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Bioethical aspects of the finitude of life in the palliative care approach

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Abstract

Death is understood individually according to experiences, emotions and spirituality. Deaths is usually surrounded by negative feelings such as fear, anguish and pain. With the advance of medicine, it has come to be seen as a process that can be postponed and prolonged, which has made it even more difficult to accept the impossibility of a cure and the proximity of the end of life. In this context, the palliative care team is fundamental to alleviating the suffering of patients and their families. To discuss the understanding of death and facilitate the approach to palliative care, a qualitative study was carried out by applying an online questionnaire to 80 adult family members of medical students at the Pontifical Catholic University of Paraná, Londrina campus. Excel tables were created to analyze the data. The importance of the multidisciplinary nature of the palliative care team was highlighted, as well as the need to individualize its approach.

Keywords: Bioethics. Death. Palliative care.

Resumo

Aspectos bioéticos da finitude da vida na abordagem dos cuidados paliativos

A morte é entendida de forma individual, de acordo com vivências, emoções e espiritualidades. Usualmente, é cercada por sentimentos negativos, como medo, angústia e dor. Com o avanço da medicina, passou a ser vista como um processo passível de ser adiado e prolongado, o que tornou ainda mais difícil a aceitação da impossibilidade de cura e da proximidade do fim da vida. Nesse contexto, a equipe de cuidados paliativos é fundamental para atenuar o sofrimento dos pacientes e de seus familiares. A fim de discutir a compreensão da morte e facilitar a abordagem de cuidados paliativos, realizou-se um estudo qualitativo por meio de aplicação de questionário on-line a 80 adultos familiares de estudantes de medicina da Pontifícia Universidade Católica do Paraná, *campus* Londrina. Foram construídas tabelas em Excel para analisar os dados. Evidenciou-se a importância da multidisciplinaridade da equipe de cuidados paliativos, bem como a necessidade de individualização de sua abordagem.

Palavras-chave: Bioética. Morte. Cuidados paliativos.

Resumen

Aspectos bioéticos del fin de la vida en el enfoque de cuidados paliativos

La muerte se entiende de forma individual desde experiencias, emociones y espiritualidades. En general, la rodean sentimientos negativos, como miedo, angustia y dolor. El progreso de la medicina llegó a considerarla como un proceso que podía posponerse y prolongarse, lo cual hace aún más difícil la aceptación de la imposibilidad de curación y la proximidad del fin de la vida. El equipo de cuidados paliativos es esencial para mitigar el sufrimiento de los pacientes y sus familias. Para discutir la comprensión de la muerte y facilitar el abordaje de los cuidados paliativos, se realizó un estudio cualitativo mediante la aplicación de un cuestionario en línea a 80 familiares adultos de estudiantes de medicina de la Pontificia Universidad Católica de Paraná, campus Londrina. Se construyeron tablas en Excel para el análisis de datos. Se evidenció la importancia de la multidisciplinariedad del equipo de cuidados paliativos y la necesidad de individualizar su abordaje.

Palabras clave: Bioética. Muerte. Cuidados paliativos.

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Meaning of death

The meaning of death is a social construct and varies according to experiences, personal and social factors, and cultural beliefs. In general, death is defined as the individual's separation from human coexistence. The idea of loss and separation refers to an unknown territory in which non-existence is unexplored [1].

Death is a subject treated in a unique way by different individuals and by different cultures. In general, it is an issue that evokes negative feelings, such as pain, anguish, and fear. In many societies, death is strongly associated with religiosity, linked to the supernatural, even as a form of punishment. It is a condition inherent to the human being and reflects not only the loss of a person but also the approach of finitude itself, a threat to life. For this reason, the topic is surrounded by restlessness, anxiety, and fear [2,3].

The difficulty in accepting death is strongly associated with the notion of the finitude of life, the absolute end of the human being. As a result, even in more religious societies, the meaning of life is incomprehensible in the face of human finitude. Unlike other beings, humans are aware of the finitude of their own existence, and this awareness leads to questioning the mystery of life [2,3]. The association of anguish and pain with death is linked to the realization that human beings do not have absolute power and control over life, a fact that generates crises and moments of distress [1].

