault, the hospital has undergone changes since the 17th century, ceasing to be a place to die– where the “dangerous people” of society were interned, in order to have their souls expiated – to become a therapeutic institution, of intervention in the sick and in the illness, with the purpose of saving lives:

“Discipline is the set of techniques by which power systems will target and result individuals in their uniqueness. It is the power of individualization that has the exam as a fundamental instrument. The exam is permanent, classificatory surveillance, which allows individuals to be distributed, judged, measured, located and, therefore, used to the maximum […], it is the introduction of disciplinary mechanisms in the confusing space of the hospital that will enable its medicalization” (Foucault, 2014, p. 107).

With the practice of intervening in the disease through medical diagnosis and drug intervention, the medical professional ascends as responsible for the institution, becoming, then, a*thanatolytic* being (from the Greek *tanatos* – death –, and *litis* – destruction), the death fighter and the holder of bodies and life[15,16].

With the increased demand for knowledge, aiming at the domain over death, the hospital also becomes “a documentary field […], of record, accumulation and formation of knowledge”[14] (p.

188). The death of the manipulated body becomes an intellectualized, logical and reductionist discourse, devoid of symbolism[17,18].

By becoming rational, death no longer requires discussion of its emotional, social and spiritual aspects. Western European societies - or societies influenced by them - have drawn up a pact of silence on death, in which the patient, family and team decide to remain in silent communication to camouflage pains that, although avoided, continue to produce anguish, fear of the unknown and of the unacceptable truth of death[19,20].

This culture of hospitalized death has spanned decades of modernity. In Brazil, an individualistic death system is shared, with a mentality averse to aging and terminality, adhering to the motto of keeping the patient alive at any cost[12].

This simplified conception covered a complex and profound problem, invading the health system, educational institutions and family nuclei[21]. A scenario was built in which patients die painfully as mysthanasic and dysthanasic, and where health professionals do not receive professional training to take care of death and dying[19].

These difficulties contribute to a distant and confused experience of the death process, for patients, family members and professionals themselves, culminating in a poorly elaborated and frustrated mourning[22].

This problem has been in evidence now with the advent of death from Coronavirus 2019 disease (COVID-19), death par excellence surrounded by machinery and loneliness. Thousands of people have progressed to death with pain, anxiety, respiratory stress, fear and isolated from the family[23,24].

It adds to the loneliness more discomfort and grief to the patient in the difficult and complex moment of the end of life in an intensive care unit, affecting their health – physical, psychological, social and spiritual. It is worth mentioning that the distance from affective relationships increases anxiety and overloads the family's stress, which may reflect on a terrible relationship between companions, medical staff and health institution[25,26].

Health professionals often face death for the first time in anatomy classes. Death produces knowledge, both in the dying process - with clinical signs and symptoms, where patients are subjected to learning experiences - and in the dead body, devitalized and fragmented into pieces. It is death without identity and without history[16].

There are no instruments capable of offering emotional and spiritual support to manage the anguish that is instilled in the individual when brutally faced with the finitude of bodies and life. Trained for the purpose of saving lives, professionals see the forgotten bed of the hospital, with the presence of a person, just as they once saw the cold marble table of the anatomy lab[27].

Anguish of death begins at graduation, shaped by the cold and fragmented bodies of anatomy classes, collaborating in the construction of the idea of death as something dark and heavy, which needs to be hardily fought by professionals[19].

The marks of this combat in the professional routine are painful and can lead to an intolerable emotional overload and burnout crises. This results in a defensive professional insensitivity, which robotizes the relationships and builds a poorly elaborated "professional mourning[28].

The current model of health schools is technical, scientific, business and commercial. This inadequate training of professionals concerning understanding the totality of the human being can lead to a harmful approach to both the family and patient, in which the pain and suffering of the other are not welcomed. The health system, then, becomes flawed, because the professional training was also deficient[29]. Thus, everything indicates that it is necessary to revise the curriculum of undergraduate health courses in Brazil, in order to include subjects on thanatology, palliative care and spirituality.

Kübler-Ross[30], a Swiss psychiatrist, analyzes how the frankness and communicative availability of the health team promote strong ties to the patient-family-professional triad, facilitating the entire process of death.

The author also develops the "theory of the psychological stages of grief", in which she explains that when the patient is aware of the inevitability of their death, they will experience denial; anger or revolt; negotiation or bargaining; depression; and, finally, the acceptance of finitude[30].

In palliative care, it is only possible to die dignifiedly through the acceptance of death and, for this, communication is fundamental, the type of communication that rational and intellectualized death seems to deny and to distance[10,17].

The concepts of PC have traveled the world and generations, raising proposals for a better management of the dying process. However, finitude still remains a strange and difficult phenomenon to face for many professionals, although it is part of every hospital routine[31].

Studies[19,32,33] have exposed that many professionals that deal with terminality are unaware of therapeutic communication, usually avoiding quality verbal and non-verbal contact, besides not evaluating themselves as able to promote adequate emotional support to the patient and family.

It is also known that health workers are a population at high risk for anxiety, depression and suicide due to the emotional exhaustion of their daily work[29,34]. Worldwide, it is estimated that approximately 20 million people die annually without adequate assistance to minimize the suffering and symptoms of their disease[35].

Not to debate death is to empower it to the limit and transform it into something scary. This avoided debate exposes the difficulties of health professionals in addressing the issue with regard to the patient, the family and even themselves[36].

MATERIALS AND METHODS

Qualitative and descriptive research with thematic analysis for the treatment of empirical data, utilizing the dialectic hermeneutics methodology to critically understand the context of the object of study[37], namely, the experience of the health professional regarding death and dying of terminal patients in palliative care.

