

# Bioethical reflections about the finitude of life, palliative care and physical therapy

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## Abstract

The significant evolution in healthcare in the last decades has improved life expectancy, providing the opportunity to live longer and generating a new perception about death. Committed to this new perspective, bioethics proposes a reflection about the end of life, directing the attention of health professionals to palliative care, the practice of humanization and the principle of human dignity. Physical therapy is increasingly present in the core of current discussions about health care facing the finitude of life, although the issue still needs further elaboration.

**Keywords:** Physical therapy specialty. Death. Terminally ill. Bioethics.

## Resumo

### Reflexões bioéticas sobre finitude da vida, cuidados paliativos e fisioterapia

Nas últimas décadas, a evolução tecnológica e científica na área da saúde tem melhorado a expectativa de vida, propiciando maior longevidade e gerando outra percepção a respeito da morte. Engajada nesta nova perspectiva, a bioética propõe reflexão sobre o fim da vida orientando o olhar dos profissionais de saúde para os cuidados paliativos, a humanização e o princípio da dignidade humana. Nesse contexto, a fisioterapia está cada vez mais presente nas discussões atuais sobre cuidados médicos no fim da vida, embora o tema ainda necessite de maior aprofundamento.

**Palavras-chave:** Fisioterapia. Morte. Doente terminal. Bioética.

## Resumen

### Reflexiones bioéticas acerca de la finitud de la vida, los cuidados paliativos y la fisioterapia

En las últimas décadas la evolución tecnológica y científica en el área de la salud ha mejorado la expectativa de vida, propiciando una mayor longevidad y generando otra percepción respecto de la muerte. Comprometida con esta nueva perspectiva, la bioética propone una reflexión sobre el fin de la vida dirigiendo la mirada de los profesionales de la salud hacia los cuidados paliativos, la humanización y el principio de la dignidad humana. En este contexto, la fisioterapia está cada vez más presente en las discusiones actuales sobre cuidados médicos en el fin de la vida, aunque el tema necesite aún una mayor profundización.

**Palabras clave:** Fisioterapia. Muerte. Enfermo terminal. Bioética.

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Declaram não haver conflito de interesse.

According to Pessini<sup>1</sup>, based on studies by Ariès<sup>2</sup>, until the beginning of the twentieth century, in the West, at the time of death, the patient summoned close people and family to his bed to say goodbye. He received extreme unction for a Christian death or simply apologized to those who lived with him or served him.

Ariès<sup>2</sup> he explains that changes in mortuary rituals did not occur dramatically, but as new behaviors were incorporated and the expression of feelings about the death of the individual or someone close changed. Over time, grief began to be faced more emotionally and dramatically. The beginning of body care, changes in scenarios (such as cemeteries), the zeal of friends and family for the memory of the deceased, among other rites and behaviors, led to the current situation: the last moments of life left the home environment for the family hospital, not always with the presence of loved ones.

Perales<sup>3</sup>, like many specialists on the subject, proposes the study of the “ethics in death” during the training of health professionals, to establish ethical reflections regarding care in dying. According to the author, understanding the process of death is as important as researching the beginning of life, so that the subject can not be hidden or treated as an appendix in vocational training. The author recommends that the disciplines of thanatology include the study of principles, values, and representations involving death - this is “*thanato-ethics*,” or “ethics in death.”

It is worth briefly resuming the *prima facie* principles arising from principlist bioethics: beneficence, doing good, avoiding paternalism and preserving the dignity of the patient; no maleficence, do no harm or cause harm; autonomy, respect the freedom of action of the individual, and justice, equal treatment without distinction. Nunes<sup>4</sup> complements these principles with that of vulnerability, which etymologically indicates the possibility of being hurt, and for bioethics demonstrates how much the individual should be respected in his fragility. Since the disease reduces the subject’s autonomy, he must be protected and protected without paternalism.

Thus, bioethics proposes reflections to health professionals to promote true care to patients, not just the maintenance of life at all costs. Thinking about ethics in scientific development implies recognizing boundaries because if the purpose of science is to improve people’s lives and social life, some ethical limits and the infinite horizon of the appetite for scientific knowledge must be equated<sup>5</sup>.