Fear and taboo regarding death are also evident when adults talk to children about the subject. Adults often find it unnecessary to explain death to children and treat the end-of-life issue as something magical, not as a real fact. Although the adults' silence regarding death is intended to avoid suffering, it inhibits the child's cognition, curiosity, and feelings about it, and also prevents them from questioning it [3,4].

Death is not just a biological phenomenon but an all-too-human event. Thus, accepting this fact is even more difficult in cases of brain death, in which there is no cardiorespiratory arrest as a criterion for death [1,5]. The dying process demands significant adaptations, especially for the family and for each individual. In the face of feelings of annihilation and helplessness, the search for acceptance drives defensive behaviors, such as denial, anger, bargaining, and depression [1].

Palliative care

Due to the advances in medicine and health-related technologies, death has undergone progressive transformations. The invention of more effective treatments has made it a process that can be delayed. These changes, combined with the difficulty of accepting the finitude of life, make the palliative care team's work difficult, given that the sick individual and their family suffer with the idea that a cure is impossible [6].

Palliative care is not intended to anticipate or prolong the dying process with disproportionate measures. Its main approach consists of supporting the patient at the end of life to alleviate their pain and provide emotional and spiritual support for them and their family members. This is done through joint actions by a multidisciplinary team composed of physicians, nurses, psychologists, and social workers trained to improve these people's quality of life [6,7].

In addition to treating pain, the team is responsible for preventing and alleviating suffering in the various dimensions that affect the individual, such as the physical, family and social, psychological, and spiritual dimensions. Therefore, these parameters must be considered in the relief of patients' and their family members' suffering. Consequently, knowing their perspectives regarding the finitude of life is extremely important to help them deal with this painful process and reduce their suffering [6,8].

The palliative care team does not focus on the disease, but rather on the patient as a whole, in all their biopsychosocial, emotional, and spiritual aspects. In this sense, professionals are committed to the purpose of dealing with the patient beyond the physical apparatus and taking care of all their individual aspects [6].

For this objective to be achieved, the fundamental principles of palliative care are defined, which include alleviating the patient's symptoms and also the patient's and family's pain, bearing in mind the integration of the psychological and spiritual dimensions and offering a support network to the family during the patient's state of illness, the dying process, and the subsequent mourning. The multidisciplinary team strives to care for the patient and their family; in this way, assistance extends after the patient's death, with support during the family's grief for as long as necessary [6,7].

In this respect, death has to be seen and understood as a natural process and part of life, and palliative care must deal with fears and anxieties regarding the finitude of life, with the aim of providing quality of life to the patient and their families [7].

Difficulties in the palliative care approach

Medical advances enabled the cure of several diseases that were previously considered incurable, and medicine became technical, with a biological approach. As a result, health professionals are mostly educated to focus on diseases and cure them at all costs, instead of analyzing the individual as a whole. Universities train physicians with the illusion that they are capable of curing all disorders and diseases, and, as a consequence, they feel frustrated when faced with inevitable death, which they end up considering a failure. This is intensified by the deficient approach to death during academic training and the lack of contact with the palliative care [9].

Technical-scientific teaching and the deficient approach to the individual's various dimensions—including the social, emotional, and spiritual—hamper the development of fundamental palliative care skills. With technical training and a lack of adequate humanitarian and emotional preparation, professionals have great difficulty communicating with patients and their families in cases where there is no possibility of a cure [9]. In the context of irreversible clinical conditions, the professional's academic limitation is added to personal limitations in understanding and accepting death.

Besides not having a solid theoretical basis to support the palliative care approach, professionals do not have any theoretical framework or protocols to guide their choices and actions. Therefore, it is essential to know and discuss the general population's understanding of death in order to establish a comfortable relationship and enable good end-of-life care [10].