Hermeneutics, as the science of interpretation of written texts, was the tool for analyzing the interviewees' statements, as well as the facts and reflections explained by them. Dialectics, assisting in the search for oppositions and contradictions of ideas, sometimes between the lines of the discourse, discussed the environment, culture, language and individuality, as pillars of critical analysis of an individual's text in the midst of its context[38].

The study was carried out in the capital of the state of Maranhão, therefore, in the Brazilian Northeast, also a component of the legal Amazon region. The data were collected in a municipal public hospital of urgency and emergency, exclusive to the Unified Health System (SUS), from May to July 2019.

The research subjects were professionals from the multidisciplinary health team of the Clinical Medicine (CM) ward of the study site, which provided Palliative Care services from January 2017 to July 2019. The service was interrupted due to the dismissal of the palliative medical professional responsible for the team.

As inclusion criteria, the health professional should have a medium, technical or higher educational level; should have been on the team for at least six months; and should deal directly with death at work. The professionals being on vacation or leave during the research period were exclusion criteria.

Mid-level professionals such as stretcher bearers were included in the sample because they are part of the health team, having important roles in the work group. Furthermore, diversification social, economic and professional proved to be important for the construction of this sample, as it broadens the context of the interviewees[39].

The decision to end the interviews was based on the thematic recurrence criterion, with the finding of the absence of new ideas[37]. The sample was ended with 21 interviews with duration varying from twenty minutes to one hour, allowing us to cover the entire problem investigated in its multiple dimensions[39].

Although the sample is small, there is a wealth of information. According to Fusch and Ness[40] (p. 1411), “volume is a quantity of data; wealth means intricate, detailed, nuanced layers [...]. We can have great wealth from little data”.

The instruments for data collection were a socio demographic data questionnaire and a semi-structured interview script. The interviews were recorded, and later were *ipsi litteris* transcribed for proper categorization and analysis. After transcription, thematic content analysis was performed.

Following Minayo's guidelines[37], the analysis of the thematic content analysis was conducted in three stages. The pre-analysis consisted in the choice of documents to be analyzed, in the resumption of hypotheses and research objectives reformulating them in relation to the collected material, and in the development of indicators to guide the final interpretation. The exploration of the material – or coding was characterized by the transformation of raw data into interpretable elements, aiming to reach the core of understanding the text.

Finally, the treatment of the results obtained or interpretation was based on the proposition of inferences and on the performance of interpretations provided for in the theoretical framework. It should be noted, however, that the thematic content analysis transcends the technicality of the process, as it encompasses a historical, theoretical-practical investigation within the scope of social research[38].

This research was approved by the Ethics Committee in Research with Human Beings of the CEUMA University through Consubstantiate Opinion nº 3.354.146 on May 29, 2019, with Certificate of Presentation for Ethical Appreciation nº 12701019.3.0000.5084.

RESULT AND DISCUSSION

The sample consisted of 18 women and 3 men; 16 individuals aged between 35 and 50 years and 5, between 25 and 43; 11 declared themselves married or in a stable relationship and 10 reported being single or divorced; 16 respondents had postgraduate degrees, 4 had technical specialization and 1 had completed high school.

Within the sample, the duration of the academic education proved to be quite variable, with 7 people with academic education between 2 and 5 years, and another 7 between 11 and 15 years; 20 people called themselves Christians among Catholicism, Protestantism and Spiritism and 1 had no defined religion. The sample consisted of 5 doctors, 4 nurses, 5 physiotherapists, 2 speech therapists, 4 nursing technicians and 1 stretcher bearer.

Thematic analysis of the data led to the establishment of 5 major categories, namely: experience at work, experience with palliative care, relationship with family, points to be improved and vision of how to build a good death. Throughout the analysis, three categories were elaborated, which will be presented below: acceptance of finitude, patient care and good death.

Acceptance of finitude: the death

Professional motivation is what gives purpose and satisfaction to the professional when performing their work on a daily basis. Part of the research subjects reported having such satisfaction through the feeling of usefulness when seeing good results, that is, when they witnessed the clinical improvement of palliative patients and/or the recovery of patients in general. Tied to this thought, they also mentioned feeling satisfied when they were recognized by the patient's family through positive feedback.

“It’s the return that we have the improvement of the patient, praise from the family that arrives and thanks us, even if the goals were not reached, which are discharge and going home.” (7)

When experiencing the clinical improvement or recovery of the patient, professionals report feelings of usefulness and are happy to know that they played a part in this improvement, on a certain level. The end of the hospital passage that is, the patient's recovery becomes the most important thing to them, also because family's recognition often accompanies such cure.

Interviewee 7 explains that his objective, as a professional, is to discharge patients and send them home. However, when this does not occur, feelings of failure and loss can be instilled much more easily in the professional, who “did not reach” their goal. Feelings of inability can emerge, building obstacles to accepting finitude[41,42].

On the other hand, other professionals registered that their motivations lie in good assistance, in communication and in creating bonds – both with the patient and family. In this way, they place their professional satisfaction in the gentle relationship of everyday life.

“[I feel motivated because] in the face of all the difficulties we have, we are able to provide humanized care, (...) provide individualized assistance, (...) establish a favorable doctor-patient relationship.” (1)

As opposed to what is presented by Interviewee 7, other professionals deposit their motivations in the assistance and in the bonds created, therefore, in the process of hospital passage. The patient's clinical improvement or recovery remains important, but their journey through the health-disease process is also important.

In that sense, literature[32] also demonstrates how finitude becomes more digestible when, even if the patient progresses to death, the professional is convinced that they walked comfortably to it.

With regard to personal experiences, most of the interviewees experienced death of a close person, whether procedural that is, perceived in advance or not. All those who ~~a~~ endured sudden (or non-procedural) death claimed it to have been a traumatic experience, and the main reason was the lack of time to prepare and properly say goodbye.

