# **Bioethical conflicts: in physiotherapy home care for terminal patients**

Lízia Fabíola Almeida Silva<sup>1</sup>, Maria da Glória Lima<sup>2</sup>, Eliane Maria Fleury Seidl<sup>3</sup>

### Abstract

The bioethical debate gives rise to considerations that foster understanding of death and terminal illness, in order to ensure compliance with principles such as respect for autonomy, beneficence, not maleficence, and human rights. The objective of the study was to analyze bioethical conflicts-related to physiotherapy home care for terminal patients. This is a qualitative descriptive study. Ten physiotherapists from the Federal District, Brazil, participated, answering a semi-structured interview. Two categories were identified: "challenges of home care for patients with terminal conditions"; and "polarization of physiotherapists between technicality and humanism". The study reveals potential bioethical conflicts in the care of these patients and their families, in which the limits for the use of therapeutic resources translate into opposite approaches – either attachment or detachment – and the challenge of promoting care guided by humanization and human dignity. **Keywords:** Bioethics. Ethics. Physiotherapy. Palliative care of terminal patients.

#### Resumo

#### Conflitos bioéticos: atendimento fisioterapêutico domiciliar a pacientes em condição de terminalidade

O debate bioético enseja reflexões que propiciam a compreensão da morte e da terminalidade de modo a assegurar a observância de princípios como respeito à autonomia, beneficência e não maleficência e os direitos humanos. O objetivo do estudo foi analisar conflitos bioéticos no trabalho de fisioterapeutas em atendimento domiciliar a pacientes em condição de terminalidade. Trata-se de estudo qualitativo e descritivo. Dez fisioterapeutas do Distrito Federal participaram, respondendo a entrevista semiestruturada. Duas categorias foram identificadas: "desafios da atuação em domicílio com pacientes em condição de terminalidade"; e "o fisioterapeuta entre o tecnicismo e o humanismo". O estudo descortina conflitos bioéticos potenciais no atendimento a esses pacientes e seus familiares, em que os limites para a utilização dos recursos terapêuticos se traduzem em posturas polarizadas – de aproximação ou distanciamento – e o desafio de promover cuidado pautado na humanização e na dignidade humana.

Palavras-chave: Bioética. Ética. Fisioterapia. Cuidados paliativos na terminalidade da vida.

#### Resumen

# Conflictos bioéticos: atención fisioterapéutica domiciliaria a pacientes en condiciones terminales

El debate bioético da lugar a reflexiones que propician la comprensión de la muerte y de la terminalidad, con el fin de garantizar el cumplimiento de los principios como el respeto a la autonomía, la beneficencia y la no maleficencia y los derechos humanos. El objetivo del estudio fue analizar los conflictos bioéticos en el trabajo de los fisioterapeutas en la atención domiciliaria a pacientes en situación de terminalidad. Se trata de un estudio descriptivo y cualitativo. Participaron diez fisioterapeutas del Distrito Federal, Brasil, respondiendo a una entrevista semiestructurada. Se identificaron dos categorías: "desafíos de la atención domiciliaria con pacientes en condición de terminalidad"; y "el fisioterapeuta entre el tecnicismo y el humanismo". El estudio revela posibles conflictos bioéticos en la atención de estos pacientes y sus familias, donde los límites para el uso de los recursos terapéuticos se traducen en posiciones polarizadas – de aproximación o distanciamiento – y el desafío de promover una atención basada en la humanización y la dignidad humana. **Palabras clave:** Bioética. Ética. Fisioterapia. Cuidados paliativos al final de la vida.

#### Aprovação CEP-FS/UnB 036/2010.

1. Mestre liziafabiola@gmail.com.br – Universidade de Brasília (UnB) 2. Doutora limamg@unb.br – UnB 3. Doutora seidl@unb.br – UnB, Brasília/DF, Brasil.

#### Correspondência

Lízia Fabíola Almeida Silva – SMPW Quadra 25, conjunto 2, lote 5, casa A, Residencial Alto do Vale CEP 71745-502. Brasília/DF, Brasil.

Declaram não haver conflito de interesse.

What makes the question of terminality, in the context of palliative care, so evident in the world of bioethical discussions? Certainly because conflicting dimensions arise that pervade the preservation of life at all costs and deal with death, as well as the promotion of human dignity. They are complex topics, loaded with values and moral judgments, which professionals can face difficulties in dealing with due to the relationship of care with the person who is out of therapeutic possibilities.

There are advances in medicine and biotechnology, new mechanisms of life extension, along with the expectations of families, and the legal and cultural aspects of each social group involved. The bioethical debate has allowed important reflections to understand the phenomenon of death in order to ensure the observance of principles based on respect for autonomy, based on the practice of beneficence and non-maleficence, and on human rights, contributing to the humanization of health care<sup>1</sup>.