These reflections, according to Alves and collaborators<sup>6</sup>, offer necessary subsidies to make decisions regarding life, death, dignity, solidarity, vulnerability, responsibility, and quality of life, always with a view to humanitarian assistance. In general, the bioethical discussions about terminality are based on three concepts: euthanasia, dysthanasia, and orthothanasia.

## Euthanasia

Legalized in the Netherlands, Belgium, and other countries, euthanasia has been increasingly debated in the media, the judiciary, and society at large, including several controversies surrounding terminally ill patients, particularly those in a vegetative state. Brandalise and collaborators<sup>7</sup> report religious and moral conflicts involving the issue, such as the risk of the patient not having control over this type of choice, especially in the case of the elderly and people with disabilities, which could lead to abuse.

In countries where euthanasia is permitted, the patient’s free and voluntary request and careful assessment of this request are required to verify that the suffering is really intolerable and there is no prospect of cure or improvement. Still, the law authorizes euthanasia only in extreme cases, and the doctor should perform it after the similar opinion of another independent professional colleague<sup>1</sup>.

Although this option has gained space in the media, it is much less practiced than dysthanasia, especially in intensive care units (ICU), where therapeutic obstinacy is so frequent that Alves and collaborators<sup>6</sup> consider them cathedrals of human suffering. To the ethical questions of respect for life is added the question of technical-scientific progress, which increases the hope of cure, but can simply prolong the process of dying: *in the struggle for life against death, a whole arsenal of technology is used that in practice death is translated as if it were a disease for which we had to find a cure at all costs!*<sup>8</sup>

## Dysthanasia

Talking about dysthanasia is still something uncommon in the Brazilian academic environment, especially in the health area, unlike euthanasia, which is frequently discussed<sup>7</sup>. The prefix “dis” refers to remoteness, thus meaning an exaggerated

prolongation of dying. Medical action to save a terminally ill patient, causing suffering to him (therapeutic obstinacy)<sup>9</sup>.

Dysthanasia is always the result of a certain medical action whose therapeutic measure becomes more harmful than beneficial<sup>9</sup>. According to Lepargneur<sup>10</sup>, therapeutic obstinacy is related to the medical team's fear of the responsibility of letting a patient die because they did not do everything within their reach to save him, however painfully or unconsciously. Lepargneur also points out that useless care-based medical conduct is less prone to neglect or malpractice lawsuits.

### Orthothanasia

Located between euthanasia (the abbreviation of life) and dysthanasia (the prolongation of life at all costs), orthothanasia, according to Pessini<sup>1</sup>, is the ethical synthesis of the values of "dying with dignity" and "respect for human life". The patient, his family and friends, in the face of imminent and inevitable death, are assisted by the professional team to face the facts with serenity.

According to Lepargneur<sup>10</sup>, orthothanasia consists of the reasonable acceptance of natural death, including suspending or waiving life support equipment and treatment, even when the patient is unconscious. This option does not dispense with analgesic measures or possible human care, with religious and psychological attention. Thus, there is a choice to make the process of dying smoother, without neglecting the quality of life at this delicate time, through the so-called "palliative care". Thus, orthothanasia constitutes therapeutic measures aimed at humanized death, surrounded by the necessary care.

The Latin term *pallium*, which means mantle, points to the essence of palliative care: to alleviate the effects of incurable diseases or to offer a "mantle" to those who are cold because they can no longer be helped by curative medicine<sup>11</sup>. This practice emerged in the UK in the 1960s, pioneered by Cicely Saunders. A physician, social worker, and nurse, she emphasized pain relief by considering organic, social, psycho-emotional, and spiritual aspects<sup>12</sup>.

In this context is physiotherapy, a profession whose history is confused with that of medicine, being considered a field of action, not an area of knowledge, as reported by Badaró<sup>5</sup>. Physiotherapy includes several specialties, which may face incurable patients, such as those admitted to the ICU and those

affected by neurodegenerative diseases. Badaró<sup>5</sup> points out that the striking feature of this field is the therapeutic approach so that the professional can be seen by the patient as a trusted person, a friend.