“[When] you discover that the person is sick, you have time (...) to take care, to share your love, to live together, to interact. With my brother, I didn’t have that chance... to accept the loss... ” (4)

On this “non-preparation”, Ariès[11] (p. 12) writes how sudden death or *mors repentina* “broke the world order”. Centuries ago, it was seen as the manifestation of divine punishment, and was therefore "infamous and shameful".

Among the interviewees who experienced a procedural death of a close person, the reports were divergent, some experiencing a traumatic process, others experiencing a healthier one. The latter reported confidence during the process, as there was good communication between patient-family-team, and eventual consensus on important points of care, such as non-referral to the intensive care unit and priority of pain relief.

These professionals, that were included in the decision-making while playing the role of family when accompanying their loved ones, felt heard and with no remaining doubts, minimizing feelings of anxiety and uncertainty.

“While maintaining a minimum quality of life and preserving daily habits, we invested in treatment (...), until we arrived at a certain moment where we stayed with my mother (...) at home, with the family. (...) Here comes the trust part. (...) There was nothing more to be done, just... to preserve from pain.” (20)

Those who demonstrated some type of difficulty referred as a major disturbance the team's lack of communication and the patient's distance, which, for the most part, was in an isolated ICU bed. Consequently, emotions of despair and stress emerged, resulting in a frustrated and conflictual goodbye.

"(...) If they had said from the beginning: 'look, she will not evolve well', (...) it would have been totally different. I would have been able to talk to my family, prepare them. No! No one, including me, knew what to do." (2)

"(...) That feeling, that anguish remains. I don't know if it's that feeling of failure. (...) Could it be that I couldn't have done anything else? (...) My father died here [name of the institution] and I was left with that feeling. I blocked it. I don't go into the yellow [wing]... " (3)

Interviewee 2's description of the events, interspersed with silence and uncertainty, shows how communication is fundamental to the process of good death. Kübler-Ross[30] argues that the intentions of this silence are generally of protection to those who "could not bear" receiving the news, causing professionals to hide their inner anguish behind smiles and gestures of happiness. For them, to maintain the illusion that "everything will be fine" is an act of love for the patient and family, even if important information is omitted.

In Kalish's tale[44], "The Horse on the Dining-Room Table", friends invited a young man to have dinner at their home. There, he comes across a big horse sitting at the table, along with all the other guests. Everyone noticed the horse and was uncomfortable; however, nobody mentioned it. At the end of the story, the reader understands that the horse represents death and, therefore, no one dared to name it.

The cases of Interviewees 2 and 3 may demonstrate that it is not merely the extra time with the patient that determines the best coping with death. The way in which the terminality process occurs also does. If gradual dismissal were the only foundation, procedural deaths as a whole would be less traumatic.

In fact, procedural death can prove to be even more traumatic than sudden death, depending on the case. Interviewee 3, for example, for a long time felt unable to enter the hospital wing in which her father had experienced a procedural death.

In that way, being able to resolve life-pending issues proved to be the most important factor in accepting finitude. This healthy way of ending life cycles is less likely to occur in a sudden death or in a procedural death with pain, suffering and no communication. Interviewee 2 was not even aware that she needed to prepare for something, as she did not know the real state of health of her relative.

On the other hand, the individuals who reported good experiences of death were able to achieve, along with their family members, the objective of closing pending issues. Both patient and family were confident, well informed and supported in a holistic process. It is worth mentioning that all the good death experiences reported in the research had palliative care instituted.

Ariès[11], when talking about the common procedural death, which sought to remedy pending matters, gives the example of the friar of São Paulo de Narbona. Upon having the premonition of his own death, he made his will among the monks, confessed and went to church in order to receive the *corpus domini*, dying shortly thereafter.

With regard to the interviewees' professional experience, it was identified that the acceptance of finitude and coping with death change depending on three variables, namely: length of professional experience, kinship and age.

Many interviewees referred feelings of sadness, incapacity and insecurity at the beginning of their careers, claiming that they did not know how to deal with death and that they could not abandon these emotions, even when out of the work environment. They were permanently concerned with the condition of the patients, bringing emotional overload and a lot of stress.

Over time, however, they reported that as they gained experience, the day-to-day relationship with death changed. This variable, length of professional experience, presented two opposite paths for coping with dying: either the professional moved further away from the patient, or became closer to them.

Professionals who move away, creating less bonds, become colder in professional relationships and less sensitive to the deepest needs of the patient. Because these professionals are not aware of the patients' pending life, they deal better with their death, as they are in a kind of "blessed ignorance".

"I don't create [a bond]. It's just professional because if we do, we don't work well. We actually become like a robot". (18)

Kovács states that this occurs due to a superhuman emotional weight, from which professionals strive to escape. In order to bear the anguish, they elaborate a logical-rational discourse for existential questions, resulting in a less intense and less emotional action in the professional-patient relationship.

On the other hand, professionals who approach the patients deeply understanding them, providing death with peace and quality of life, and helping them to end a cycle also seem to be able to deal with the death of patients, since they knew their pending issues and helped to remedy them.

“I face it [patients’ death] with the feeling that I offered the best I could, I respected the patient's limits and in the end... I feel like I have done my job because I have provided what I can.” (17)

In the process of accepting their terminality, patients have the opportunity to take their mortality as real and to create renewed views of the world[46]. Death is the last stage of human development, the final stage of growth, and it is there that patients build their own mourning and reshape their existence in the last days[5,45].

This study showed us that professionals manage to conceive a healthier mourning for themselves by helping PC patients to do their own, solving pending issues, finishing tasks and tying the forgotten loose ends during life.

Another impacting variable was the level of kinship with the patient. Some professionals brought a contradictory view on death and dying between patients from work and patients from family.