In this sense, according to Sigueira, Zoboli and Kipper<sup>2</sup>, the end of life became one of the convergent poles of the ethical challenges of the contemporary world. For Singer<sup>3</sup>, the advancement of medical technology has forced us to think about issues we had not faced previously. These issues can perpetuate a life without cure, as in the case of patients - mainly elderly patients with oncological diseases, dementia, severe neurological sequelae - undergoing high-tech, often unnecessary, invasive procedures. In these cases, the suffering of the person kept in bed, controlled by artificial respiration, with body scabs and strong pains, is disregarded, thereby damaging the quality of life of patients and their relatives. This form of treatment is based on the ethics of healing, to the detriment of the ethics of attention to the person, which is based on the centrality of care and human dignity<sup>4</sup>.

Palliative care has as ethical principles the understanding of death as a natural process, respect for life and human dignity, which are important premises for the work of health professionals<sup>4</sup>. However, the literature researched highlights the difficulty of professionals in different health areas to care for and promote the dignity of patients with no possibility of cure and at the end of their life. According to Pessini and Bertachini<sup>5</sup>, the World Health Organization has among its premises the work in a multidisciplinary palliative care team, including, as one of its members, the physiotherapy professional.

The work of the physiotherapist is fundamental in the entire health-disease process, as it contributes to the promotion of health, treatment, rehabilitation and prevention of further harm, as well as palliative care, with an emphasis on quality of life, an important precept incorporated into the new Code of Ethics and Deontology of Physical Therapy (Código de Ética e Deontologia da Fisioterapia)<sup>6</sup>. To perform their work, physiotherapy practitioners use manual techniques, mechanotherapy, and thermodigital electrotherapy resources and, as a general practitioner, work in the most diverse areas of health: respiratory<sup>7</sup>, neurology<sup>8</sup>, orthopedic trauma<sup>9</sup>, gynecology<sup>10</sup>. For example, in the case of patients in a severe state, confined to bed and submitted to artificial respiration, the physiotherapist usually monitors the parameters of mechanical ventilation and performs procedures aimed at maintenance and/or the patient's quality of life  $^{6,11}$ .

Physiotherapists who work with palliative care also use resources to relieve pain. For this type of work, the professional will have available some therapeutic procedures that may reduce the pain and suffering of the patient and help in its management. The professional is also responsible for the initial evaluation to identify the physical and psychosocial needs, as well as aspects of the environment where the patient is situated. However, before beginning any procedure, physiotherapists should inquire about the patient's desire - if he / she is able to choose and make decisions - to receive physiotherapeutic treatment. Failure to comply with the patient's consent regarding the procedures to be performed may result in bioethical conflict, violating respect for autonomy<sup>12</sup>.

It is worth emphasizing the fact that the subject of palliative care and the end of life is still little discussed in the academic training of physiotherapy students, an area that demands the future professional contributes to the psychological wellbeing to deal with the pain, suffering and expectations of the person and family members regarding the physiotherapeutic treatment<sup>13</sup>. It is important that professionals know the limits of their abilities, in order not to generate unrealistic expectations and frustrations, once, as Kovács points out, *there is no solution to death, but the possibility to help die well and with dignity*<sup>14</sup>.

For Badaró and Guilhem<sup>15</sup>, the placing of physiotherapists into bioethical scenarios, such as the end of life, is still very incipient, and it is fundamental that professional education and training aim to prepare them to deal with these conflicts, by means of bioethics. It is necessary to take into account the dignity of human beings, their corporeality, the quality and sacredness of life, the benefits and potential harm caused by physiotherapeutic treatments, but without failing to consider the vulnerability and personal integrity of each patient. It is understood that bioethics, through the understanding and application of its principles, could strengthen decision making regarding the therapeutic activity of physiotherapy professionals, providing them with theoretical and practical support for the best approach to benefit the patient.

For Marques, Oliveira and Marães<sup>16</sup>, it is important that physiotherapists study the phenomenon of death, revealing the main conflicts existing in the therapeutic practice with patients in the context of death, especially those of a bioethical nature. However, the authors call attention to the importance of adopting an academic approach that is more focused on the comprehensive training of professionals - and not on technicists -, that is, on persons who, besides performing good technique, can adopt new postures regarding issues related to pain, suffering and the finitude of life, as Pessini and Bertachini<sup>17</sup> point out. For a humanized work in the field of health, Ferreira<sup>18</sup> points out that it is important to create a new culture in health and humanize the therapeutic process through professional education based on the improvement of working relationships in teams, having as a reference the respect for the human dignity.

The objective of this study was to identify and analyze bioethical conflicts in the work of physiotherapists providing home care for terminal patients. For this research, bioethics has become a tool for reflection in the face of biotechnological advances, because through these, life starts to be monitored and also prolonged<sup>14</sup>. In this sense, considering a scenario in which the aim is to increase survival, especially of terminal patients, we should also think of the humanization of care, since, according to Masiá, we are becoming more aware of the need to humanize the process of dying<sup>19</sup>. Thus, issues related to technicalism versus humanism, identified in the participants' reports and that can result in bioethical conflicts - regarding respect for autonomy, beneficence, non-maleficence and human dignity -, were also discussed in this study.

