Death and dying from the perspective of multiprofessional residents in a teaching hospital

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Abstract

This study aimed to analyze and describe the understanding of multi-professional residents of a teaching hospital regarding death and dying. A qualitative study was performed using Bardin subject analysis. A semi-structured interview was used for the collection of data, which was analyzed with QSR NVivo 11 software. It was noted that the interviewees believe that working with the theme of death and dying is entirely pertinent, and that it is an indispensable subject in academic training for integral care. It was found that the interviewees did not feel they were prepared to deal with the process of death and dying.

Keywords: Death. Attitude to death. Palliative care. Health education. Bioethics.

Resumo

Morrer e morte na perspectiva de residentes multiprofissionais em hospital universitário

Este artigo tem como objetivo analisar e descrever o entendimento que residentes multiprofissionais de hospital universitário têm sobre a morte e o morrer. Trata-se de estudo de abordagem qualitativa, com emprego da técnica de análise de conteúdo de Bardin. A ferramenta utilizada para coleta de dados foi entrevista semiestruturada, analisada com auxílio do software QSR NVivo 11. Verificou-se que na perspectiva dos entrevistados é totalmente pertinente trabalhar o tema da morte e do morrer, temática indispensável à formação acadêmica para assistência integral. Conclui-se que os entrevistados sinalizaram a sensação de não se sentirem preparados para lidar com o processo de morrer e a morte.

Palavras-chave: Morte. Atitude frente à morte. Cuidados paliativos. Educação em saúde. Bioética.

Resumen

Morir y muerte en la perspectiva de residentes multiprofesionales en un hospital universitario

Este artículo tiene como objetivo analizar y describir el entendimiento que los residentes multiprofesionales de un hospital universitario tienen sobre la muerte y el morir. Se trata de un estudio de enfoque cualitativo, con la utilización de la técnica de análisis de contenido de Bardin. La herramienta utilizada para la recolección de datos fue la entrevista semiestructurada, analizada con la ayuda del software QSR NVivo 11. Se verificó que en la perspectiva de los entrevistados es totalmente pertinente trabajar el tema de la muerte y del morir, temática indispensable en la formación académica para la asistencia integral. Se concluye que los entrevistados señalaron la sensación de no sentirse preparados para lidiar con el proceso de morir y la muerte.

Palabras-clave: Muerte. Actitud frente a la muerte. Cuidados paliativos. Educación en salud. Bioética.

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Declaram não haver conflito de interesse.

The discussion of the meaning of death accompanies the history of mankind. Its irreversible character and the impossibility of formulating it in symbolic terms terrifies the human being, since we can not describe or name it ¹⁻³, although it is the only great certainty ⁴. Several understandings, emphases and comprehensions have been given and are given to this process in different societies and periods, and the conduct of the human being in the face of death has changed several times in the course of time.

What is now characterized as a lonely end of life in the hospital has, in the past, been faced as "tamed death", in which the dying or terminal patient presided over his death ceremony. In the Middle Ages, with this perspective of family death, the person acted calmly and in tranquility before death, accepting his/her destiny and the end of life. They waited serenely and organized their departure, including their funeral or funeral procession. Death was public and a farewell at home surrounded by relatives, friends and neighbors, with the participation of children as well^{5,6}.

With the changes that society has undergone over time, people have become less receptive to death because, due to sanitary measures, the deceased and the patient in the process of termination began to be moved away from the others, in order to avoid risks and the spread of diseases. This displacement of death, which is no longer at home with the family, but in the hospital bed, may have accelerated its interdiction in discursive and psychological terms ⁷. This understanding that the hospital would be the most appropriate place to die, surrounded by invasive devices and heavy technology, was called by Menezes the "modern death" ^{8,9}. Thus, dying became a lonely and feared act ¹⁰.

In addition to these differences, inherent to the historical process, during the development of the medical sciences new criteria were elaborated to define death, which further intensified the diversity of interpretations. From a technical-scientific point of view, death, which was previously classified as an absence of cardiorespiratory function ¹¹, started to also be characterized by the brain criterion. That is, death is attested when the irreversible cessation of brain functions occurs as a result of severe aggression or severe organ injury, blocking blood flow and causing the organ's destruction ^{12,13}.