In their perspective, patients from work should preferably die more quickly, with the justification being that this way, they “would feel less pain and suffering”. On the other hand, patients who are also family members of the professionals should go through the death process more slowly, since they would have time to “remedy their pending issues”.

There are indications of professionals’ difficulty in managing their own suffering in these cases. There is a contradictory wish that patients from work have a non-prolonged death, while their loved ones prolong their lives. The solution is the following: that the relatives of others die quickly and mine die slowly. Such conflict is seen in Interview 9:

“It makes me very upset when I see a death like that… of the patient… when there is no prospect of dying quickly...” (9)

“My family has a very big problem: they die suddenly. (...) Because sometimes you don't do what you have to do when you're alive. (...) We need that person, so the more you stay with him, the better.” (9)

The last variable was the patients’ age and how this alters the feeling about death. There was a greater acceptance of death of elderly people, since this would be the “natural cycle of life”. The elderly already “have lived long enough”, “had their opportunities”, “produced”, “had children”, and “now it's time to rest”. In these cases, feelings of relief, rest and conformity prevail, unlike youthful death, which regains feelings of failure, sadness and helplessness.

“(...) the elderly we understand better, we accept better. They have lived long enough and need to rest. As for a young person, we think "wow, but they’re so young”... the sign of impotence.” (4)

Kovács[48] says that situations of youthfulness can mark professionals. Other authors[22,41,49] have also attested that there is greater tranquility and acceptance when death occurs in older ages. It appears that, once again, it is not finitude *per se* that is accepted, but the end of human decrepitude.

One interviewee (15) brought up the concept of a private cemetery. She explains that health professionals have their own private cemetery of deaths and losses of patients and it is up to each one to choose how to deal with it. She recalls, with satisfaction, the good care provided to these patients.

“When I started in medicine, I heard a saying that every medical professional has their own private cemetery. (...) All professionals who work in the health field, including the janitor who cleans the blood, have. (..) My cemetery is big. (...) I have smiles, beautiful goodbyes...”(15)

Patient care: the dead

The technical competence and the team's relationship with patients and family are the main factors that determine the quality level of patient care. Interviewees expressed that they feel the team needs further study and strengthening of humanization, despite being a reliable team in its entirety.

Only two respondents have formal education on Palliative Care. All the other research subjects got into this service without prior preparation. Similarly, in the study by Bifulco and Iochida[50], 93.3% of their respondents said there was a lack of training on death and, when studied, it was presented to them as a lonely and cold period.

As for the full palliative patient, the interviewees claimed that the view of care changes in this situation. Professionals reported giving priority to patients' comfort and analgesia, performing fewer procedures and administering pain medication, which had its use increased after the institution of Palliative Care. Regarding resuscitation, they pointed out that the order of non-resuscitation is often necessary and that they can understand its prescription.

"What I was going to do was going to make her uncomfortable, so I didn't have to. She was terminally ill, she had priorities for certain procedures and mine wouldn't fit at that time. It was only going to make her suffer even more." (12)

It is possible to think that the vast majority of respondents recognize dysthanasia and strive to avoid it – although no respondent has used the specific term. The team conducts the death process in order to avoid measures that will not bring any benefit, as those may even accelerate it.

In addition, these measures can frustrate patients, family and the team itself, by generating expectations of clinical improvement that will not be achieved due to the patients' organic status and their limitations to endure or respond to treatment[51].

With regard to relationships and emotions, we observed ideas of including the family, managing emotional symptoms, developing communication (verbal and non-verbal) and establishing bonds, in addition to fulfilling desires – such as tasting coffee or dying at home.

"You know that you gave some pleasure. We know that coffee is not going to feed, but it is about the quality of life, the patient being happy, feeling pleasure." (5)

“He passed away less than 7 days later... but at least it was a dignified death for him, his desire was to go home since the day he had arrived.” (13)

Kindness in relationships was a recurring theme in the interviews. “Listening”, “respecting”, “embracing” and “giving comfort” were frequent terms. Professionals feel happy and satisfied by providing comfort, pleasure and tranquility.

“[The patient's mother] said: ‘I know you liked my son’... a loving look that we give to that family, the relatives gets attached to us. We become kind of a connection inside that hospital.” (5)

Fernandes *et al* affirm: “Good communication between professional and patient can promote effective assistance, facilitate the assistance provided and minimize fears and anxieties caused by terminal illness” (p. 2594). Communication is essential for establishing a relationship based on trust, in which patient, family and professional can be sincere with each other, solving any doubts that may arise during the process.

Studies[15,19,32] have shown that, when dealing with terminally ill patients, non-verbal communication is crucial, because it values the emotions of patients and family. It also creates stronger and clearer bonds, providing an understanding of the expressions and symbolic language during the end of life.

However, there was a case of negligence. In Interviewee 14's report, a patient died without care, lonely and in agony, which could have been avoided. Even with the previously reported good communication and assistance, mysthanasic cases can still occur.

“He got sick in the ward, so I called the nurse, but she was very busy, and it took a long time for her to support the boy and he ended up dying. (...) What I had to do, I did... But for the doctor, I can't do it. When the nurse got there, it was too late. This one marked me, I even cried. It was like neglect.” (14)

Palliative Care aims to promote good quality of life for patients, however, in this hospital experience, it was also seen as a means of saving resources. Thus, there is a risk that PC ends up becoming a justifying tool “to not do anything for the patients”. Such conception is a mistake, since the palliative patient must continue to receive treatment for treatable causes.