### Methodology

This is a qualitative and descriptive-exploratory study. Participants were ten physiotherapists from the Federal District, selected for convenience, who accepted the invitation published on the website of the Regional Council of Physiotherapy and Occupational Therapy of the 11<sup>th</sup> Region (Conselho Regional de Fisioterapia e Terapia Ocupacional da 11<sup>a</sup> Região - Crefito 11) and also by the Union of Physiotherapists of the Federal District (Sindicato dos Fisioterapeutas do Distrito Federal - Sindfisio).

Through the contact of the researcher responsible for the study, the physiotherapists who met the following inclusion criteria were selected: 1) to provide home care for terminal patients; and 2) to have been working with these patients for at least six months. After this selection stage, the physiotherapists were contacted, and a convenient day, time and place was scheduled with each professional, and the researcher (first author of this article) went to see them. At the time, the participants agreed and signed the free and informed consent form, according to the resolution of the Brazilian National Health Council in force at the time: Resolution CNS 196/1996 (Resolução CNS 196/1996) <sup>20</sup>. The participants were guaranteed confidentiality and anonymity, as well as assured the right to refuse to continue participation at/in the study, if they so wished, voluntarily and free of charge.

In depth interviews for data collection were carried out from May to July 2010, through a semi structured script with questions to characterize the sociodemographic profile, and four open questions about the practices of the physiotherapists involved in home care for terminal patients. In the interviews, participants were given fictitious names to preserve confidentiality. Of the ten professionals, eight were interviewed at the workplace in a reserved environment, and two were interviewed in their homes, without interruptions during the interviews, which were recorded with the consent of the participants.

The data was analyzed using the comprehensive technique for qualitative data, according to procedures described by Minayo<sup>21</sup>: transcription of interviews and organization of verbal reports, horizontal readings for cross-sectional elaboration aiming to classify data, extracts from participants' conversations for eventual comparisons, and exhaustive reading to identify units of meaning and categorization. Two categories were highlighted in this article: the challenges of home care for terminal patients and the polarization of physiotherapists between technicalism and humanism.

#### **Results and discussion**

Regarding the profile of the physiotherapists interviewed, six were women and four men, aged

between 25 and 41 years. Of the total, six were single, three married, and one divorced. Half of the physiotherapists were from the Federal District and the others from the states of Goiás, São Paulo and Minas Gerais. Respondents, with one exception, reported having religious beliefs. All of them practiced physiotherapy in the Federal District, four of whom had employment contracts within the private health network, one was a public servant of the Federal Department of Health, and the other five were self-employed. Of the ten physiotherapists, only one mentioned having attended a training course in palliative care, an aspect that may favor the development of technical and relational skills for care in the field in question.

#### Challenges of home care for terminal patients

Accordingtothetestimoniesofphysiotherapists, caring for people in terminal condition in the home environment has revealed a process permeated by feelings and emotional reactions triggered by polarized experiences, perceived at the same time as both difficult and rewarding. The feeling of anxiety was predominant in the conversation of physiotherapists. Professionals reported having experienced anxiety when perceiving patients' pain and suffering. The non-acceptance of death felt by patients, as well as by the professionals, was also a frequent emotion originating from the involvement developed throughout the therapeutic process. One participant said: "I was very distressed and that was very distressing to us, I was too distressed by that situation ... And she, what most moved us, was that she was not ready for death, she was not, she had not accepted yet that it was near "(Fernanda).

In Fernanda's account, the situation may constitute a bioethical conflict related to the principle of beneficence 12,22 because she was prepared to fulfill her professional duty to do good, to provide benefits through her therapeutic intervention, whether monitoring mechanical ventilation parameters and/or minimizing possible through thermo-photoeletric physical pain therapeutic resources. However, the professional felt distressed because the patient was terminally ill and nothing she could do within her therapeutic intervention would modify the prognosis. For Sadala and Silva<sup>23</sup>, in dealing with the finitude of life, health professionals face a situation feared by human beings, which manifests itself in feelings such as anguish and pain. In this sense, for the authors, dealing with death on a daily basis is extremely distressing and exhausting, giving rise

to feelings such as impotence, frustration and insecurity in the face of patients' suffering and failure of professional actions  $^{24}$ .

As Singer<sup>3</sup> points out, in these times of biomedical and biotechnology advances, one must rethink life and also death. The latter is governed by reflections such as the question of orthatanasia and the right to choose not to prolong suffering. It is important to prepare, in fact, not only the health team, but also the family members in the process of accepting death as a logical consequence of an irreversible and fateful process<sup>3,16</sup>. This awareness, however, is frightening and can be permeated by conflicts, because it refers to the finitude of all those involved - professionals, family members and patients themselves - who may hesitate to face this situation.

