

# Futility and orthotanasia: medical practices from the perspective of a private hospital

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## Abstract

Futility and orthotanasia are among the concepts related to the terminality life. Futility means therapeutic obstinacy to delay imminent death. Orthotanasia means death in its natural process, not prolonging treatment. The aim of this study was to analyze the perception of patients' family members in private general hospital on orthotanasia and futility, assessing which the most widely accepted alternative is. This was a cross-sectional, observational study, in which 190 families were interviewed using a standardized questionnaire containing questions about social aspects and knowledge on the subject. Most respondents (64.2 %) opted for the realization of futility as a conduct for their relative. Of the 122 participants who did not know the meaning of "terminal condition", 85.9% would choose futility. However, among those who knew what they meant, 70,9% would choose orthotanasia. The study indicates that this topic needs to be discussed by society, encouraging them to understand the individual and collective implications of life prolongations when suffering.

**Key words:** Critical illness. Social perception. Population. Medical futility. Bioethics.

## Resumo

### Distanásia e ortotanasia: práticas médicas sob a visão de um hospital particular

Dentre os conceitos relacionados à terminalidade da vida, encontram-se a distanásia e a ortotanasia. Distanásia significa a obstinação terapêutica para adiar a morte iminente. Ortotanasia significa morte em seu processo natural, não prolongando o tratamento. Este estudo objetivou analisar a percepção de familiares de pacientes internados acerca da ortotanasia e distanásia, avaliando a alternativa mais aceita. Trata-se de estudo transversal e observacional, no qual foram entrevistados 190 familiares por meio de questionário padronizado contendo perguntas sobre aspectos sociais e conhecimento da temática. A maioria (64,2%) manifestou preferência pela distanásia como conduta para seu familiar. Entre 122 participantes que desconheciam o significado de "estado terminal", 85,2% optariam pela distanásia. Porém, entre os que conheciam o significado, 70,9% optariam pela ortotanasia. O estudo indica a necessidade de trazer o tema para discussão da sociedade, sensibilizando-a a entender implicações individuais e coletivas do prolongamento da vida em situação de sofrimento.

**Palavras-chave:** Estado terminal. Percepção social. População. Futilidade médica. Bioética.

## Resumen

### Distanasia y ortotanasia: prácticas médicas bajo la visión de un hospital privado

Entre los conceptos relacionados con el fin de la vida, están la distanasia y la ortotanasia. Distanasia significa la obtinación terapéutica para postergar la muerte iminente. Ortotanasia significa muerte en su proceso natural, sin prolongar el tratamiento. El objetivo de este estudio fue analizar la percepción de los familiares de pacientes hospitalizados sobre la ortotanasia y la distanasia, evaluando la alternativa más aceptada. En este estudio observacional y transversal 190 familiares fueron entrevistados mediante un cuestionario estandarizado que contenía preguntas sobre los aspectos sociales y de conocimientos sobre el tema. La mayoría (64,2%) manifestó su preferencia por la distanasia como conducta para su familiar. De los 122 participantes que no conocían el significado de "estado terminal", el 85,2% optaría por la distanasia. No obstante, entre los que conocían el significado, el 70,9% optarían por la ortotanasia. El estudio indica la necesidad de plantear el tema para discusión de la sociedad, sensibilizándola a entender implicaciones individuales y colectivas de la prolongación de la vida en situación de sufrimiento.

**Palabras-clave:** Enfermedad crítica. Percepción social. Población. Inutilidad médica. Bioética.

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Although most deaths occur in the XXI century in hospitals, doctors are not trained to care for the patient victim of terminal illness. Difficulty in accepting death discussion about the standoff between the artificial methods to prolong life and to leave the choice facing the disease follows its natural history arises <sup>1</sup>. The study by Moritz <sup>2</sup> about the behavior of health professionals before death occurred the need to further discuss the topics of death and terminal illness life. The author observes that the present Western culture makes death matter avoided socially and politically incorrect. The word death is often associated with feelings of pain.

With regard to doctors, trained to save and heal, death is associated with feelings of failure or error. Several studies show that the physician should recognize the terminally ill and modify their behavior, from the struggle for life for the provision of comfort <sup>2</sup>. For this to occur, it is essential that it be given teaching about death and dying in academic debate and the constant theme during professional practice.

The increased prevalence of terminal illness is current being faced by physicians, health services and society indeed. Paradoxically, there is a lack of adequate palliative care, causing the majority of the population is not provided this attention. In addition, there are cultural, ethical, social and structural barriers to offering appropriate care to patients undergoing final life. Occurring faults and gaps in training professionals health as well as those who come from other areas of knowledge, which add up huge difference in health systems and also ignorance about the reflection proposed by bioethics and the biolaw <sup>3</sup>.

Regarding this issue, there is much discussion when making decisions on health / disease process is necessary, considering two concepts of great relevance: dysthanasia and orthothanasia. Dysthanasia therapeutic aggression is for the purpose of delaying the inevitable death <sup>4</sup>; orthothanasia is death in its natural process in which the patient receives only treatment to eliminate or decrease their pain and suffering <sup>5</sup> To assist this decision making by individuals familiar with terminal is fundamentally a humanistic, ethical and academic education of health team in search of compassionate and humane doctor-patient relationship, establishing a bond of affection and respect between patients and professionals.