To deprive palliative patients of attention is to promote miserability in their death, in other words, mysthanasia. In PC, there is a principle of avoiding unnecessary procedures; however, there is also the principle of in-depth holistic monitoring. Only two professionals talked about the dichotomy between “being palliative” and “doing nothing”, emphasizing Interviewee 21:

“We needed an ICU bed, ‘no, she is palliative, with a brain tumor’, ‘no, guys, the patient aren’t treating the brain tumor, she is neurosequeled, but now she is treating pneumonia’. There are people who want to palliate everyone! They don't want to cure no one more! ” (21)

While learning how to heal – in the biomedical curricular model –professionals make use of the “there is nothing left to do” weapon when healing is not possible[27]. The lack of resources and poor condition of the work environment is also revealed a justification for interrupting attention to terminal patients[15].

This lack of harmony between the healthcare sectors stems from a culture that lacks co-responsibility and shared care, implying contradictory decisions between institutions, sectors and employees[54]. Added to this, the majority of hospitals in Brazil do not have guidelines or protocols for terminally ill patients, nor systematic data about care for such patients and their families[2].

The implementation of PC in the hospital institution brought, primarily, the purpose of avoiding such mysthanasias and achieving orthothanasia. Such practice is a fundamental instrument to transmit that dying can be contemplated from a different perspective and be managed in a healthier way.

Despite the negligence, there was a paradigm shift in relation to death and dying, patients and family and what is necessary or expendable (Interviewee 6). Even medical conduct has changed and the multidisciplinary team has understood it (Interviewee 3).

“(...) It’s a very great elucidation, which came as a light in our life [team]. (...) In the past it was an obscure thing, which we saw only as loss, only as pain but not today, (...) people pass away without pain and in peace.” (6)

“(...) Today I see the patients' side... they have suffered so much... when they say that the patient will not be resuscitated it is because they are no longer able, really.” (3)

In the study by Oliveira et al[49] on the perception of death and dying of professionals at a long-term care facility for the elderly, it was revealed that the lack of knowledge about death is one of the main influencing aspects on how professionals are going to cope with it. It points to the fact that, if there is adequate knowledge, there is a better confrontation of finitude.

Palliative Care, according to our interviewees, instigated a change of vision in care, teaching professionals to face the death process in a healthier way, making them more prepared to assist patients.

The perception of the professional as a contributor in the health-disease process, even when death is imminent, became recurrent, as well as the exclusively oncological view of PC lost its emphasis. The understanding of the terminal patients' needs also became more individualized, bringing the awareness that patients' comfort and autonomy are more important than professionals' will.

“(...) [It is important to] know how to improve their [patients] quality of life (...) and stop thinking about what you want for them, but what they want for themselves. (...) Realize that the important thing is not what you think, but, with your knowledge, see what they can do.” (5)

In the study by Bifulco and Iochida[50], PC also influenced the personal and professional lives of health workers at the studied institution. The authors highlighted the fact that PC has directed professionals to look for the best treatment possible for other patients– and not only palliative ones –, expanding their professional performance and making them better human beings, even when the focus was not on caring or working in the specific area.

Adjustments in the interviewees' personal lives were also reported, such as the transformation of the “way of seeing and living life”, the emerging desire to carry out their Anticipated Directives of Will and conversations with family and friends in order to prepare them and themselves for future death.

Good death: the dying

The majority of respondents said they believed in the existence and possibility of a good death for patients and their family, emphasizing that PC is important to achieve it. On the other hand, there was frequent discussion of the term "good death". Some interviewees claimed to prefer not to use it because they had the concept that such a term is associated with "happy death" and this could be understood as a disregard or disrespect for the family's feelings.

However, a good death is not a festive event, but death that brings the least possible level of trauma, accompanied by comfort, tranquility and companionship[55]. Fewer respondents said they did not believe in the possibility of good death, despite the fact that "some deaths are better than others". According to them, however, the process as a whole will be always unpleasant in the end.

"Because from the moment the patient is in a hospital bed, he is no longer well. (...) It's a lot of suffering. (...) I think, impossible. Nobody wants to die!" (18)

Regarding the concept of good death, four types were identified: holistic, physical-psychological, psychological and physical. Only two medical deponents brought up the holistic concept of good death, that is, with physical, psycho-emotional, social and spiritual management.

"(...) [To provide a good death is to] know how to respect patients' time (...), comforting not only them but also the family, (...) having psychological support, spiritual support, (...) forgiveness, family visit, (...) relief from pain and suffering." (17)

The physical-psychological concept was the most frequent. Almost half of the sample mentioned it. It covers only physical and emotional management, with the tools previously mentioned: pain medication, avoidance of futile procedures, kindness and family inclusion. This concept is not incorrect, but incomplete.

"Respect and try to relieve the pain, (...) so that they feel comfortable. (...) They're suffering; (...) the family is suffering. (...) Relieve not only physical pain but also emotional pain." (19)

The psychological concept was the second most frequent and expresses that a more emotional view of care would achieve a better death. The team should promote kindness and family participation.

“[Good death] for me is being close to my family. Let me get the rest back at home.” (5)

Finally, only one interviewee alluded to a purely physical view, in which comfort can be summed up in not feeling physical pain, through medication and avoidance of unnecessary procedures.

“I’m gonna give him the medicine that relieves that pain, (...) I’m gonna give him that comfort, he won't be suffering. To give comfort is to decrease a little the pain he is feeling.” (8)

The interviewees of Fernandes et al[52] also bring a recurring physical-psychological discourse, inclined to relieve pain and suffering, as well as sharing the experience with family members.

The authors[52] say the following: “there is a tendency among research participants to relate patients' quality of life to the relief of pain and suffering” (p. 2591). This statement reiterates the palliative principles, even though the concept of total pain[8] needs to be constantly remembered since pain is not only a physical perception, but social, emotional and spiritual.

The level of knowledge regarding the concepts demonstrates if the team really understands the essence of PC and good death. It is noticed that the image of “morphine and love” is still common in PC. Due to this incomplete concept, issues such as forgiveness and spirituality were only scarcely mentioned, even though the research sample proved to be religious.