According to Moritz<sup>25</sup>, during academic education it is taught that *physicians hold the greatest responsibility for healing, exhibiting a greater sense of failure and fear of failing regarding their patients' death*. Physiotherapists are also prepared for the healing and reinsertion of patients in society, as illustrated by the words of Laís: *"we do not have this training of palliative care, we were guided in college, we were trained to rehabilitate, to reinsert the individual in the society"*. This aspect further complicates the admission of finitude in the process of coexisting with death, since in addition to perceiving oneself to be mortal, professionals may feel they failed/unsuccessful because they did not have the possibility of healing the patient.

In general, physiotherapists are prepared in their training to act with beneficence - to relieve, diminish or prevent harm, provide and balance benefits versus risks and costs <sup>6,11,12</sup> - and, although the death of terminal patients is inexorable, it is often difficult for professionals to deal with the situation and to understand that, when the therapeutic resources are exhausted, they would not be acting with maleficence (causing damage). Dealing with death is not, in fact, an easy task in a society that legally sanctifies life <sup>26</sup>.

Implementing health services aimed at professionals can also ensure better preparedness and ability to cope with the process of losing a patient<sup>27</sup>. Albuquerque<sup>28</sup> reinforces this perspective when pointing out that, in order to humanize health care, professionals must also be considered, taking into account the needs arising from the professional practice itself. Biopsychosocial training can help them cope with difficult situations. In addition, professional training for the provision of palliative care is of paramount importance when we consider that life is an inalienable right and we must be prepared to safeguard it with all possible technical diligence. However, dying with support and dignity is not yet a right provided for in Brazilian law, which *does not formally recognize the right to die*<sup>29</sup>. This fact implies, unequivocally and consequently, the deontological duty of professionals to safeguard life<sup>6,11</sup>.

Despite the advances in biotechnology in recent years, little progress has been made in teaching and bioethical discussions in Physiotherapy courses, as pointed out by Badaró<sup>15</sup> and Figueiredo<sup>30</sup>, who verified the deficiency of bioethics teaching in the physiotherapy undergraduate course. In general, the professional education of physiotherapists reveals a lack of preparation for the topic "end of life", as pointed out by a recent survey that interviewed 222 undergraduate students from the physiotherapy course at the University of Brasília. The survey revealed that 79.7% of the interviewees from the first to the tenth semester reported not having participated, in any of the courses provided, concerning any analysis or discussions regarding death<sup>31</sup>.

This data allows us to infer that conflict when dealing with patients' death arises from the moment physiotherapists encounter the reality of the professional monitoring of the terminal process, as Fernanda's words reveals: *"I had no preparation for dealing with death, on how to deal with those patients who have no prospect of functional recovery, and so I think it's a great challenge to deal with those who have no prospect of healing"*. Prepared to promote healing, to act with beneficence and not maleficence and immersed in a society that denies death, professionals are thrown into an adverse work situation, for which delicacy and empathy are required, which can end up depleting their strength, causing depression and illness.

Bioethical conflicts may arise from the therapeutic choices available to the professional. To what extent can one's conduct in fact bring benefits to the patient: to act with beneficence rather than maleficence? How to identify the limit of action without prejudice to the health of the professional? How to communicate with the health team maintaining an open relationship for joint and shared decisions, based on solidarity and cooperation?<sup>16,22,26</sup>

Physiotherapists, like other health professionals, are prepared to act with beneficence, preserving the life of their patients and reinserting

them in society, as has been occurring since the teaching of history and fundamentals of physiotherapy in undergraduate courses. However, students are not involved in discussions regarding death and the loss of patients; usually they are not encouraged to talk about their feelings during and after care practices, or about the feelings of their patients and family members, which may lead to conflicts in decision making in treatments involving bioethical issues<sup>22,32,33</sup>. It is necessary for professionals to consider the limit of biotechnology for the maintenance of life, and that they are also prepared to accept that there are limits to therapeutic intervention, recognizing the fine line between benefits and damages, not only linked to the physical body, but also to the psychosocial dimension.

# The physiotherapist between technicalism and humanism

The research pointed out polarity between eminently technical or humanistic performances, a challenge that fits with the reflection regarding bioethical conflicts. It was observed that the execution of technical procedures was predominant, using available means for the therapeutic work to be carried out without demonstrating in their speeches a concern to interact with patients as persons inserted in a psychosocial context, as shown in the following statements:

"Usually when I start a terminal patient session, I first make an evaluation of the vital data (...) finishing the session I put the patient in a better posture so that he or she will facilitate the breathing work again" (Tobias);

"Most of the terminal patients I attended required mechanical ventilation, so basically bronchial hygiene, then, this way, I really practiced bronchial hygiene with Ambu, aspiration in bed" (Amanda);

"Daily I performed the evaluation of the patient, performed aspiration when necessary, thoracic maneuvers, postural drainage, passive mobilizations and stretching to avoid deformities, respiratory exercises" (Rubens).

