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Experiences of death of older adults in medical practice and human dignity

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Abstract

This study focuses on the experiences of death of older adults in medical practice, and human dignity in hospital environments. It discusses the medical perspective regarding their experience with death of older adults, as well as the behavior and reactions of the family when their loved ones are on the verge of death. The research was qualitative, exploratory, and descriptive. Researchers conducted semi-structured interviews with eleven doctors, who have worked for over five years in a large hospital in the State of Rio Grande do Sul. Through thematic content analysis, this research analyzed the “experiences of death of older adults in medical practice” and the subcategories related to it. It concludes that it is necessary to include within medical training opportunities for the discussion and study of how to approach and deal with death, in order to minimize ethical dilemmas faced by professionals in their daily practice.

Keywords: Aging. Bioethics. Palliative care. Death.

Resumo

Vivências da morte de pacientes idosos na prática médica e dignidade humana

Este estudo objetivou conhecer as vivências da morte de pacientes idosos na prática médica e a dignidade humana em ambiente hospitalar. Aborda o olhar do médico em suas experiências com a morte de pacientes idosos, bem como o comportamento e as reações dos familiares na iminência da morte de seus entes queridos. Trata-se de pesquisa qualitativa, de caráter exploratório e descritivo. Realizaram-se entrevistas semiestruturadas com 11 médicos que atuam há mais de cinco anos em hospital de grande porte do interior do Rio Grande do Sul. Por meio de análise temática de conteúdo, esta pesquisa analisa a categoria “vivências da morte de pacientes idosos na prática médica” e suas subcategorias. Conclui-se que é necessário inserir na formação médica a discussão e o estudo sobre abordagem e enfrentamento da morte, a fim de minimizar dilemas éticos vivenciados pelos profissionais em sua prática cotidiana.

Palavras-chave: Envelhecimento. Bioética. Cuidados paliativos. Morte.

Resumen

Vivencias en torno a la muerte de pacientes de edad avanzada en la práctica médica y dignidad humana

El estudio tuvo como objetivo conocer las vivencias en torno a la muerte de pacientes de edad avanzada en la práctica médica y la dignidad humana en el ambiente hospitalario. Se aborda la perspectiva del médico en sus experiencias con la muerte de pacientes ancianos, así como el comportamiento y las reacciones de los familiares ante la inminencia de la muerte de sus seres queridos. La investigación fue cualitativa y de carácter exploratorio y descriptivo. Se realizaron entrevistas semiestructuradas con 11 médicos, que trabajan desde hace más de cinco años en un hospital de gran porte en Río Grande do Sul, Brasil. A través del análisis temático de contenido, esta investigación analizó la categoría “vivencias en torno a la muerte de pacientes de edad avanzada en la práctica médica” y las subcategorías relacionadas a la misma. Se concluye que es necesaria la inserción en la formación médica de espacios de discusión y estudio sobre el abordaje y el afrontamiento de la muerte, con el fin de minimizar los dilemas éticos que enfrentan los profesionales en su práctica cotidiana.

Palabras clave: Envejecimiento. Bioética. Cuidados paliativos. Muerte.

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The finitude of life, be it natural or associated with terminal diseases, reports to new perspectives and transformation of knowledge about aging. In the final process of the human being, health professionals need to consider the quality of life as survival is not enough: the time left must be enjoyed with dignity. This requires that professionals who care for someone in his last moments develop skills and knowledge of symptoms and physical signs, and have the ability to respond to the spiritual and emotional needs of patients, attributes the art of care, which can be very appropriate in this situation¹.

Prolonging the suffering of a life in the terminal phase is a sensitive issue, involving difficult decisions that require knowledge of a complex process, careful observation of behaviors and honest dialogue on the part of those involved in decision-making. Traditional medical education tends to “train” the health professional to save the patient at all costs, because the “enemy to be defeated” is death. The professional is prepared for life, not for death. This view seems to relegate to a lesser place the notion that it is necessary that this survival is experienced with dignity. If there are no more possible behaviors that lead to healing, it is necessary to adopt palliative care to ease suffering in this important and final stage of life and ensure the dignity of the patient.