Difficulty communicating in terminal situations and the fear of informing patients and their families that death is approaching are due to little contact with this type of situation and the inability to deal with feelings of denial, anger, and guilt at this moment of intense fragility. The lack of preparation to deal with these feelings and with the finitude of life is linked to the gaps in understanding death and terminal illness, the insecurity in reporting the therapeutic impossibility of a cure, and the predominant perspective of cure rather than care in medicine [11].

Communication is fundamental to palliative care provision, as it is an essential tool in caring and supporting terminally ill patients and their families. This concept is based on the humanitarian nature of health and the act of caring. In this sense, the approach must be effective and inclusive so that care is possible and provided in a subtle and delicate manner. Communication is also essential for choosing the best treatment and care plan for the patient, given that the approach adopted influences the patient's acceptance of their terminal illness. This approach brings together the humanitarian skills of listening, empathy, and verbal and nonverbal communication, necessary for interpersonal relationships in caring for patients and their families even after death [11].

The recovery of these empathic skills and communication of the terminal status are facilitated by understanding how society in general perceives death, which serves as a parameter to guide an approach that is subtle and effective and that considers the individual's multiple dimensions [9].

Rationale and objectives

As death approaches, patients and their families present complex demands, and at this moment, it is paramount that health professionals have a strategy to prevent and alleviate their suffering in the physical, emotional, and spiritual dimensions.

This highlights the palliative care team's relevance, which needs an adequate diagnosis of suffering and its causes to provide palliative care in an appropriate manner. However, there is great difficulty in verifying, addressing, and standardizing the individual's various dimensions and facets, especially in the face of death.

Given the deficiency in the approach to the topic of death both in the family and in the academic sphere, to achieve a satisfactory palliative care plan in hospitals, it is extremely important to understand how death is viewed and understood by the general adult population. The objective of the work was, based on the analysis of data from the questionnaire completed by the participants, to discuss the understanding and acceptance of the finitude of life, as well as the understanding of death in its broad aspects, to facilitate the relationship between the physician and the patient and their families in the face of the proximity of death and palliative care provision.

Method

This qualitative study was carried out after approval by the Research Ethics Committee, with consent signed by the participants, following a detailed explanation about its conduction, in accordance with the National Health Council (CNS) Resolution 466/2012 12 and the Declaration of Helsinki [13].

It was made from August 2022 to October 2022, when a questionnaire was made available via Google Forms to 80 family members of medical students from Pontifícia Universidade Católica do Paraná (PUCPR), in Londrina, all over 40 years old—due to greater life experience and possible previous contact with the death of family members or acquaintances. A link to the form and an explanation about the survey were disclosed on the Londrina PUCPR medical students' social networks so that they could forward it to their families.

Individuals who were recently mourning a loss (one month), individuals who did not want to sign the informed consent form, or who did not meet the inclusion criteria, which consisted of being a family member of a medical student from Londrina PUCPR, were excluded from the group.

The data were converted into Excel tables and presented in absolute frequency (n) and relative frequency (%), with the prevalence of responses for each questionnaire question. A free online word cloud generator (wordclouds.com) was used to create a word cloud based on the frequency with which they were reported in open-ended question 1. The main terms mentioned in the responses were inserted into a table (Table 2), from the greatest to the smallest frequency.

Regarding open-ended question 2, ChatGPT was used to describe a network diagram based on the words and phrases observed and adapted from each response. The list of terms and their interconnections was submitted to the Insite Linguistics Group's word counter (http://linguistica.insite.com.br/corpus.php) for the obtainment of the frequency of words, which were listed in Table 3.

Results

Among the 80 people who completed the survey, 72.5% (n=58) identified death as natural and inevitable; 27.5% (n=22) identified death as liable to be delayed, and none (n=0) identified death as preventable. The responses regarding the personal definition of death can be seen in Table 1.

Table 1. Prevalence of responses to questionnaire questions

For you, death is...	n	%
Natural and inevitable	58	72.50%
It can be delayed	22	27.50%
Preventable	0	0.00%

continues...