Technological advances and the view of the body as a production machine refer to death as something to be feared, avoided, and stalled ^{4-6,13}. Such advances allowed the prolongation of life by

new artificial methods, but they did not necessarily do enough for the human being to live with better quality ^{4-6,14}. In this way, therapies that prolong their existence are imposed without worrying about the consequences of living, without taking adverse effects into account ¹⁵. The goal became to save lives "at any cost", prioritizing the years of life, that is, the quantity, regardless of the quality of the living ^{16,17}. This culminated in detachment from death, which came to symbolize therapeutic failure ^{13,14}, generating a lack of empathy among the care team, withdrawal from the understanding of the patient's suffering, and the interdiction of the subject itself.

The discussion of dying and death can be performed in all contexts, be them family, professional or educational ⁴⁻⁶. Thus, the prospect of death is present at any stage of human life, from birth to extreme old age. Health professionals, from the stages of their academic and professional training, just as every living being, have death present in their daily lives. Multi-professional residents are exposed to situations involving death and dying. However, there are few spaces for discussion and reflection on the theme.

This justifies the need to work the issue properly during the training of health professionals, as well as to provide them with permanent support. There is also an urgent need to open dialogic spaces to discuss the subject of death and dying, in order to improve their understanding and recognition that death is a part of life, thus improving the integral care of the patient. The aim of this article is to describe the perception of residents in the formation of the Integrated multi-professional Health Residency Program (Programa de Residência Integrada Multiprofissional em Saúde - Rims) about death and the process of dying.

Methods

A qualitative, descriptive study was carried out using the content analysis of Bardin ¹⁸ for the construction of thematic categories. The three stages of the content analysis were observed: pre-analysis, which consisted in the choice of the documents to be analyzed, systematization of hypotheses and initial ideas and creation of categories of analysis; exploration, in which classification and categorization of the material occurred; and, finally, the treatment and interpretation of the results obtained.

The sample consisted of ten residents of RIMS residents of the Hospital of Clinics of Porto Alegre (Hospital das Clinicas de Porto Alegre - HCPA), from

the following concentration areas: Critical Adult (n=1), Cardiovascular Attention (n=1), Onco-Hematology (n=3) and Child Health (n=5). The inclusion criterion comprised students who began their participation in RIMS between 2013 and 2015, and were participating in the Residence Program during the interviews. The sample was selected for convenience.

Data were collected through semi-structured interviews (see annex) conducted from January to August 2016 by a researcher with experience in qualitative research. Participants were invited to participate in the study via institutional e-mail and personally during the training period. Sixty invitations were sent and the first 15 respondents were selected to participate in the study. After ten interviews, the saturation of senses was reached. The interviews were carried out at the Clinical Research Center of the HCPA, recorded and transcribed in their entirety with the authorization of the participants. All subjects participated in the informed consent process and, after communicating possible risks and benefits, decided to participate in the study.

In order to keep the privacy and confidentiality of the participants, it was decided not to inform the training area of each subject, considering the small number of easily identifiable residents at the study site. In the presentation of the speeches, it was decided to use the letter "E" followed by the number corresponding to the interview - for example, the first interview was designated code E1. The data obtained in the transcription of the interviews were analyzed using the software QSR NVivo 11, version Windows 19, using the Bardin content analysis technique. The program used allowed the crossing of information, to code data and to manage information, and helped in the assembly of thematic categories. In addition, it also enabled basic statistical analysis and grouping of the speeches in clusters, trees and word frequencies.

Results and discussion

The sample was composed of ten Rims residents of the HCPA, 80% (n=8) being females and 20% (n=2) being males. The average age was 28 years, ranging from 25 to 41 years. Health professionals from the areas of physical education, nursing, pharmacy, physiotherapy, nutrition and social services participated. In order to preserve the confidentiality and privacy of the participants, their interviews were not identified by profession or area of activity.

Four thematic categories emerged from the analysis of the interview transcripts: 1) relevance of the theme and preparation of professionals to deal with death; 2) understanding of the multiprofessional resident about death and its definition criteria; 3) feelings related to loss - subdivided into feelings related to family loss and loss of patients; and 4) symbolism of death for the multiprofessional resident.

