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# Perception of physiotherapists on bioethical aspects in palliative care

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#### **Abstract**

The study investigates physiotherapists' perception on bioethical aspects involving care to patients without therapeutic possibilities of cure. This is a cross-sectional, descriptive study with professionals from the Regional Council of Physical Therapy and Occupational Therapy of the First Region. A survey questionnaire was applied based on the principles of autonomy, beneficence, non-maleficence, and justice. Results showed that most professionals work with patients with no therapeutic possibility of cure, consider the decision-making process during care to be extremely relevant, respect the patient's will, seek to defend the principle of beneficence, and recognize the importance of bioethics and ethical discussions in academic education. In conclusion, physiotherapists seek to make ethical decisions, but there is a conflict of values regarding principles such as autonomy and beneficence.

**Keywords:** Bioethics. Ethics. Palliative care. Health personnel. Physical therapy specialty.

#### Resumo

## Percepção de fisioterapeutas sobre aspectos bioéticos em cuidados paliativos

O objetivo do estudo é investigar a percepção de fisioterapeutas sobre aspectos bioéticos que envolvem o atendimento a pacientes sem possibilidades terapêuticas de cura. Trata-se de estudo transversal, descritivo, com profissionais do Conselho Regional de Fisioterapia e Terapia Ocupacional da Primeira Região. Foi aplicado questionário tipo *survey*, baseado nos princípios de autonomia, beneficência, não maleficência e justiça. Os resultados mostraram que a maioria dos profissionais atua com pacientes sem possibilidade terapêutica de cura, considera extremamente relevante o processo de tomada de decisão durante o atendimento, respeita a vontade do paciente, busca defender o princípio da beneficência e reconhece a importância da bioética e das discussões éticas na formação acadêmica. Conclui-se que os fisioterapeutas buscam tomar decisões de modo ético, mas há conflito de valores no que se refere a princípios como autonomia e beneficência.

Palavras-chave: Bioética. Ética. Cuidados paliativos. Pessoal de saúde. Fisioterapia.

## Resumen

## Percepción de fisioterapeutas sobre los aspectos bioéticos que involucran los cuidados paliativos

El objetivo del estudio es investigar la percepción de fisioterapeutas sobre los aspectos bioéticos que involucran el cuidado de pacientes sin posibilidades terapéuticas de curación. Se realizó un estudio descriptivo transversal con profesionales del Consejo Regional de Fisioterapia y Terapia Ocupacional de la Primera Región. Se aplicó un cuestionario de encuesta basado en los principios de autonomía, beneficencia, no maleficencia y justicia. Los resultados mostraron que la mayoría de los profesionales trabajan con pacientes sin posibilidad terapéutica de cura, consideran de extrema relevancia el proceso de toma de decisiones durante el cuidado, respetan la voluntad del paciente, buscan defender el principio de beneficencia y reconocen la importancia de la bioética y de las discusiones éticas en la educación académica. Se concluye que los fisioterapeutas buscan tomar decisiones de forma ética, pero existe un conflicto de valores en torno a principios como la autonomía y la beneficencia.

Palabras clave: Bioética. Ética. Cuidados paliativos. Personal de salud. Fisioterapia.

The author declares no conflict of interest. Approval CEP-IESC-UFRJ 2.419.989 With the increase in the number of cases of chronic and degenerative diseases, cancers, dementia, and other pathologies, palliative care emerges as an example of comprehensive care to individuals, meeting their desires and needs. In the clinical routine, it is common for physiotherapists to face ethical issues, which intensifies when treating patients with no therapeutic possibilities of cure, an issue that involves other types of questioning.

Understand the uncertainties involved in this context and how professionals position themselves before the conflict is fundamental for the ethical foundation of care. According to Gracia, the study of such dilemmas does not aim to resolve them definitively, but, first of all, to understand them correctly, comprehending different arguments, their weight and limitations, so that we can have sufficient elements to make thoughtful and prudent judgments <sup>1</sup>.

Considering that the physiotherapist's clinical decision-making is essential for patient care without therapeutic possibilities of cure and that Brazilian studies on the subject are still scarce, the relevance of this study is prominent. It aims to investigate bioethical aspects that involve physiotherapeutic care to these patients, searching to understand the ethical criteria that these professionals rely on.

Several questions permeate clinical practice, especially regarding the end of life. For physiotherapists, issues such as therapeutic limitation and lack of resources are experienced as ethical dilemmas. But what do these professionals consider when they need to make decisions involving patients without chances of cure? This study also aims to contribute to understand this process.

## Materials and method

This is a descriptive, cross-sectional survey conducted with professionals registered in the Regional Council of Physical Therapy and Occupational Therapy of the First Region (Crefito 1)<sup>2</sup>. Data were collected via internet using a semi-structured questionnaire in the states of Alagoas, Paraíba, Pernambuco, and Rio Grande do Norte, based on a

partnership established with Crefito 1 between December 2017 and January 2018.