The current perception indicates that *when we go back in time and study cultures and ancient peoples, we have the impression that man has always abhorred death and has probably always rejected it*². The ritualization of death is a particular case of a human strategy against nature; thus it was not abandoned, but rather trapped in ceremonies, transformed into a spectacle: mankind tried to restrain it in rituals³. These rites relate to the difficulty of dealing with death, reinforcing the notion of the importance of palliative care in the end of life.

Thus, the objective of this study was to understand the experiences of death in elderly patients in medical practice and human dignity in the hospital environment.

Methods

This is an exploratory, descriptive and qualitative study. The sample included 11 physicians who had been working for over five years in a large general hospital in a city of the mountainous region of Rio Grande do Sul, Brazil, in the specialties of medical and surgical clinic, treating elderly patients both in the hospital and in their practices.

Data collection was performed through a semi-structured individual interview, recorded by means of electronic audio device with consent from the participants. These were assessed through thematic categoric content analysis⁴, adapted from Minayo⁵, after transcription/decoding. Data collection was performed between April and September, 2011.

It is noteworthy that the interviews were conducted until data saturation, which became evident when interviews began to repeat themes and bring little significant increase regarding the objectives initially proposed for this research⁶. Although all participants contributed to the amount of data, it was deemed necessary to present the statements of only five of the respondents, since the others only confirmed previous statements.

The questions in the data collection instrument were about: 1) the experience of the medical professional facing the death of hospitalized elderly patients; 2) the behavior and actions taken in medical practice on the question of the process of death of hospitalized elderly; and 3) the behavior of family members in the imminence of death. All these issues contributed to the results obtained in this article.

Interviews were conducted individually, after acceptance and signature of the free and informed consent. Each respondent was heard by appointment, in time and place set by the subject, in order to interfere as little as possible in their daily lives. Data collection took place through closed questions relating to the characterization of the participants, and open questions, with structured questions set to meet the goals of the study.

Interviews lasted for approximately 30 minutes. They were recorded on MP3 devices after authorization of the interviewee. Interviews were fully transcribed. In order to avoid ethical problems related to data confidentiality of research data, participants were characterized as “interviewee” and each interview was identified through a numeric sequence (1, 2, 3 etc.), thus ensuring anonymity.

After transcribing the interviews, data were considered from the thematic analysis, developed in three phases: pre-analysis, which organizes the empirical material, systematizing the initial ideas and creating subcategories; exploration of the material that defines the category of analysis, in which out search operations and cataloging the empirical material were performed; and finally, treating the results and their interpretation in order for them to be valid and meaningful to the goals of the research.

Results and discussion

Characterization of participants

Among the interviewed physicians, seven were male and four were females. According to the observation of the researcher, all were white. One participant was a widower, and ten were married. As for religion, ten were catholic and one was a spiritist.

The age of respondents ranged between 39 and 63, and medical experience was in the range 16-38 years. All were postgraduates. Six respondents were trained in private colleges, two in federal universities in the capital and three in federal universities not in the capital. Five had suffered the loss of family members with prolonged terminal illnesses.

As to the law applicable to the research issue, particularly regarding ethical issues related to death and dying process of their patients, there were questions about their knowledge of the code of medical ethics and the status of the elderly. Two respondents fully knew the current code of medical ethics and nine did partially. One of them fully knew the elderly statute, seven knew it partially and three did not know the legislation.

Category and subcategories

In this article, the category "Experiences of death in elderly patients in medical practice" was considered. This was comprised of sub-categories: 1) "Elderly and the process of death and dying"; and 2) "family behavior in the imminence of death." In the subcategory "Elderly and the process of death and dying", the participants expressed, quite emphatically, the manifestations of fear and uncertainty, moments of concern and revelations and experiences without fear of terminal illness.

There is a moment in the patient's life when the pain ceases, the mind enters a state of torpor, the need for food becomes minimal and awareness of the environment almost disappears into the darkness. It is the period in which the relatives go to and from in the corridors of hospitals, waiting for the moment of death⁷.

It is the time when it is too late for words. As human beings and professionals, we are able to reflect on the path of death, transforming the way of looking at life, and the contemplation of the life can lead to a different experience of death. Then, *and only then, we can face death laid bare, unmade-up, and dissect it in its pure biological reality*⁸.