Relevance of the theme and preparation of the professionals to deal with death

From the perspective of the residents interviewed, the theme of death and dying should be part of the preparation for integral care, making its discussion relevant. In practical training, many residents are young students with no prior experience in hospital care, and they had dealt few or very few times with losses in the workplace. Given this, it is natural that they feel unprepared to deal with the subject. Thus, it is essential that they receive adequate training on how to deal with death, as well as the support of other professionals through talk rounds, exchanges of experiences, and other support activities. The need to be prepared to deal with death is evidenced several times in the interviews:

"I do not think I'm prepared to deal with death. Mainly because there are not as many deaths in the hospitalization unit as in the ICU, for example" (E1);

"No, not at all [prepared to deal with death]. We are prepared to deal with life and sickness in a sick human being, but not with this issue of death, of the end" (E4);

"No, I had no preparation to deal with this subject before I started at the hospital. During the period of the residence, I had the opportunity to attend lectures and participate in events on the subject, but I feel that the preparation is still inadequate, either in the undergraduate course or in RIMS. There are gaps on the subject that need to be worked and fulfilled" (E10).

The health professionals interviewed reported not feeling fit to deal with patients' deaths, demonstrating the lack of adequate preparation regarding the subject studied. This unpreparedness is also identified by the participants in the undergraduate course, which does not address the subject. Professional training emphasizes life and does little about death. Many professionals assume antagonism between life and death and do not

identify them as a whole process, which can lead to a sense of failure at the death of the patient.

Words like "no" (in Portuguese: "não"), in the sense of lack of preparation; "worked" ("trabalhado"), in the sense addressed during training; "death" ("morte"); "coping" ("lidar") in the sense of personal and emotional management; and "training" ("formação"), in the educational and professional sense, were the most frequent in residents' interviews. A brief analysis allows the observation that all words converge to the feeling of unpreparedness, implying that death needs to be addressed in the training of the health professional with a broader approach.

Figure 1. Word cloud on the relevance of the theme and professional preparedness. (Original words in Portuguese.)



Working on the "death" theme is fundamental in all contexts. The phenomenon of death is inherent to living beings, and, sooner or later, the loss falls upon all. For the health professional, in addition to the family environment, it is necessary to reflect on this issue in the teaching environment or in the workplace ⁴⁻⁶. These professionals, and, here, specifically multi-professional residents, have death in their daily work, which makes it much more pertinent to approach the theme throughout the training process.

According to the residents interviewed, discussing death is very important, especially in the health area and throughout the training. Understanding or dealing with it helps to deal with feelings and with families in a less painful way ²⁰. The conventional hospital context generally does not encourage broad discussion on how to deal with the physical and mental suffering of critically ill patients and their caregivers ¹⁻³.

"We have to be prepared to deal with the end, with the palliative patient, with the patient who is in a very sever condition, that the team makes clear that in no way will return (...) I think we have to get used to it, but at the same time you can not lose sensitivity as a human being. I think that this is a part of it, it has to be touched in some way, it is important to also have this separation from what we feel, from being sensitized." (E8);

"When the husband [of the patient who died] came to the hospital, he wanted to thank us, but he was lost. That was a situation that could destabilize me. Those who enter a hospital environment should approach the issue in a mature way. I did not know what to say. Just like I did not have any training on how to behave in difficult situations. This issue of empathy is very personal, being able to say the right things at the right time is an exercise in very 'human being', you have to be too big to say something comforting at such a time. The professional who allows himself to cry for a patient is extremely rare, even because our preceptors do not do it and they are our models" (E9).

Thus, the analysis of the statements allowed us to conclude that we should invest in a more humane formation of health professionals, teaching them to understand each other's pain and how to behave in times of loss and sadness. In order to do this, we must be aware that interactions occur in multiple ways and act in different ways in the processes of equilibrium of different people ²⁰. Moreover, it is indispensable to observe that the professional-patient relationship does not take place in a closed system - taking into account the interests and desires of those involved, patients and their families ²¹⁻²⁴. This awareness highlights the importance of welcoming the person with affection, giving him/her emotional support and respect.