Crefito 1 is a federal agency of last resort established by Law 6,316/1975 ³, which created the Federal Council (Coffito) and the regional councils of physiotherapy and occupational therapy. These entities were created to supervise the exercise of these professionals ². Among their roles is to standardize ethical, scientific, and social issues and inspect companies that provide physical therapy assistance ³. Crefito 1 covers four states in the Brazilian Northeast: Alagoas, Paraíba, Pernambuco, and Rio Grande do Norte ².

According to article 3 of Resolution Coffito 424/2013<sup>4</sup>, the profession can only be exercised by those registered in the Regional Council of their working region. All professionals registered in Crefito 1 who agreed to participate in the research were included in the sample. Those who lacked an electronic mail registered in the Council were excluded.

Data was collected using a questionnaire on bioethical aspects of physiotherapy care for terminally ill patients. The instrument was built based on the Physical Therapy Code of Ethics and Deontology <sup>4</sup>, which converges in its provisions with the principlist approach to bioethics, emphasizing autonomy and beneficence. The works of Barnitt <sup>5</sup> and Renner, Goldim and Prati <sup>6</sup>, were also used as a reference.

The answers were presented on a five-point Likert scale (ranging from 1, not relevant, up to 5, extremely relevant), with space for suggestions and comments. The questionnaire was applied using the LimeSurvey program, which reduces possible biases caused by the interviewers' presence and has advantages such as low cost, easy access, and the possibility of being applied remotely. The data was organized in a Microsoft Office Excel spreadsheet and analyzed according to the findings.

The instrument was sent by Crefito 1 simultaneously to all registered professionals, along with an invitation letter for participating in the research, including instructions on how to fill the questionnaire and return it. The invitation had a password-protected link that led to a home page with the informed consent form (ICF).

This document needed to be read and accepted by the participants to access the questionnaire.

Upon finishing filling out the instrument, the participants received a copy of the ICF via e-mail. The research followed the ethical criteria established in Resolution 466/2012 of the National Health Council <sup>7</sup>. The invited professionals were duly informed about the objectives and methods of the study, and those who agreed to participate expressed their consent.

## Results and discussion

Thirty days after the invitations were sent, only 50 (0.3%) of the 17,000 questionnaires sent were answered. Of the total respondents, 32 (64%) were female, 16 (32%) were male, and two (4%) did not declare their gender. A similar trend towards greater female participation was found by Pereira<sup>8</sup>, and Renner, Goldim and Prati<sup>6</sup>. According to the National Institute of Educational Studies and Research Anísio Teixeira<sup>9</sup>, in 2015 the number of female graduates (548,682) in Brazilian undergraduate courses was considerably higher than of male graduates (367,681). The difference in the number of returns to the invitation is perhaps due to this greater presence of women in the academic-professional scene.

Participants' average age was 27.51 years (24-46 years), and the respondents had graduated, on average, five years ago. This profile contrasts with that of Guardia Mancilla and collaborators <sup>10</sup>, in which their average age was 44.58 years, with an average training time of 20 years. However, this finding is similar to Pereira's study <sup>8</sup>, in which 42% of the sample graduated up to 5 years ago.

Pernambuco was the state where more physical therapists worked with terminally ill patients. Among the cities considered in the research, Pernambuco has the largest number of higher education institutions and the largest population <sup>11</sup>.

Most physiotherapists had only a bachelor's degree (44%), followed by those with specialization (32%) and master's degree (24%). As for the most representative specializations, 32% of the participants said they work in the trauma-orthopedic

area, and 16% in gerontology; the other 52% were dispersed in other areas. In Pereira<sup>8</sup>, the most prevalent area of expertise was orthopedics, while Renner, Goldim and Prati<sup>6</sup> found great variation. Both studies, therefore, converge with the present research.

When asked if they worked with patients with incurable conditions, 72% answered "yes," 22% "no," and 6% did not answer this question. Most respondents, therefore, work in palliative care.

The second part of the questionnaire asked participants to rate several statements on a relevance scale from 1 (not relevant) to 5 (extremely relevant). Regarding decision-making during physical therapy, 54% answered that it is extremely relevant. Machado, Pessini, and Hossne 12 ratify this data when highlighting that the daily routine of professionals who work with end-of-life patients is permeated by dilemmas that require preparation to make decisions.

Most of the sample (68%) also considered the discussion of ethical conflicts in teams to be extremely relevant. When discussing the topic, Machado, Pessini, and Hossne <sup>12</sup> emphasize that palliative care needs bioethical reflections so that the team's decisions are based on respect for the patient's autonomy and dignity.