Kübler-Ross⁷ reports that people's imaginary views death as a ghastly and dreadful fact that is shared by all. Everyone tries to ignore death or dodge it, thus negating the condition of being mortal. Note this experience among respondents: "*They do not want to die (...) Death is a mystery, no one knows what's there*" (Interview 2). In turn, the aging population and epidemiological transition imply prolonged terminal illness which increases the demand for health services and the need for greater support to people and families in the process of death and dying, which currently occurs more generally in hospitals.

The difference in the perception of death among people in general and health professionals is that, for the latter, it is present in everyday life. However, when losses occur without the proper preparation of mourning, the possibility of disease grows. From this perspective, if the issue of death and the dying process, and the finitude of life are not dealt with, every disease is seen as a threat to life, a call to death⁹ and, therefore, a distressing situation. Thus, it is necessary to discuss the disease process and its prognosis for the patients and their families to be informed, aware and empowered in their positions.

This information will contribute to the treatment process and the preparation for the end of life as they will promote the dignity and autonomy of the patient until the moment of death¹⁰. In the words of Santin Bettinelli, *the principle of human dignity establishes a degree of protection of the person in relation to the state and to other human persons or public or private legal entities and imposes the satisfaction of basic existential conditions to make it possible for humans to actually live and not only survive. It reaches all sectors of the Brazilian legal and political order, being a duty of the state to enact laws and carry out policies aimed at meeting the basic living needs of its citizens by ensuring their existence with dignity. Likewise, it is the duty of the society to act together for the concrete realization of such laws and public policies*¹¹.

Therefore, it is necessary to consider the principle of human dignity, provided in article 1, item III, of the Brazilian Federal Constitution¹², in all stages of life, including the terminal stage, which demands closer attention by the State and society. Death is a part of human life, and the fear of death is necessary, since it is the expression of the instinct of self-preservation, a way to protect life and overcome destructive instincts. One can not live all the time under the overwhelming presence of death. In

this sense, it is necessary to “educate” for finitude, which is education understood as a possibility of integral personal growth, involving subjective development throughout life and also in preparation for death¹⁰. However, this notion is not constant among patients. Some professionals interviewed observe that some elderly do no fear death:

“As for the finitude, what I see in my professional activity, mainly of aged patients, the most important is that patients do not fear finitude (...) the elderly include terminal illness as part of life. They accept and even determine the moment that is definitive for them” (Interview 1).

In some responses it is noteworthy the report by physicians that patients express themselves, besides not fearing death, using metaphors to reinforce control of the situation by setting up where they want to make their passing, as in this excerpt:

“At this time of ending I am not a coward, I am fighting’ (...) A few days later the person reported a dream [referring to the report of the patient in question] ‘I dreamed that I was writing a book’, I asked what chapter it was and he told me it was the last chapter. The metaphor was fantastic. A few days later they called me that he was not well. I went to his house and asked him where he wanted to stay. He asked to be in the hospital and he died a few hours after [admission]” (Interview 1).

In the content of the interviews, it becomes clear that, according to the professionals interviewed, the greatest concern expressed by the elderly in the death and dying process is in relation to family members who stay, they express themselves like this: *“A patient who suddenly started an hepatic decompensation process. He did not know of the disease to that moment and the diagnosis was of a liver cancer. At the hospital he said: ‘I needed this disease to tell my family that I am bankrupt, neither my wife nor son are aware of this. I have nothing left’”* (Interview 1).

As reported, patients also *“say they have accomplished their mission”* (Interview 1). Therefore, there is the identification of two fears of the elderly in the terminal phase. One is that family members keep bad memories from seeing them die at home. The other is the fear of death, which makes the elderly deny their own end. Both are related to the fear of suffering, of the unknown and of one’s own extinction¹³.

The “Behavior of family members in the imminence of death” *subcategory* shows interfaces in the process of dying in the words of families, reported by the physicians. This clearly shows the difficulty of dealing with the issue of finitude of the loved one, the influence of financial issues in this moment, as well as the existence of omissive family members in this process:

“I see, in relation to men, for example. Many men are bad husbands, bad parents or are not as they should be, right? They get separated from the wife. But what we see in the terminal stage is that the one to give support, who is always going to be there is the first wife. The one who was the first love. The second, third wifem they don’t care. The guy is there, dying, let him die. They say goodbye and the one to do all the hard work is the first wife. This is something that calls my attention” (Interview 11).