Considering that physiotherapists often treat terminally ill people, Silva<sup>13</sup> emphasizes the need for relational and dynamic training of these professionals, considering that the end-of-life process is complex and involves many conflicts. Moreover, it is important for the physiotherapist to have academic training focused not only on technical performance but also on ethical issues.

### Results and discussion

In his work "On death and dying", Kübler-Ross<sup>14</sup> questions about the real demands of the terminally ill and those around them, family members and care staff, reflecting on how they deal with the situation. Often the sick person is surrounded by people who monitor each heartbeat but are unwilling to hear about their needs, anxieties, and doubts.

According to Kübler-Ross, health professionals are increasingly adopting a technician approach to the detriment of doctor-patient interaction, as, among other reasons, death causes team members and families to break the false sense of immortality. The author describes dialogues she had with terminal patients in an attempt to create a more human bond and stimulate reflection in other professionals about the meaning of their work and life itself.

For Kovács<sup>11</sup>, in the context of bioethics, the difficulty in dealing with the issue of death and with terminally ill people stems mainly from the confusion between the concepts of euthanasia, orthothanasia, and dysthanasia. At this point, there are also palliative care that rescue, from the second half of the twentieth century, the possibility of humanizing death, contrary to what was being imposed on the medical scenario, ie the view of death as a circumstance to be overcome. No room for acceptance.

Palliative care is the principle of prevention and relief of suffering, intended for patients in clinical conditions that threaten the continuity of life. They arise with the advancement of health technologies in hospitals and seek to prioritize the control of pain and other symptoms associated with each case, to provide a better quality of life to the sick person<sup>15</sup>.

From the perspective of bioethics, human dignity is the fundamental value of the ethics of

palliative care. According to Pessini<sup>1</sup>, in the eyes of bioethics, palliative care assumes that the incurable or terminally ill person should be treated as a person, never as a biological residue by whom nothing can be done. Caregivers should be aware of their assignments to the terminally ill patient to assess pain, assessing benefits (beneficence) and risks (non-maleficence) of each case, and procedures to avoid futile treatment (dysthanasia), unrelated to the goals of palliative care<sup>16</sup>.

Kovács<sup>11</sup> emphasizes the need for health professionals to have action and training focused on the ethics of palliative care, since this knowledge broadens the view on life and death phenomena, allowing a better discussion with patients and their families. The health professional should not only worry about “treating the disease” or “relieving physical pain”, even if it is fundamental, but also about knowing how to listen, understand and welcome the patient, establishing a relationship of openness, understanding, and trust.

### Palliative care and physiotherapy

The practice of palliative care requires professionals prepared to work in different sections of hospitals, clinics or even at home, seeking to provide maximum physical and psychological well-being for the terminally ill, without omitting the religious dimension, if desired of the patient<sup>2</sup>. According to Silva<sup>13</sup>, restricting treatment to palliative care is not enough to identify the impossibility of a curative approach, but also to define when a given therapeutic or clinical measure will not provide well-being to the patient, but their survival in suffering.

Machado, Pessini and Hossne<sup>16</sup> emphasize that health professionals need to develop the ability to be with the sick person and the family. According to the authors, the academic background of these professionals usually does not go deeply into issues of how to deal with the end of life and the process of dying. Moreover, they emphasize that palliative care is a function of the multidisciplinary team, which should be prepared to alleviate the suffering, fear, and distress of patients and families. Thus, it is necessary to reflect from the beginning of university graduation on ethical issues in the process of dying and on the best way to treat these patients.

Palliative physiotherapy<sup>12</sup> uses resources aimed at relieving pain and promoting quality of life, respiratory and/or motor well-being of the

terminally ill. Thus, the professional should properly assess the patient in the first contact, getting to know their physical needs and the environment that surrounds them.