Regarding the patient's will, 46% answered that it is extremely relevant to respect it, once again confirming what Machado, Pessini, and Hossne <sup>12</sup> propose. To consider autonomy as important for professional practice means complying with the Code of Ethics and Deontology of Physical Therapy <sup>4</sup>.

Besides autonomy, respect for the principle of beneficence was also observed, as 56% of the participants deemed it extremely relevant, in a stance that can be considered principlist <sup>13,14</sup>. However, the principle of beneficence is the one that most often conflicts with autonomy. On one hand, patients need to have their decisions respected; on the other, medical practice often opposes the patient's will in the name of beneficence, falling into paternalistic attitudes <sup>15</sup>.

The sample's principlist inclination is confirmed by the fact that 42% of respondents consider it extremely relevant to make decisions based on the idea of justice. Beauchamp and Childress emphasize that no single moral

principle can address all the problems of justice <sup>16</sup>. Thus, "decide with justice" is understood as considering all the patient's rights, while to decide with injustice is to deprive them of their rights, failing to distribute the benefits.

In Brazil, the most used bioethical model is principlism, based on autonomy, beneficence, non-maleficence, and justice <sup>15</sup>. In a literature review on Brazilian articles relating physiotherapy and bioethics, Lorenzo and Bueno <sup>17</sup> pointed out that all analyzed studies referred to the principlist trend. According to Beauchamp and Childress, founders of this approach, the principles are general guidelines that leave room for specific judgment in specific cases and explicitly help develop more detailed rules and lines of action <sup>16</sup>. These principles, therefore, are not absolute, and there is no hierarchy between them.

Pessini and Bertachini <sup>18</sup> revealed the principlist trend in palliative care by emphasizing the World Health Organization principles for this type of assistance. The questionnaire developed for the present research included questions related to the principlist theory without presenting the concepts of the approach. In the study by Renner, Goldim, and Prati<sup>6</sup>, which provided definitions, professionals were unable to correlate principles and practice.

As for the professionals' lack of financial resources for treating patients, we observed more split results: 25% of them considered this point relevant, but there was no consensus. However, based on studies such as that of Silva, Lima, and Seidl <sup>19</sup> we note that financial problems can affect the performance of health professionals who work in palliative care, interfering with their view of justice.

Regarding the patient's financial resources, the result is similar to the previous question: 26% of the respondents considered this issue a critical ethical conflict, but many rated it as little (14%) or not relevant (8%). This shows a lack of reflection on bioethical aspects from a significant part of the participants, since the issue is significant. This type of ignorance points to the dehumanization of care, with professionals tending to value critical patient management and discuss the clinical decision without entering the subjective universe <sup>19</sup>.

When asked if the lack of financial resources in the hospital, clinic, or health unit would constitute an ethical conflict, 42% answered that this point is extremely important. This indicates that the research participants perceive the institution's financial responsibility as more crucial than the professionals' and patients' resources.

Regarding communication with the patient and respect for bioethical principles, participants were asked how relevant it is to tell the sick person the truth. Most physiotherapists considered this issue an extremely pertinent ethical conflict (46%). On the subject, Kovács <sup>20</sup> states that it is no longer acceptable to discuss the duty to inform, being an essential part of the process of dying with dignity.

Another ethical conflict that can emerge in the physiotherapists' daily routine is the need to limit the efficiency of a therapy in favor of learning, an issue considered extremely consistent by 44% of the participants. Such conflict is also part of the communication process, with professionals being required to consider bioethical principles in decision-making, always respecting the patients' rights, especially the right to die with dignity <sup>19-21</sup>.

Concerning physical therapy practice with end-of-life patients in a hospital environment, 54% considered this conflict extremely relevant. In this sense, the physiotherapist's importance in palliative care is confirmed, contributing to the quality of life of the terminally ill and increasing the chances of dying with dignity.

As Silva, Lima, and Seidl point out, the performance of this professional is fundamental throughout the health-disease process, as it contributes to health promotion, treatment, rehabilitation, and prevention of diseases, as well as palliative care, with emphasis on quality of life, a vital precept incorporated into the new Code of Ethics and Deontology of Physical Therapy (...). The physiotherapist who works with palliative care also uses resources to relieve pain. For this type of work, some therapeutic procedures will be available to reduce pain and suffering and assist in their management <sup>22</sup>.

Oliveira, Bombarda, and Moriguchi <sup>23</sup> studied physical therapy in palliative care in primary

care and found that professionals are still more focused on rehabilitation. But its insertion in primary care could significantly contribute to reduce symptoms and improve the patient's quality of life.

On the physiotherapist's importance in palliative care, and more specifically on home care, 52% of the respondents considered this an important issue. Silva, Lima, and Seidl <sup>19</sup> ratify the physiotherapist's purpose in home care for dying patients; but they stress the question of better preparing these professionals based on bioethics, considering that the family environment also brings ethical conflicts, mainly related to the limit of therapeutic action and the patient's lack of autonomy.