Three interviewees recognized the importance of these factors in the death process as tools to face suffering and death and improve the patients’ clinical condition, by reestablishing bonds and relieving body and soul.

Researches[56,57] emphasize that there should be an integration of religious beliefs of terminally ill patients with their professional caregivers. Thus, in practice, it will be easier to develop a healthy grief.

"The process of accepting death involves much more than accepting death itself. (...) It tells a lot about the experiences you have had in relation to death, your religiosity; what you follow as a religious principle." (1)

"It [forgiveness] restores bonds. He [patient] had a very heavy weight on his conscience in relation to his ex-wife, (...) he was very tearful, and from the moment she came, they talked (...), he asked her for forgiveness, he had an improvement! Because patient care is not just organic, right? He was someone else, he talked, he played, and he was completely different." (17)

Almost a quarter of the interviewees raised the issue of the quality of life, considering it fundamental to the process of good death and being better achieved with the institution of Palliative Care. Some professionals raised the dichotomy between quality of life and life extension.

Life extension is chronological, that is, adding days to patients' life, regardless of how much it would cost to their dignity and peace. Quality of life, on the other hand, means adding life to the years, comfort and calmness in the death process, even if this results in not postponing it. The interviewees were aware that there is a distinction between the terms and this must be taken into account.

"(...) Several chronic patients who died in the ward went on to spend 6, 7, 8 months there. (...) Patients would no longer leave and nothing of value was done to ensure they had quality of life. (...) They had an extension of life but did not have ~~a~~ quality of death. " (5)

CONCLUSION

This study analyzed the perception of palliative care professionals in a public urgency and emergency hospital regarding the terminality of patients and how death process affects their personal and professional scenarios. Palliative practice has shown to have influenced the patient, family and team.

The theoretical framework of Ariès[11] and Kübler-Ross[30] allowed us to carry out an exegesis of current death, supported by eight characteristics. Today, death is prepared, meaning it requires preparation of where and how to occur. It is administered, filed and cleaned. Death is hidden and private in the hospital. It is also displaced from the community experience to the solitude of the hospital bed. Death started to have pornographic outlines, in which dialogue is avoided and debate is shameful.

Death was institutionalized, categorizing the medical professional as responsible for the time of death and the process of dying. It became academic, because the hospital is a permanent place of teaching and learning. Finally, death was intellectualized as a phenomenon without history, identity, devoid of symbolism and becoming logical and rational.

The interviewees saw the patients' illnesses, and not only their diseases, which contributed to the achievement of a good death. The main ways to achieve it were through the relief of pain and suffering, avoiding useless procedures and administering medication, and through psychosocial and spiritual support, with kindness, family inclusion, wish fulfillment and completion of pendencies.

The family was valued as a pillar in the death process and was included in decision-making and in the communicative link, as well as being cared for, at a certain level.

Professionals faced death, including their own, more lightly, looking at themselves as contributors to the healthy closure of life cycles, with the expansion of professional performance and the growth of humanization capacity.

The team seems to provide good assistance, in which the patient and family are heard and cared for. Professionals were empathetic, recognizing and understanding the loneliness of the patient and family, which usually accompanies the death process and was helpful in situations of emergency, difficulty or great complexity.

The acceptance of finitude *per se* was not noticed. The acceptance of death or the end was more usual when there was decrepitude of the elderly person, with failure of biological systems, when compared to the opposite death process.

The preparation time for death did not prove to be a decisive factor in reducing the trauma of dying. If accompanied by pain, suffering and silence, the so-called "preparation time", in fact, does not prepare and does not show itself as a component element of what is called a good death.

The holistic view of good death – physical, psychological, social and spiritual – was rare, the physical-psychological view being more frequent. This may also have been influenced by the fact that most of the interviewees did not have academic theoretical training in palliative care or thanatology.

The training on death in health science majors was deficient, which can result in professionals with difficulties in dealing with death, bearing a painful weight and proving to be poorly qualified to provide quality care to terminal patients.

The curricula of educational institutions would need to be revised, so that death is no longer presented with a reductionist character such as simple loss of vital functions, but with subjectivity and symbolism. It is worth mentioning, however, that the lack of adequate training did not prevent, in this study, the empathy and kindness of professionals.

Brazilian health institutions have very few official terminality protocols and/or guidelines the researched institution included and these would need to be established. Likewise, it is recommended the existence of conversation circles with the exchange of experiences and ideas between professionals who deal with death daily, so that they receive help and support to deal with the anguish that the theme produces.

The lack of guidelines, inputs, labor and health management leads many patients to the end of their lives with miserable deaths, without dignity, in pain, suffering and loneliness. The real and symbolic death of the private cemeteries of health professionals also seems to approach the real losses of concrete physical death.

The artificial and disproportionately prolonged time of incurable patients does not make procedural death less traumatic. The possibility of reframing life's losses and gains, before the end, seems to be the most striking variant for a good death, and for this purpose, the implementation of palliative care will always be essential.

REFERENCES

1. Matsumoto DY. Cuidados paliativos: conceitos, fundamentos e princípios. In: Carvalho RT, Parsons HA, organizadores. *Manual de cuidados paliativos da ANCP*. Rio de Janeiro: Diagraphic; 2012. p. 23-30.

2. Santos Junior JC, Silva JRG, Zaganelli MV. Mistanásia: ineficiência de políticas públicas, violência e vulnerabilidade social. *Interdiscip Sci J.* 2017;4(5):31-48.

3. Barbosa DM, Damasceno DKS, Belo FAS, Carmo HO, Gaudêncio JPR, Santos MN, Lemes NR, Melo CM, Fernandes VLS, Pinheiro IF. Morte, eutanásia, ortotanásia e distanásia: uma revisão bibliográfica. *CIPEEX*. 2018;2:1804-1808.