In physical therapy practice, touch is frequent, and this acquires dimension that goes beyond the technical aspect. Montagu<sup>17</sup> highlights the importance of touch in caring for those who no longer correspond as expected, especially in old age, when one sees the increasingly close finitude. In a context of need and weakness, touch has a vital function for those who suffer. When the distance is reduced, the patient feels more welcomed, worthy of affection.

### Physiotherapy, bioethics and the terminality of life

Dealing with the patient’s death and dying generates feelings of helplessness, frustration, and insecurity in the health professional because theoretically, their goal is to save lives<sup>13</sup>. Similarly, physiotherapists also face death situations for which they do not always feel prepared. In these cases, common in home care for terminally ill patients, physiotherapists seek to improve motor, sensory and neurological functions, in addition to treating pain with various resources, prioritizing reducing the patient’s suffering, but also suffering from end-of-life frustration.

It is necessary to invest appropriately in the training of these physiotherapists, as in other health professionals, regarding the fundamentals of bioethics, especially regarding the essential relationship between therapist and patient<sup>18</sup>. The approach to these questions in physiotherapy is based on the four principles proposed by Beauchamp and Childress, as pointed out by Schuh and Albuquerque<sup>19</sup>. With the development of the profession and the evolution of health and education, autonomy and ethical dilemmas are increasingly present in the life of the physiotherapist, which reflects directly on the care of the patient. Thus, it is an extremely important approach to good professional performance<sup>6</sup>.

Pessini<sup>9</sup> stresses that rehabilitation is one of the goals of palliative medicine. Many terminally ill patients are unnecessarily restricted by family members, while they could still perform some activities that would improve their self-esteem and dignity. The author also reports that some palliative care programs have an overprotective approach,

adopting longer hospitalization times. In such cases, rehabilitation is important for the patient to live as actively as possible until the moment of death. It is about emphasizing the patient's *doing* rather than being *attended to*.

Silva<sup>13</sup> describes the importance of physiotherapists being aware of this issue related to death, observing the conflicts found in the situation of terminally ill patients. The author defends the inclusion of such reflections since the beginning of professional education, aiming to develop and stimulate the ethical analysis of cases. Thus, reflection based on bioethics becomes a tool to promote truly humanitarian care:

*Physiotherapy ethics shares its most important issues with the calls to medical ethics, bioethics and ethics in general. Physical therapists are concerned about their responsibilities to patients, the values inherent in the goals of physical therapy, the appropriate decisions about patient care, the ethics of the relationship between professionals and the social responsibilities of the profession*<sup>21</sup>.

About the training of the physiotherapist, Schuh and Albuquerque<sup>19</sup> mention the fact that several authors emphasize the importance of the study of bioethics and the deepening of the discussion by analyzing practical examples from each area. Badaró and Guilhem<sup>18</sup> indicate that the main issues involving ethics and physiotherapy are limited to legal and deontological aspects, and currently there are few studies focused on the participation of physiotherapists in the context of palliative care. Nevertheless, these studies are pioneers in bringing this reflection to the field of physical therapy.

A study by Machado, Pessini and Hossne<sup>16</sup> with 58 professionals (21 physiotherapists, 25 nurses and 12 doctors) reveals that most physiotherapists are not yet familiar with the meaning of terms such as "end of life". As for the academic background, 81% of respondents denied having studied the "end of life" theme; 62% stated that the course did not address the subject of "death", 71% denied having seen palliative care content, and 95% denied the approach to dysthanasia. Given these results, Silva<sup>13</sup> describes several conflicts and experiences of physical therapists regarding terminal patients. Professionals recognize the importance of their performance in these cases, but report difficulties in dealing with issues such as patient autonomy and the feelings involved in these situations.

### Final considerations

It is concluded that death and the process of dying are present events in the professional experience of the physical therapist. However, the topic is not sufficiently addressed in academic training. Therefore, it is necessary to emphasize the theme and its scientific foundations so that the future physiotherapist is better prepared to deal with both the bioethical issues related to the finitude of life and the practical care for people in this condition.

In any case, it is important to emphasize that physical therapy is constantly evolving, and the tendency is for professionals in this field of medicine to take an increasingly effective posture in these discussions, as ethical dilemmas become more present in their work experience.

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