Although the conduct described in these statements reflects the intention to act based on beneficence, through eminently technical and objective actions, it also points out the lack of appreciation of subjective aspects, from practices such as listening to patients or dialogue with caregivers and family members. The absence of these aspects can transform professionals into *mere caretakers of diseases*, as stated by Siqueira<sup>34</sup>, or in technicians to monitor apparatuses, which implies a potentially harmful behavior (maleficence). It is possible to see that the rigid observance of the technical aspects comforts professionals, who feels that they are discharging themselves from the task of providing care in the best possible way, without compromising their emotions and feelings by the intense contact with the situation of the finitude of patients.

What can be verified with this research is that, in professional practice, appreciation of the technique occurs, especially when physiotherapists providing home care for people in terminal condition perform their work almost without verbal interaction with patients or their relatives. In this case, the greatest concern of professionals, from the first approach, is to check physical signals and move to the stage of performing the work through the chosen technique(s). This approach emphasizes the distance between professionals and patients, turning the latter into objects of the technique of the former. In these situations, the risk of ethical infraction is accentuated, especially the lack of respect for the autonomy of patients.

In contrast, when professionals manage to ally technique and a more humanized attitude, both they and the patients enjoy enriching moments during therapy, bringing comfort to a situation marked by suffering and pain. This form of professional performance can generate even greater participation of family members, who are better oriented as to how to deal with the terminal condition of patients, implementing functional adaptations and sharing their own anxieties and apprehensions. In the care of the terminal patients, an important aspect to be analyzed, especially from the bioethical perspective, is strict technicalism, exercised in objective therapeutic practices, which limits the integration of the humanistic approach to care.

Machado and collaborators<sup>35</sup> define this process as *dehumanization*, when the professional starts to see the disease and no longer the human being, when they begins to value the *management of critical patients* and discuss the clinical decision without entering the subjective universe. This occurs, for example, when they ignore the emotional and financial situation of the family. For these authors, *to perceive the other is a question that involves a deeply human attitude*<sup>35</sup>.

To break with dehumanization and practices centered on the model based on the cCartesian paradigm - which welcomes the object (or objective) and not the subject (the patient), the biological body and not the integral human body - it is necessary to emphasize the relational process in the therapeutic action, which can bring benefits and reduce vulnerabilities. Society today requires professionals capable of developing not only technical skills but, as Crippa and collaborators<sup>36</sup> point out, values such as compassion, sensitivity, dedication, and ethics. Barchifontaine<sup>37</sup> also points out that care is *pertinent* to the dignity and humanity of the patient and reinforces the ethical fields of simple attention, opens participation and solidarity and affects the way others are seen. That is, the relationship between health professionals and patients should be the focus of care and based on the recognition of human dignity and solidarity, which consequently leads to humanization.

In the cases reported by professionals Tobias and Amanda, the conflict of autonomy was evident, that is, the freedom to decide which behaviors to adopt, more technical or more human, depending on personal characteristics, and not only on professional training. There are professionals who do not want to bond or interact more with their patients, because they are there to carry out their work and move on to the next appointments. The use of verbal communication is also therapeutic, especially for patients with no possibility of cure, and implies quality of care, which is a safeguarded benefit for patients in the *Universal Declaration on Bioethics and Human Rights*<sup>22</sup>.

humanistic The dimension, in turn, appeared in the discourses of some of the participants associated with the appreciation of the quality of communication and with the interaction developed between physiotherapists, patients, patients' caregivers and families. In this research, it was verified through testimonials that physiotherapists value the fact of establishing and maintaining constant communication with patients. Interviewees reported that, at the initial moment of the physiotherapeutic care, they sought to turn the attention and interest to the patients' overall picture. To know how they felt, which included feelings and sensations regarding their physical conditions, explanations about the care provided to patients, as well as to identify the affective and relational climate present among family members. From this scenario, they defined the therapeutic action to be adopted in the intervention, as exemplified by excerpts from the participants' narrative:

"Look, I usually try to figure out how things are first, how it was, how the environment is, how the person is feeling" (Pedro);

"To show him that he is very important to us ... I would come in, say hello, talk a little, even if he did not speak ... I would talk to him with or without answers" (Sheila);

"Well, I arrive at the patient's home, I talk to the family member responsible, if the patient communicates verbally, I also do, of course, I talk a lot about how he/she has been since the last session, how he/she is feeling that day, if he/she is in pain, If there is anything special I could do on that day" (Laís).