Table 1. Continuation

Is death a subject that is easily discussed in your family?	n	%
Yes	54	67.50%
No	26	32.50%
For you, medicine...	**n**	**%**
It is able to cure the disease to a certain extent	78	97.50%
It is always able to cure diseases	2	2.50%
Would you accept receiving a terminal diagnosis, with no possibility of a cure?	**n**	**%**
Yes, as difficult as it may be, sometimes it is inevitable	61	76.25%
No, I believe there is always more to be done	19	23.75%
Do you believe that, in a terminally ill patient, it is important that healthcare professionals support the patient and their family?	**n**	**%**
Yes	79	98.75%
No	1	1.25%
Have you ever heard of palliative care?	**n**	**%**
Yes	72	90.00%
No	8	10.00%
How would you, as a patient or family member, like to be approached regarding palliative care?	**n**	**%**
In a delicate and supportive manner	60	75.00%
In a clear and direct manner	18	22.50%
I would not like to be approached; I believe that doctors have to try everything, even if there is no longer any chance of a cure.	2	2.50%

For 67.5% (n=54) of the individuals who completed the survey, death is a subject that is easily discussed in the family; for 32.5% (n=26), it is not. For 97.5% (n=78) of the participants, medicine is able to cure diseases to a certain extent, while 2.5% (n=2) believe that medicine is always able to cure diseases. Among the interviewees, 76.25% (n=61) reported that they would accept receiving a terminal diagnosis in which there was no possibility of a cure because they know that death is inevitable, no matter how difficult it may be, while 23.75% (n=19) would not accept receiving this diagnosis, given that they believe there is always something more to be done. In addition, 98.75% (n=79) believe in the importance of healthcare professionals supporting the patient and their family members in cases of terminal illness; 1.25% (n=1) do not believe it is important.

Survey participants who answered "no" to the question "Is death a subject that is easily discussed in your family?" were asked in open-ended question 1 what the main reason for this would be. The main responses are contained in Table 2.

Table 2. Main terms used in the responses to the question "If your answer to the previous question was "no," what is the main reason you believe this subject is not discussed so much in your family?"

Terms	Number of responses presenting such term	Percentage of responses presenting such term
Sadness	6	23.07%
Fear	5	19.23%
Pain	4	15.38%

continues...

Table 2. Continuation

Terms	Number of responses presenting such term	Percentage of responses presenting such term
Loss	3	11.53%
Difficult	3	11.53%
Inevitable	2	7.69%
Acceptance	2	7.69%
Spirituality	2	7.69%
Escape from reality	1	3.84%
Memories	1	3.84%
Grief	1	3.84%
Necessity	1	3.84%
Anxiety	1	3.84%
Insecurity	1	3.84%
Traumatic	1	3.84%

When asked about palliative care, 90% (n=72) of the interviewees reported having some knowledge of the subject, while 10% (n=8) reported having no knowledge of it (Table 1). After a brief explanation about palliative care and its objectives, participants were asked how, as patients or family members, they would like to be approached regarding this care. Seventy-five percent (n=60) would like to be approached in a delicate and supportive manner; 22.5% (n=18), in a clear and direct manner; 2.5% (n=2) would not like to be approached, as they believe that physicians should try other ways to maintain life, even if there is no longer a chance of cure (Table 1).

At the end of the survey, participants were asked, in open-ended question 2, how they would like to be approached regarding palliative care and how they think the best health professional approach would be (Table 3). The main responses mentioned clarity, acceptance, objectivity, clarification, and delicacy, as well as other positive feelings such as love, affection, respect, care, and empathy.

Table 3. Main terms used in the answers to the questions "How would you, as a patient or family member, like to be approached regarding palliative care?" "For you, what would be the best approach by the health professional?"