The understanding of the multi-professional resident about death and its definition criteria

It can be said that understanding about the criteria of death tends to vary according to our beliefs and worldview. According to the data obtained in the interviews, death is defined as the decomposition of the body, the end of the physical body, the end of life, that is, perceiving the appreciation of the physical aspect in the definition of death in the discourse of the participants of the study. This way, for those interviewed, death is a physical state, when the body no longer supports

life and can not maintain its biological functionality. It is possible to say that this vision is strongly based on the biomedical view, in which we see the body as a machine. Death evokes feelings of frustration and impotence, associated with grief, mourning, pain, despair, contradicting the technical and biomedical concept of life and development ^{12,14,16}.

Dying is an irreversible process; once installed in the body, there is no way to prevent it, although it is possible to delay it with therapeutics, in many cases applied in an artificial and futile way. It also represents the end of a cycle, the life that ceases. It is to cease to live physically, which is seen as a natural phenomenon. However, understanding about death may vary according to the person's religious orientation. For those who believe in the perspective of spiritism, as reported in the interviews, death refers to the closure of the body as physical terminality, in which the spirit leaves the physical state, but its soul or essence does not cease to exist. These considerations are illustrated in the following statements:

"It depends a lot on your beliefs, anyway... For me, death refers more to the physical body, because I believe in the spirit, in the soul, I am a Spiritist. (...) The physical body dies and life ends there, but that refers to the physical body. This does not mean that the individual's essence or soul has been lost. It is only the death of the physical body" (E1)

"Death is the end of life. I'm not religious, I do not think there is much more than that. So, I think it's when your body enters a state that no longer supports life, from there on you are already in a state of death" (E5).

When analyzing the following statements, we observed that the interviewed residents see different criteria to define the death outcome, such as brain death and that caused by cardiorespiratory arrest (CRA):

"I think that in brain death, you, with some maintenance, you will have your body functioning, depending on technologies, but you no longer have your conscience, you will not revert your case, this is confirmed by several tests, brain death... And in the cardiothoracic death, the lung and the heart, progressively stop, the brain also loses functions... Both are deaths, yes, in my understanding, both are deaths" (E3);

"Death is when the person really ceases all vital signs, right?, the heart stops beating and the person has no more reaction" (E6);

"I understand death as the end of life, like the closing of a cycle, something irreversible. Death by the brain criterion is a diagnosis without reversion. I think it's wrong to revive" (E9).

Residents perceive the relationship between brain death and futile therapies. In this way, the artificial maintenance of life is considered undesirable, except in case of organ donation. In relation to death by CRA, there is a different perception, in which the body is suffering slowly, since the brain, understood as the main organ of the nervous system, is still preserved. Although there may be an apparent dichotomy between death by CRA and brain death, both are criteria for the characterization of death.

Figure 2. Word cloud of the understanding about death and the criteria of its definition. (Original words in Portuguese.)



Feelings related to the loss

In this category, the word "no" ("não") takes on a larger proportion in relation to the frequency of words, making clear the strong sense of denial associated with death.

Other feelings related to loss are quite frequent, such as sadness and suffering. According to the professionals interviewed, the loss generates ambivalent emotions that manifest in different ways in each individual, because now we miss the lost loved one, or we hate them to have left us. This sense of ambivalence has also been verified in correlated studies ²⁵⁻²⁷. In the view of the subjects, we can and should feel and cry the loss of patients,

provided that in a controlled way, without letting it disrupt the care routine and the relationship between the professional and other patients.

Experienced by all human beings at some point in their lives, loss is a universal phenomenon. Regardless of the type of situation to which the loss is circumscribed, all have in common the difficulty of the individuals involved in enduring the lack of the one who is gone ²⁵. After an unexpected loss, there always seems to be a protest stage, in which the individual who lost the loved one strives to recover the lost person. Hope, despair and anger alternate. The mourner goes through the destabilization of the phase of despair and reorganizes oneself based on the person's permanent absence ²⁵. Anger and social isolation are necessary feelings for the process of mourning to be healthy. The statements referring to these aspects are transcribed below:

Figure 3. Word cloud of feelings related to loss. (Original words in Portuguese.)