In the reports from the professionals, it is observed that when the option is made to establish adequate communication channels with patients and their relatives, from the initial interaction and during the therapeutic intervention, the physiotherapist starts to participate in the patient's daily life. This approach makes them more sensitive and attentive to physical, emotional and psychological needs, thus helping to minimize the vulnerability of those under their care. Kovács <sup>14</sup> calls these professionals who deal with death, employing their professional diligence as well as biopsychosocial, as "palliativists", precisely for putting into practice the beneficence when a simple dialogue can contribute to the relief of pain and suffering. According to Coelho and Ferreira <sup>38</sup>, the conversation provides relief, conveys a sense of welcome and has a beneficial or therapeutic effect.

By means of proper evaluation, when interacting verbally with patients and relatives, professionals can perceive their characteristics and individuality, know their history, not only that of the disease, and may interact with patients in this universe of senses and meanings<sup>18</sup>. On the other hand, professionals should recognize patients' desire for silence, but should not discourage them from saying what they feel, leaving them at ease, so that they can trust the professional who cares for them and accompany them at this difficult time. This established connection can help professionals build humanistic values based on compassion, mutual respect, solidarity and integrity. Given the specific characteristics of their performance, to provide quality care physiotherapists need to touch and talk topatients, approaching them physically, psychologically and emotionally.

For O'Sullivan and Schmitz<sup>39</sup>, people are not born with these values, but these are acquired

through personal and interpersonal experiences. For the authors, patients' values are important factors to be considered in their treatment, since they reach physiotherapy in diverse stages of their lives, and with unique histories<sup>40</sup>. How does one identify these values if physiotherapists do not establish a more humanized relationship, based on dialogue, on listening and on the process of welcoming and bonding? Therefore, it is necessary to interact not only with patients, but also with their family members, and to build humanized relationships, with the potential to prevent bioethical conflicts. Professionals need to feel safe, be prepared to act in extreme situations, and to understand that in these situations there is a fine line between beneficence and maleficence and between technicalism and humanism.

Undoubtedly, the technical dimension is essential for good physiotherapeutic practice. It is the application of appropriate procedures that will allow the maintenance of the integrity of the patients' body while working, for example, the prevention of severe pain and deformities due to the great time restricted to the bed. However, the technique must be permeated by the relationship of affection, by the perception of patients' psychological and existential conditions. After all, it is this humanistic relationship that will allow professionals to recognize that the illness is not strictly a biological phenomenon, but a biopsychosocial, and spiritual phenomenon as well. When professionals value human interaction with patients in their therapeutic practice, they begin to pay attention to the sick person and not specifically to the disease.<sup>34</sup> This passage from Samuel's account exemplifies the idea:

"The person is terminal but, while he/she is there, you can talk to him/her, you can touch him/her, you can give affection, you can do a lot of things, you can act like a person on his/her side, you cannot treat them like a plant, he/she is a human being. "

Another important aspect in the analysis of question of technicalism is that it seems to place professionals as the center of the care process. Moritz<sup>41</sup> emphasizes aspects of the technicist education and discusses the development of health professionals' defense mechanisms when dealing with death. The author emphasizes that, at the beginning of their training, medical students have contact with corpses in the study of anatomy and are faced with *a disfigured body, blackened by the formaldehyde, in which students can barely identify a human being that has passed through life and felt* 

the emotions that mark them as an individual<sup>41</sup>. We can affirm that this context is not different for physiotherapy students.

Physiotherapists need to be prepared to recognize the psychosocial needs of their patients, not only the physical ones, even if they are in a vegetative state, as was observed in Samuel's speech, which emphasizes the need for a more humanized and integrated treatment: "he/she is not a plant, he/she is a human being". When patients are seen as what they are - human beings -, the bioethical principle of human dignity materializes, which, as Albuquerque <sup>42</sup> points out, is one of the core concepts of patient-centered cares. Regardless of the disease stage, advanced or not, human beings needs to feel accepted, understood and valued<sup>43,44</sup>. To see patients in the first place, not the illness, is to attribute fundamental value to the human being in terms of his/her dignity and integrity.

The concept regarding the interface between bioethics and patients' human rights is still recent. More discussions and advances are needed to guide health practices, to prepare and sensitize professionals to minimize the conflicts arising from facing limit situations<sup>45</sup>.

## **Final considerations**

This study does not exhaust the topic, but reveals some bioethical conflicts often experienced in the daily work of physiotherapists in the care of terminally ill patients and their relatives. Situations in which the limits for the use of therapeutic resources are translated into polarized attitudes of approach or distancing - and the challenge of promoting care based on humanization and human dignity. In providing humanized care, professionals are exposed to the anguish and existential suffering experienced by patients in the process of dying. Without being adequately trained to deal with these situations, and without support to manage them, professionals can succumb to stress, which will prevent them from exercising their activities effectively and, worse, can lead professionals to chronic illness.