The present research allowed us to verify deficiencies in the participants' knowledge about palliative care and bioethics, although 80% of the sample rated the discipline of bioethics as essential in undergraduate studies. Its importance for physical therapy training is indisputable, considering that ethical conflicts are inevitable, requiring the professional to be prepared to deal with them <sup>19-21</sup>. But despite advances, bioethics is still embryonic in physical therapy courses <sup>24,25</sup>.

Regarding the discussion of ethical conflicts during undergraduate studies, 82% of participants considered this practice extremely relevant. Silva, Lima, and Seidl <sup>19</sup> confirm this, but highlighting the incipiency of such a debate in the physiotherapist's academic education, especially concerning palliative care and terminality of life.

Ladeira, Silva Junior, and Koifman <sup>26</sup>, in a research with physical therapy students from a Brazilian federal university, point out that it is essential to reconsider academic education to promote more direct and firm decision-making. In the same vein, Santos <sup>27</sup>, in a study with professors from higher education institutions in the state of Rio de Janeiro, concluded that most of them do not perceive ethical problems related to confidentiality or privacy of individuals, observing only professional and deontological issues.

Based on these studies, we see that higher education in physical therapy does not contemplate the students' ethical training, remaining focused on applying therapeutic techniques. But as Bispo Júnior <sup>28</sup> points out, professional training models should be built from the relationship between social issues and physiotherapeutic knowledge, and the courses need to contribute to transforming society.

In the present study, when asked if they could identify and describe any ethical conflict in their practice, 72% of them answered "yes," 24% "no," and 4% left the question unanswered. Only 65% actually described an ethical conflict. Six (12%) physiotherapists pointed out respect for autonomy as an ethical conflict, and another three (6%) mentioned the limits of professional performance, describing therapeutic programs pre-established by doctors. Two (4%) participants described issues related to decision making, raising concerns about deliberations not shared among the team, besides patients and family members. Other dilemmas mentioned concerned the therapeutic futility related to palliative care, the problem of not telling the truth to patients and their families (often related to the difficulty, or even fear, of communicating bad news), and the patient's lack of financial resources. Two statements showed a lack of understanding about palliative care.

Santos and collaborators <sup>29</sup> analyzed the understanding of nurses, physicians, nutritionists and physiotherapists about care for end-of-life patients in an oncology ICU. The authors found some misunderstandings, confirming that professionals experience difficulties in identifying ethical dilemmas. Oliveira and Rosa <sup>30</sup> reached a similar result in a study with surgical center nurses, in which dilemmas were wrongly understood as decisions in (...) experienced situations <sup>31</sup> and conflicts as divergence of opinions <sup>31</sup>.

This lack of understanding about bioethical issues may have affected the present study – as in Renner, Goldim and Prati 6, and Pereira 8 – since adherence to the research was small, and in many cases the answers to the questionnaire were not pertinent.

## Final considerations

The physiotherapists who answered the questionnaire had, on average, five years of

training, suggesting a greater interest in the topic among recent graduates. From the answers obtained, we conclude that decision-making and discussion among the team are critical in clinical practice for these professionals. However, they report a lack of real autonomy to decide, since patients often arrive with a physician's plan.

Physiotherapists show concern in respecting the sick person's wishes and not adopting conducts that may cause harm. These were the main criteria reported for therapeutic decisions when treating an end-of-life patient. However, we noticed a particular difficulty in describing situations of ethical conflicts experienced in practice. The answers obtained show that many dilemmas are linked to the professionals' lack of technical-scientific preparation, perhaps due to deficient academic training. Conflicts exist, permeate professional practice, influence conduct, but are solved without much reflection.

The results reinforce the importance of training professionals capable of dealing with

ethical issues. This importance is recognized by most respondents, who said a discipline related to bioethics is pertinent in undergraduate studies.

The research data must be interpreted considering its limitations. There was little adherence to the study by physiotherapists, either because of the short time to answer the questionnaire (30 days) or because the individuals are not used to answering surveys by e-mail. Besides, the questionnaire never described or defined what a conflict or ethical dilemma would be. If this concept had been explained in the instrument, the number of professionals who could describe dilemmas would have possibly been greater.

Palliative care is on the rise in Brazil, and the figure of the physiotherapist has been highlighted, reaffirming the importance of multidisciplinary teams in this type of care. But the discussions on palliative care and bioethics have much yet to evolve, integrating this knowledge from the beginning of academic training.

This article was based on a master's thesis presented to the Graduate Program in Bioethics, Applied Ethics, and Collective Health at Universidade Federal do Rio de Janeiro.

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