"I was very sad, because it was a patient in whom we were investing a lot, despite having no perspective of life (...). But even so he was being invested a lot, in all kinds of treatment, specialties were involved, so it was a pity, because the mother had hope about the life of the son and she was always there and so dedicated" (E1);

"Sadness, longing after the person dies. Sadness for the family, when we put ourselves in the place of the family. I think so, I am a person, I have feelings, and the moment I do not feel anything, I will need to review if I really want to continue working in this area" (E4);

"Feeling is just sadness, right? Missing the person..." (E6).

According to these statements and other ones transcribed previously, it can be seen that residents

are bothered by futile investment in patients with no prospect of cure or reversion of the condition. However, although the discomfort that this generates is evidenced, they often perform these therapies in an attempt to preserve the patient's family members from this suffering.

According to Bowlby ²⁵, mourning is composed of three stages: protest, despair and detachment. People of all ages who experience the loss of loved ones feel regret and go through the mourning period. The reorganization of the suffering individual varies according to the way one faces these stages. Denial is the first reaction of the human being in the face of bad news and serves as a temporary defense mechanism ²⁴. We interdict the subject of death and do not touch the subject by the false illusion that, by denying it, we would be protecting people from contact with pain and suffering ⁴⁻⁶. However, denying the fact of death makes it more difficult to elaborate the mourning ²⁵.

Feelings related to a family loss (of close people)

Losing people is always painful, especially when they are our family or very close people. When asked about the feelings involved in family losses, the participants showed greater regret regarding patient losses, which was normally expected. We have stronger affective bonds with our family members. It was highlighted in this category that residents report being more prepared to deal with the death of relatives by talking about the diagnosis and talking openly with the patient about the possibilities of living or dying.

Even though it is inherent in human beings, death often produces feelings of anguish and suffering, which make it difficult to cope with them and increase their dualism ¹⁶. This is because we react to the news sometimes with relief that the suffering of the patient has ended, sometimes with extreme sadness and regret, sometimes even angry at the loss. The following are some statements associated with these feelings:

"The first close loss I had, (...) I dealt very badly [with it], [it was] my grandfather, who was my patient. I suffered a lot, I felt bad for a long time and I did not want to go to my grandparents' house, where he lived. And then my family worked on that with me" (E5);

"I lost my stepfather and my two maternal grandparents, I also had my brother-in-law, who died

very unexpectedly. Chronic diseases, like this, one even understands going through death more easily; now, I had an 18-year-old brother-in-law who died falling from a balcony, so it was very traumatic" (E6);

"The loss of my father was something unexpected, he was not in the hospital, he died at home, sleeping. His death was very shocking, because I had talked to him just hours before, but despite all the pain of the loss, the suffering of the family, we always considered the fact that he did not suffer from terminal illnesses like cancer, nor did he have invasive procedures that caused cause pain. We believe it was a quiet death" (E10).

Feelings related to the loss of patients

When asked about feelings related to the loss of patients, the answers diverged. In a way, some residents think it is a mistake to get involved and suffer the loss of a patient because they see this as lack of preparation and professionalism. This is due to cultural, historical and hierarchical constructs within hospitals with biomedical structures ^{26,28,29}. Death completes the life cycle ³⁰. However, practitioners are emotionally unprepared to deal with the feelings it arises, thus presenting difficulties in providing support and assistance to the terminally ill patient ³¹. Sentences that expose the thinking of the establishment and maintenance of links with critically ill patients:

"Yes, I will not feel [the death of a patient] as [if it were] a relative of mine, but I will certainly feel it... I do not think there is any way to compare" (E1);

"It is very difficult for you to lose a child, such a young being to lose one's life. It affects one a lot, you cling... No matter how hard you try not to take work home, from the hospital to the personal life, just to protect yourself" (E3);

"There was a patient to whom I got a little more attached. I knew that he was already in palliative care and that some time it was going to happen [death] (...). I was attached, and I do not think I should have been attached. We can not hold on, otherwise it becomes a negative thing for us. Because critical patients die a lot" (E5).

Although it is not consensus, the feeling of commotion largely affects the participants. Professionals learn to bond with patients and their families to cope with the illnesses that afflict them. Residents strongly bonded with patients who have died suffer their loss, which is predicted in a situation

in which the bond is broken, either abruptly or not. However, neither these nor any other physicians can suffer a loss like this without having support from other professionals. It is necessary that the pain be shared and that the multi-professional resident receive adequate support.