There is a great challenge for the institutions that train physiotherapist to include in the whole formative process, in an integrated way, knowledge that bases health care bioethics on autonomy, dignity and human rights. It is important to establish a guideline for training these professionals in the logic of permanent education, both in home care programs and other health tools. We consider that, in order to face the issue decisively and appropriately, it is indispensable to include the discussion of the issue of death and of dying in professional training, to promote permanent training to work in palliative care and to provide psychological support to professionals, when necessary. These tasks should be adopted by educational institutions, promoted by the professional bodies and fostered by and for all professionals who are concerned with the ethical practice of the profession.

# Referências

- 1. Batista RS, Schramm FR. A eutanásia e os paradoxos da autonomia. Rev Ciênc Saúde Coletiva. 2008:13(1):207-21.
- 2. Siqueira JE, Zoboli E, Kipper DJ, organizadores. Bioética clínica. São Paulo: Gaia; 2008. p. n./d.
- Singer P. Repensar la vida y la muerte: el derrumbe de nuestra ética tradicional. Barcelona: Paidós; 1997. p. n./d.
- Academia Nacional de Cuidados Paliativos. O que são cuidados paliativos?. [Internet]. 2009 [acesso 14 out 2016]. Disponível: http://bit.ly/2jOcCvC
- 5. Pessini L, Bertachini L. O que entender por cuidados paliativos? 2ª ed. São Paulo: Paulus; 2006.
- Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 424, de 8 de julho de 2013. Estabelece o Código de Ética e Deontologia da Fisioterapia. [Internet]. Diário Oficial da União. Brasília, nº 147, 1º ago 2013 [acesso 8 mar 2016]. Seção 1. Disponível: http://bit.ly/2jO88Fg
- 7. Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 318, de 30 de agosto de 2006. Designa especialidade pela nomenclatura Fisioterapia Respiratória em substituição ao termo Fisioterapia Pneumo Funcional anteriormente estabelecido na Resolução nº 188, de 9 de dezembro de 1998, e determina outras providências. [Internet]. Diário Oficial da União. Brasília, nº 33, 15 fev 2007 [acesso 15 out 2016]. Disponível: http://bit.ly/2khNuP7
- Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 189, de 9 de dezembro de 1998. Reconhece a especialidade de Fisioterapia Neuro Funcional e dá outras providências. [Internet]. Diário Oficial da União. Brasília, nº 237, p. 59, 10 dez 1998 [acesso 15 out 2016]. Seção 1. Disponível: http://bit.ly/2iSN55q