4. Rodrigues JV. Esferas da responsabilidade: uma revisão dos princípios bioéticos. In: Curado M, Ferreira E, Pereira A, coordenadores. *Vanguardas da responsabilidade:* Direito, Neurociências e Inteligência Artificial. Lisboa: Petrony; 2019. p. 111-136.

5. Ellington L, Cloyes KG, Xu J, Bellury L, Berry PH, Reblin M, Clayton MF. Supporting home hospice family caregivers: insights from different perspectives. *Palliat Support Care.*2018;16(2):209-219.

6. Moritz RD, coordenador. *Cuidados Paliativos no final da vida*. Florianópolis: CRM-SC; 2016.

7. Carvalho RT. Cuidados paliativos – conceitos e princípios. In: Carvalho RT, Souza MRB, Franck EM, Polastrini RTV, Crispim D, Jales SMCP, Barbosa SMM, Torres SHB. *Manual da residência de cuidados paliativos*. Barueri: Manole; 2018.

8. Saunders CF. *Oxford textbook of palliative medicine*. In: Clark D. *Cicely Saunders*: selected writings 1958-2004. New York: Oxford University Press; 2006.

9. Oliveira FFB. *Cuidados paliativos para profissionais de saúde atuantes em oncologia* [dissertation]. Campina Grande: Universidade Estadual da Paraíba; 2018.

10. Shepperd S, Gonçalves-Bradley DC, Straus SE, Wee B. Hospital at home: home-based end-of-life care. *Cochrane Database Syst Rev.*2016;2(2):CD009231.

11. Ariès P. *O homem diante da morte*. São Paulo: Unesp; 2014.

12. Martinez RTO, Conde AFC. Morte na contemporaneidade: a negação do conceito de finitude. *Rev Iniciação Científica Unifamma.* 2019;4(1).

13. Gorer G. *Ni pleurs, ni couronnes*. Paris: Epel; 1965.

14. Foucalt M. *Microfísica do poder.* 28th ed. São Paulo: Paz & Terra; 2014.

15. Machado RS, Lima LAA, Silva GRF, Monteiro CFS, Rocha SS. Finitude e morte na sociedade ocidental: uma reflexão com foco nos profissionais de saúde.*Cul Cuid.*2016;20(45):91-97.

16. Santos MA, Aoki FCOS, Oliveira-Cardoso EA. Significado da morte para médicos frente à situação de terminalidade de pacientes submetidos ao transplante de medula óssea. *Cien Saude Colet.*2013;18(9):2625-2634.

17. Silveira B, Araújo D, Silva DV, Vieira MA, Sampaio C. O cotidiano de profissionais da saúde nos cuidados paliativos: um estudo na fenomenologia social de Alfred Schültz. *Rev Enferm Atual In Derme.* 2020;91(29):73-79.

18. Zimerman DE. *Vocabulário contemporâneo de psicanálise*. Porto Alegre: Artmed; 2008

19. Bastos BR, Fonseca ACG, Pereira AKS, Silva LCS. Formação dos profissionais de saúde na comunicação de más notícias em cuidados paliativos oncológicos. *Rev Bras Cancerol.* 2016;62(3), 263-266.

20. Ismael SMC. A família do paciente em UTI. In: Mello Filho J, Burd M, organizadores. *Doença e família*. São Paulo: Casa do Psicólogo; 2004. p. 251-257.

21. Baldwin PK. Death Cafés: death doulas and family communication. *Behav Sci.* 2017;7(26):1-8.

22. Floriani CA. O fim da vida, o idoso e a construção da boa morte. In: Freitas EV, Py L. *Tratado de geriatria e gerontologia*. 4th ed. Rio de Janeiro: Guanabara Koogan; 2018. p.1342-1351.

23. Hendin A, La Rivière CG, Williscroft DM, O'Connor E, Hughes J, Fischer LM. End-of-life care in the emergency department for the patient imminently dying of a highly transmissible acute respiratory infection (such as COVID-19). *CJEM.* 2020:1-4.

24. Domenico BG, Claudia G, Monika O, Ralf J. COVID-19: decision making and palliative care. *Swiss Med Wkly.*2020;150:w20233.