Terms	Number of answers presenting such term	Percentage of answers presenting such term
Clarity	24	24
Support	16	20.00%
Objectivity	15	18.75%
Sincerity	8	10.00%
Delicacy	6	7.50%
Clarification	5	6.25%
Humanity	5	6.25%
Respect	4	5.00%
Affection	4	5.00%
Calmness	4	5.00%

continues...

Table 3. Continuation

Terms	Number of answers presenting such term	Percentage of answers presenting such term
Empathy	4	5.00%
Comfort	3	3.75%
Love	3	3.75%
Care	3	3.75%
Conversation	3	3.75%
Sensitivity	2	2.50%
Compassion	2	2.50%
Frankness	2	2.50%
Realism	2	2.50%
Honesty	2	2.50%
Humility	1	1.25%
Confidence	1	1.25%
Spirituality	1	1.25%
Patience	1	1.25%
Psychological care	1	1.25%
Kindness	1	1.25%
Subtlety	1	1.25%

Discussion

Although most people understand death as natural and inevitable, many still see it as something that can be delayed; for this reason, it must be treated as a natural process, as recommended by palliative care[8], which is based on a humanistic approach[14]. Death is a delicate subject and difficult to communicate, mainly due to the negative feelings associated with it, such as fear, sadness, pain, and insecurity. Therefore, it is important to deal with death not as an isolated event[15] and to consider that there are important relationships between the individual and others, especially with family members.

Palliative care must have an approach based on improving the patient's and their families' quality of life[16], preventing and alleviating suffering[17], also providing comfort for negative and distressing feelings. In view of this, support should be offered to family members before and after the patient's death to help them cope with the disease, in the acceptance, and in the grieving process[8].

It is also possible to observe difficulty accepting the approach of death in the case of a disease that no longer has any possibility of cure, given that some people believe that medicine is always able to cure diseases and do not accept receiving a terminal diagnosis. As a consequence, care for these individuals with limited life expectancy and their families have to be provided based on the guiding bioethics principles: autonomy, beneficence, non-maleficence, and justice[18].

Aiming at good professional practice, palliative care must be based on unique approaches, with an assessment of the physical, psychological, and spiritual symptoms[19] of the patient and their family, in order to provide them with comfort and support. To this end, the approach has to be clear, delicate, explained in simple and easy-to-understand terms, and with respect, calmness, and patience. Therefore, solidarity, compassion, and empathy are essential characteristics for the palliative care team, in addition to good communication skills[16].

The palliative care team must be able to embrace the individual as a biopsychosocial and individual being, ensuring that their beliefs and spirituality are also respected, as they are frequently sources of comfort and support for the patient and their family. Care must then be comprehensive and include multidisciplinary monitoring, with psychologists and chaplains capable of alleviating spiritual, existential, and psychological suffering, which often overlap[20].

Final considerations

The study has shown the importance of individualizing the palliative care approach. During a delicate moment, surrounded by negative feelings, fear, and insecurity, each patient must be seen as a unique being and treated in their various dimensions—physical, psychological, emotional, and spiritual—according to their preferences.

The palliative care team must offer comprehensive care to patients and their families, ensuring a better quality of life and providing comfort and relief from pain and suffering. Therefore, the approach has to be always in a supportive and cautious manner, with respect and patience, so that the experience of death is meaningful and centered on the patient.

The study emphasis is also on the fundamental importance of the palliative care team committed to the patient's treatment and the need for individualized approaches, based on the guiding bioethics principles of autonomy, beneficence, non-maleficence, and justice, as well as empathy, compassion and solidarity. Given the multidisciplinary nature of this team, which works on the physical, psychological, emotional, and spiritual dimensions of the individual and their families, professionals must be more prepared and trained to work together and for the benefit of the patient and their families. It is also necessary to encourage, through public policies, hospitals to maintain palliative care teams.

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Izabella Paulino de Souza Candido was responsible for the initial preparation of the project, the bibliographic review, and the writing and review of the article. Adriano Torres Antonucci and Carlos Eduardo Coral de Oliveira contributed to the writing and review of the text.

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Research