Still on the experiences of death and the dying process, families transmit to the physician that there are family members who are assertive, have decision-making power and are concerned about the costs of this terminal process:

“I have VIP health insurance plan, how come it may not be possible to stay here in the hospital?” [patient’s relative]. They say: ‘I want to leave the patient in the hospital’. But then there is all the paperwork, you know how it works, don’t you? Then, when it starts to get difficult, when the patient is getting complications, they [the family members] want to outsource death” (Interview 5);

“I was going to do the clinical assessment and the son [of the patient] said: ‘no, no. We are not going to have the surgery, there’s no use for this assessment. (...) If we pay for this, what will be left for us?’” (Interview 9).

These aspects of the financial situation of the family, like hospital costs, also have to be analyzed by the physician, and are often crucial for the decision of some families. However, despite the influence of the economic aspect on the decisions about proceedings to which the patient will be submitted, the professional also needs to deal with the difficulty of the family in accepting the finitude of the loved one. The obstinacy of the family often requires that medical staff do everything possible to prevent the last moment, even if, in practice, it means dysthanasia.

And, in this sense, excessively prolonging life with the suffering of the patient is considered a

crime against the physical integrity, an aggression against the human body and even against the liberty of the person, *there being increased suffering or not. And the gravity of the penalty is greater if one proceeds against the will of the patient that there be no dysthanasia*¹⁴. One of the interviewees expressed this issue with the following statement in which the family's intention of almost never "give up" in the face of the terminal state is made clear: *"It is very rare for a family to say 'yes, let's let the person rest'. Very rare. Normally, they say 'do everything possible'. That is the usual 90%"* (Interview 9).

Thus, what the professionals interviewed note is that both the patient and the family have hope for the cure, at first denying the possibility of death. The medical opinion of "there's nothing to do" is hardly accepted¹⁵. If the analysis of the discourse allows us to observe that the family finds it difficult to cope with their suffering and dilemmas inherent to death and the dying of their loved one, it is clear that the attitude of the professional toward the terminal illness can help one better understand this point:

"I had a breast cancer patient (...) whose family despaired and, when I saw that she was in a very bad condition I called them outside and said: 'people have to be born, grow up, live and die with dignity, from now on there's nothing we can do and you have to accept this for her own good'. This patient died and no one cried and it was a good thing." (Interview 2).

In this excerpt one can note that the interviewee guides the acceptance of the family in the process of death of their loved one and is able to manage the feeling of loss. The situation of the ones involved exemplified in this category corroborates the previous statements that, in most cases, the elderly is afraid of his own extinction and uses metaphors as a defense mechanism. In turn, family members are afraid of not seeing their loved one again and the physician who knows these

experiences from the practice, tries to manage them in such a way as to respect the autonomy of the patient and the will of the family¹³. After all, it is necessary to preserve human dignity both in life and in the terminal stage of the patients.

Final Considerations

This study shows that there is a need for effective interventions on the issue of human finitude, seeking to develop actions and coping strategies for the process of death and dying with dignity. In addition, the stimulus is imperative to support professionals working in the care of the elderly, as they face the reality of terminal illness of patients. The death of a patient is a complex phenomenon with deep individual implications, and must be addressed and monitored in interdisciplinary work.

Awareness of the problems involved in the everyday work of physicians in relation to aspects of the limit of life/death is a dilemma that offers subsidies for reflections that may generate discussions to develop coping strategies. With this study, it was possible to apprehend the experiences both of physicians and families on death and the process of dying, which may create disturbing situations in the life of every professional. This provided reflections and redirected to the new conduct as well as the search of care at this difficult time in the life of every human being.

Within this perspective, it is imperative to create spaces for discussion on living and coping with the death of their patients, in medical education. These spaces/experiences can minimize ethical dilemmas faced in the daily work of future medical professionals. New studies are suggested to further expand the knowledge on the subject, involving other segments of society.

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Participation of the authors

Luiz Antonio Bettinelli and Janaína Rigo Santin, supervisors of the MSc. Dissertation that that gave origin to this article, helped in the elaboration of the text, corrections and final revision. Sadi Poletto is the author of the dissertation that gave origin to this article and collaborated in writing the text and the corrections.

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