25. Arya A, Buchman S, Gagnon B, Downar J. Pandemic palliative care: beyond ventilators and saving lives. *CMAJ*. 2020;192(15):E400-E404.
26. Costantini M, Sleeman KE, Peruselli C, Higginson IJ. Response and role of palliative care during the COVID-19 pandemic: a national telephone survey of hospices in Italy. *Palliat Med*. 2020;34(7):889–895.
27. Souza MCS, Sousa JM, Lago DMSK, Borges MS, Ribeiro LM, Guilhem DB. Avaliação do perfil de atitudes acerca da morte: estudo com graduandos da área de saúde. *Texto Context Enferm.*2017;26(4):e3640016.
28. Percival J, Johnson M. End-of-life care in nursing and care homes. *Nurs Times*. 2013;109(1/2):20-22.
29. Silveira ALP, Colleta TCD, Ono HRB, Woitas LR, Soares SH, Andrade VLA, Araújo LA. Síndrome de Burnout: consequências e implicações de uma realidade cada vez mais prevalente na vida dos profissionais de saúde.*Rev Bras Med Trab.*2016;14(3):275-284.
30. Kübler-Ross, E. *Sobre a morte e o morrer*. 10th ed. São Paulo: Martins Fontes; 2017.
31. Chover-Sierra E, Martínez-Sabater A, Lapeña-Moñux Y. Knowledge in palliative care of nursing professionals at a spanish hospital.*Rev Lat Am Enferm.*2017;25:e2847.
32. Oliveira JPM. *De frente com o fim:* os profissionais de cuidados paliativos e o luto [dissertation]. Natal: Universidade Federal do Rio Grande do Norte; 2018.
33. Araújo MMT, Silva MJP. Estratégias de comunicação utilizadas por profissionais de saúde na atenção à pacientes sob cuidados paliativos.*Rev Esc Enferm USP.*2012;46(3):626-632.
34. Oliveira AV, Nascimento EB, Lima RN, Aoyama EA. Suicídio entre os profissionais de saúde. *ReBIS*. 2020;2(4):11-16.
35. Queiroz AHAB, Pontes RJS, Souza AMA, Rodrigues TB. Percepção de familiares e profissionais de saúde sobre os cuidados no final da vida no âmbito da atenção primária à saúde. *Cien Saude Colet*. 2013;18(9):2615-2623.
36. Bez J. A importância de falar sobre o processo de morte e morrer no âmbito coletivo. *Rev Longeviver*. 2019;1(1):44-49.
37. Minayo MCS. *O desafio do conhecimento:* pesquisa qualitativa em saúde. 14th ed. São Paulo: Hucitec; 2014.
38. Minayo MCS. Hermenêutica-dialética como caminho do pensamento social. In: Minayo MCS, Deslandes SF, organizadores. *Caminhos do pensamento*: epistemologia e método. Rio de Janeiro: Fiocruz; 2013.
39. Pires AP. Amostragem e pesquisa qualitativa: ensaio teórico e metodológico. In: Poupart J, Deslauries J, Groulx L, Laperriere A, Meyer R, Pires AP, organizadores. *A pesquisa qualitativa*: enfoques epistemológicos e metodológicos. 4th ed. Petrópolis: Vozes; 2014.
40. Fusch PI, Ness LR. Are we there yet? Data saturation in qualitative research. *Qual Rep*. 2015;20(9):1408-1416.
41. Silva LDM, Resende MC, Andrade RZ. Atitudes de profissionais de saúde em cuidados paliativos sobre a morte e o morrer. *Perspect Psicol*. 2019;23(1):213-235.
42. Carvalho GAFL, Menezes RMP, Enders BC, Teixeira GA, Dantas DNA, Oliveira DRC. Significados atribuídos por profissionais de saúde aos cuidados paliativos no contexto da atenção primária.*Texto Context Enferm.*2018;27(2):e5740016.
43. Tolstói L. Trois morts. *La Revue des Deux Mondes (1829-1971)* 1882;52(4):913-925.
44. Kalish RA. *Death, grief, and caring relationships*. Pacific Grove: Brooks/Cole; 1981.
45. Kovács MJ. *Educação para a morte*: desafio na formação de profissionais de saúde e educação. São Paulo: Casa do Psicólogo; 2003.
46. Rodrigues JD, Machado JMT, Calixto G. Cuidados paliativos: perspectiva singular do olhar humano. In: Doring M, Moretto CF, Diehl AA, organizadores. *Envelhecimento humano:* aspectos populacionais e de saúde na contemporaneidade. Passo Fundo: Editora Universidade de Passo Fundo; 2017.
47. Franco ISMF. *Morte e luto em cuidados paliativos:* vivência de profissionais de saúde [dissertation]. João Pessoa: Universidade Federal da Paraíba; 2019.
48. Kovács MJ. *Morte e desenvolvimento humano*. 5th ed. São Paulo: Casa do Psicólogo; 2008.
49. Oliveira PP, Amaral JG, Viegas SMF, Rodrigues AB. Percepção dos profissionais que atuam numa instituição de longa permanência para idosos sobre a morte e o morrer. *Cien Saude Colet*. 2013;18(9):2635-2644.
50. Bifulco VA, Iochida LC. A formação na graduação dos profissionais de saúde e a educação para o cuidado de pacientes fora de recursos terapêuticos de cura. *Rev Bras Educ Med*2009;33(1):92-100.

51. Neri AL, Batistoni SST, Ribeiro CC. Bem-estar psicológico, saúde e longevidade. In: Freitas EV, Py L. *Tratado de geriatria e gerontologia*. 4th ed. Rio de Janeiro: Guanabara Koogan; 2018. p.1342-51.
52. Fernandes MA, Evangelista CB, Platel ICS, Agra G, Lopes MS, Rodrigues FA. Percepção dos enfermeiros sobre o significado dos cuidados paliativos em paciente com câncer terminal. *Cien Saude Colet.* 2013;18(9):2589-2596.
53. Ferreira S. A mistanásia como prática usual dos governos. *J Cremerj.* 2019 Mar 20; p.6.
54. Tallman K, Greenwald R, Reidenouer A, Pantel L. Living with advanced illness: longitudinal study of pacient, family and caregiver needs. *Perm J.* 2012;16(3):28-35.
55. Cano CWA, Silva ALC, Barboza AF, Bazzo BF, Martins CP, Iandoli Júnior D, Benites LSB, Terceros LB, Nantes RSG. Finitude da vida: compreensão conceitual da eutanásia, distanásia e ortotanásia. *Rev Bioet.* 2020;28(2):376-383.
56. Ferreira AGC, Oliveira JAC, Jordán APW. Educação em saúde e espiritualidade: uma proposta de transversalidade na perspectiva do estudante. *IJHE.* 2016;1(1):3-12.
57. Farinasso ALC, Labate RC. Luto, religiosidade e espiritualidade: um estudo clínico-qualitativo com viúvas idosas. *Rev Eletr Enferm.* 2012;14(3):588-595.
58. Melo AGC, Caponero R. O futuro em cuidados paliativos. In: Santos FS. *Cuidados paliativos:* diretrizes, humanização e alívio de sintomas. São Paulo: Atheneu; 2011.