Another notable feature of this category was the non-acceptance of the loss of pediatric patients. We more easily accept the loss of adults or the elderly because there is a certain naturalness in death in old age ¹⁶ - these are expected deaths and we managed to prepare the mourning in advance. When a child is lost, there is an early rupture of the bond, and there is the conception that children "still have their whole lives ahead of them."

The symbolism of death for the multi-professional resident

Death represents sadness, loss, the end. It is something that is generally not thought of, precisely due to being associated with these negative feelings. It is the absence of the physical body that leaves an emptiness full of longing. To feel the loss is natural, provided that in a controlled way. Death can be considered a relief, a passage, the end of a cycle, whether or not continued on another spiritual dimension. Death is a complex phenomenon with innumerable external and internal influences that hinder its comprehension and its integration into everyday life.

The vision of death is loaded with symbolism, socially constructed in a gradual way, impregnated with values and meanings that depend on the historical, cultural, economic, political and environmental context in which the subject is inserted, exerting strong influences in different generations. Therefore, such conceptions about death are extremely relevant to assist in understanding the social representations of residents who work in health care. Their attitudes toward dying and death will be in accordance with their understanding. The following are some statements referring to the symbolism of death:

"The end of a cycle. *The end of suffering. The end of life*" (E2);

"Loss. It depends on the point of view - it is a loss for some, but it can be a relief for others" (E7);

"It represents sadness, suffering, change, closure and rest" (E10).

Final considerations

It can be said that the results obtained with the report of the participants of this study are corroborated by the findings in the literature, that is, the perception of inadequate preparation to deal with death. This gap in professional qualification is attributed to several reasons, with emphasis on cultural issues. The interviewees perceive death as a process of separation, passage and finitude, indicating the end of life, the closing of a cycle, and characterizing an irreversible phenomenon.

The results also indicate that the perception of death depends on the beliefs of each individual. In this perspective, religious people understand death as just the end of the physical body, the soul and spirit being preserved in another dimension. Less religious people understand death as the end of the natural process, the act of ceasing to exist physically, the end of the cycle that begins at birth, the cessation of life, the body that loses energy. One of the interviewees cites the fear of death that manifests in certain

people, which derives from their awareness of how they used the opportunities they had in life, if they led his life in a way that was worth living.

Death is a stressor, and facing the loss alone without being adequately prepared can generate intense suffering even in more experienced professionals. There are significant gaps in health education, both undergraduate or graduate, on issues involving death and dying. Although health professionals have continued education, they do not find dialogic spaces that allow them to share their losses, afflictions and sufferings. Likewise, they are also not supported, in a structured way, in their emotional and social questions concerning death.

Based on the information obtained, we suggest that greater attention be given to the issues involved in death and dying during the training of health professionals, in undergraduate school and multiprofessional residency, with spaces of dialogue that allow the exchange of experiences, facilitating the overcoming of difficult and distressing situations.

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Participation of the authors

Daniel Tietbohl Costa participated in the conception of the study, in data collection and elaboration of the manuscript. José Roberto Goldim participated in the conception of the study. All authors contributed to the data analysis and critical review of the manuscript.



Annex

Script of the semistructured interview Participant's data:

Participant's code: Date:/	
Sex: () female () male Age: years	
Religious practice: No () Yes() Which? Training: Field of action in the Rims:	
Year of Residency: R1 () R2 ()	
Previous experience (to the RIMS) in health assistance activities: years	

- 1. What do you understand by "death"?
- 2. Do you understand that death attested by the brain criterion is equal to death verified by the cardiothoracic criteria?
- 3. What does death represent to you?
- 4. Do you think you were properly trained to deal with subjects that approach the themes of death and dying?
- 5. Do you find it relevant to work on this theme throughout your academic training?
- 6. In undergraduate activities, did you have any discipline or activity that addressed the issue of death and dying?
- 7. Have you ever had personal experience of the death of a family member or friend? (Specify)
- 8. If you answered "yes" to the previous question, what were your feelings in relation to this loss?
- Have you ever had personal experience of the death of a patient death accompanied as an activity linked to RIMS? (Specify)
- 10. If you answered "yes" to the previous question, what were your feelings in relation to this loss of a patient?
- 11. Would you have any comment or additional suggestion to make about the theme of death and dying?