- 9. Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 260, de 11 de fevereiro de 2004. Reconhece a especialidade de Fisioterapia Traumato-Ortopédica Funcional e dá outras providências. [Internet]. Diário Oficial da União. Brasília, nº 32, p. 66-7, 16 fev 2004 [acesso 15 out 2016]. Seção 1. Disponível: http://bit.ly/2jnfGvS
- 10. Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 372, de 6 de novembro de 2009. Reconhece a Saúde da Mulher como especialidade do profissional Fisioterapeuta e dá outras providências. [Internet]. Diário Oficial da União. Brasília, nº 228, p. 101, 30 nov 2009 [acesso 15 out 2016]. Seção 1. Disponível: http://bit.ly/2jQTvS7
- Conselho Federal de Fisioterapia e Terapia Ocupacional. Resolução Coffito nº 10, de 3 de julho de 1978. Aprova o Código de Ética Profissional de Fisioterapia e Terapia Ocupacional. [Internet]. Diário Oficial da União. Brasília, 22 jul 1978 [acesso 8 jun 2009]. Seção 1. Disponível: http://bit.ly/2kibUb3
- 12. Beauchamp TL, Childress JT. Princípios de ética biomédica. São Paulo: Loyola; 2002.
- Marcucci FCI. O papel da fisioterapia nos cuidados paliativos a pacientes com câncer. Rev Bras Cancerol. [Internet]. 2005 [acesso 15 out 2016];51(1):67-77. Disponível: http://bit.ly/2jR4xGT
- Kovács MJ. A caminho da morte com dignidade no século XXI. Rev. bioét. (Impr.). 2014;22(1):94-104. p. 101.
- Badaró AFV, Guilhem D. Bioética e pesquisa na fisioterapia: aproximação e vínculos. Fisioter Pesqui. 2008;15(4):402-7.
- 16. Marques AF, Oliveira DN, Marães VRFS. O fisioterapeuta e a morte do paciente no contexto hospitalar: uma abordagem fenomenológica. Rev Neurociênc (Impr.). 2006;14(2):17-22.
- 17. Pessini L, Bertachini L. Op. cit. p. 19.
- Ferreira J. O programa de humanização da saúde: dilemas entre o relacional e o técnico. Saúde Soc. [Internet]. 2005 [acesso 10 mar 2016];14(3):111-8. p. 113. Disponível: http://bit.ly/2jQHTyo
- 19. Masiá J. Dignidad humana y situaciones terminales. An Sist Sanit Navar. [Internet]. 2007 [acesso 8 jun 2009];30(3 Suppl):39-55. p. 44. Disponível: http://bit.ly/2jeU1s3
- Brasil. Conselho Nacional de Saúde. Resolução CNS nº 196, de 10 de outubro de 1996. Dispõe sobre diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. [Internet]. [acesso 27 jun 2016]. Disponível em: http://bit.ly/2jeUaM9
- Minayo MCS. Análise qualitativa: teoria, passos e fidedignidade. Ciênc Saúde Coletiva. [Internet]. 2012;17(3):621-6. Disponível: http://bit.ly/2bcM7hz
- 22. Organização das Nações Unidas para a Educação, a Ciência e a Cultura. Declaração universal sobre bioética e direitos humanos. Brasília: Unesco; 2005.
- 23. Sadala MLA, Silva FM. Cuidando de pacientes em fase terminal: a perspectiva de alunos de enfermagem. Rev Esc Enferm USP. 2009;43(2):287-94.
- 24. Sadala MLA, Silva FM. Op. cit. p. 288.
- 25. Moritz RD. Os profissionais de saúde diante da morte e do morrer. Bioética. 2005;13(2):51-63. p. 55.
- Ribeiro DC. Autonomia: viver a própria vida e morrer a própria morte. Cad Saúde Pública. [Internet]. 2006 [acesso 8 jun 2009];22(8):1749-54. Disponível: http://bit.ly/2kic81Z
- Santos MA, Hormanez M. Atitude frente à morte em profissionais e estudantes de enfermagem: revisão da produção científica da última década. Ciênc Saúde Coletiva. [Internet]. 2013 [acesso 8 jun 2009];18(9):2757-68. Disponível: http://bit.ly/2c6BcjV
- 28. Albuquerque A. Direitos humanos dos pacientes. Curitiba: Juruá; 2016.
- 29. Ribeiro DC. Op. cit. p. 1750.
- Figueiredo AM. O ensino da bioética na pós-graduação stricto sensu da área de ciências da saúde no Brasil [tese]. Brasília: UnB; 2009.
- Mizuno YA. Experiências frente à morte em graduandos de fisioterapia: perfil sociodemográfico [monografia]. Brasília: UnB; 2015.
- Marta GN, Marta SN, Andrea Filho A, Job JRPP. O estudante de medicina e o médico recémformado frente à morte e ao morrer. Rev Bras Educ Méd. [Internet]. 2009 [acesso 8 jun 2009];33(3):416-27. Disponível: http://bit.ly/2iSXoGw
- Rebelatto JR, Botome SP. Fisioterapia no Brasil: fundamentos para uma ação preventiva e perspectivas profissionais. Barueri: Manole; 2008.
- 34. Siqueira JE. Reflexões éticas sobre o cuidar na terminalidade da vida. Bioética. 2005;13(2):37-50.
- Machado D, Carvalho M, Machado B, Pacheco F. A formação ética do fisioterapeuta. Fisioter Mov. 2007;20(3):101-5. p. 104.
- Crippa A, Lufiego CAF, Feijó AGS, Carli GA, Gomes I. Aspectos bioéticos nas publicações sobre cuidados paliativos em idosos: análise crítica. Rev. bioét. (Impr.). 2015;23(1):149-60. p. 156.
- Barchifontaine CP. Humanismo y dignidad. In: Tealdi JC, director. Diccionario latinoamericano de bioetica. Bogotá: Unesco; 2008. p. 278-80. p. 280.
- Coelho MEM, Ferreira AC. Cuidados paliativos: narrativas do sofrimento na escuta do outro. Rev. bioét. (Impr.). 2015;23(2):340-8. p. 341.
- 39. O'Sullivan SB, Schmitz TJ. Fisioterapia: avaliação e tratamento. 2ª ed. Barueri: Manole; 1998.
- 40. O'Sullivan SB, Schmitz TJ. Op. cit. p. 117.
- 41. Moritz RD. Op. cit. p. 54.
- 42. Albuquerque A. Op. cit. p. 75.
- 43. Coelho MEM, Ferreira CA. Op. cit.

- 44. Selli L. Cuidados ante el dolor y el sufrimiento. In: Tealdi JC, director. Diccionario latinoamericano de bioetica. Bogotá: Unesco; 2008. p. 62-3.
- 45. Oliveira, AAS. Interface entre bioética e direitos humanos: perspectiva teórica, institucional e normativa [tese]. Brasília: UnB; 2010.

#### Participation of the Authors

Lízia Fabíola A. Silva planned the research, collected and analyzed data and drafted the article. Maria da Glória Lima assisted in the data analysis and participated in the drafting of the article. Eliane M. F. Seidl contributed to drafting and reviewed the article.

		_
		1
Aprovado.	5.12.2010	ľ
	Revisado:	Recebido: 29.4.2016 Revisado: 4.11.2016 Aprovado: 3.12.2016