In most countries occur many discussions about the ethical decisions of end of life <sup>6</sup>. Worldwide, orthothanasia is legally practiced in Sweden, England, Canada, Japan and Brazil <sup>7</sup>. However, according to Hill <sup>8</sup>, only 4% of medical schools United States bother to give teachings about the process

of death. Latin America is a considerable amount of research aimed at terminally ill patients and the subject of end of life <sup>9</sup>, although there is scarcity of publications on practices and processes of decision making, involvement of family members and patients, or changes in treatment based on awareness and responsibility required by bioethical reflection <sup>10</sup>.

In general, the death event is complex and focus of ethical, bioethical and professional, in which emotions need to be addressed and discussed from bioethical principles that can be summarized by little word dilemmas, which matters a lot to the terminal patient: dignity. The objective of this research was to analyze the perceptions of family members of patients in private general hospital on orthothanasia and dysthanasia evaluating which of the two is the most widely accepted alternative.

### Terminality of life and the practice of dysthanasia and orthothanasia

The development of new technologies, medicines and surgical techniques have made amazing improvement there was in increase in life expectancy in the population. Currently, various intractable diseases have treatments with good performance and good prognosis. These changes were instrumental in creating the dogma that always cure the patient or the maximum extension of one's life must be achieved <sup>11,12</sup>.

History shows this change. Initially, Hippocrates formulated as goals of medicine: relieve the suffering of the sick, minimize the aggressiveness of the disease and to refuse treatment when medicine recognizes that it can no longer contribute <sup>13</sup> These prerogatives were maintained until the early sixteenth century when Francis Bacon considered three purposes for medicine: preserving health, cure disease and prolong life <sup>14</sup>.

The search for the prolongation of life in patients without curing conditions, without concern for the quality of life and patient's opinion, constitutes a futile <sup>14</sup> In addition to bringing more suffering to the patient and family, this practice eventually allocate resources to unnecessary treatments that could be used for patients with potentially curable diseases <sup>15</sup> This exaggerated and disproportionate prolongation is termed as medical futility, and its practice prohibited by the Code of Medical Ethics (CME) <sup>10</sup>.

Opposed to this concept, orthothanasia is defined as death at the right time, no abbreviation or disproportionate prolongation of the dying

process<sup>3,12</sup>, this concept should be distinguished from euthanasia. Euthanasia death will occur due to the action / omission of a third party. However, orthothanasia be due to the disease itself<sup>11,12</sup>. In Brazil, the practice of orthonasia is authorized by CEM 10, but so far there are no national federal laws to regulate it<sup>12</sup>.

## Method

This research is characterized as cross sectional, descriptive, observational and quantitative analysis. Approved at the University of Pará State Committee for Ethics in Research, was conducted between the months of June and July 2013. 190 caregivers of patients at the Hospital Porto Dias, a private hospital in the city of Belém (Pará) were interviewed. Founded in 1995, reference is generally high-complexity care, with a focus on traumatology, neurosurgery, and emergency medical and surgical emergencies. It has 270 beds, divided into apartments (135), wards (45), ICU beds (52) and emergency care (38).

The survey included the family of curable patients and hospitalized terminally ill, being allowed more than one companion per patient. Exclusion criteria were: under 18 accompanying persons; those who refused to participate in the interview or signing the informed consent - which reported in detail the objectives of the study.

Interview was conducted - based questionnaire (Appendix 1) - with the accompanying patient in a private room and away from the patient. The questionnaire contained questions regarding the social conditions (sex, marital status, age, education level, race / color) and general knowledge (concepts orthothanasia and futility, what attitude would with terminally ill family) about the practices of futility and orthothanasia. Participants were asked about the knowledge of "terminal illness" and who said to ignore the meaning of the term received standard explanation of the researchers as well as those who reported not knowing the concepts of futility and orthothanasia - seeking, however, does not influence the choice of which method you choose. Thus, they could pursue the questionnaire and respond whether or not they had a family member in a terminal state.

BioEstat® the 5.3 software to perform the statistical analysis, the contingency test in C and Fisher's exact test was used to compare the variables and the preference for futility or orthothanasia. To reject the null hypothesis was adopted less than 5%.

## Results

190 accompanying patients were interviewed in all sectors of the hospital during the study period. Of the total, 106 (55.7%) were women and 84 (44.3%) men were aged between 18-78 years with a mean of  $41.71 \pm 14.90$  years. Regarding marital status, 86 were married (45.3%); 86 (45.3%), unmarried; 11 (5.7%), widowed and seven (3.7%), divorced. With regard to religion it was found that 111 (58.4%) of respondents were Catholic; 51 (26.8%), Protestant; two (1%), spiritualists and others (26 to 13.8%) reported not follow any religion.

Regarding education, two (1%) participants were illiterate, nine (4.7%) had incomplete primary; 18 (9.5%), the complete key; 14 (7.4%), completed secondary school; 65 (34.2%) completed high school; 22 (11.6%), incomplete higher education; 38 (20%) completed higher education; three (1.6%) had a master's degree and 19 (10%) did not answer.

When questioned, 36 (19%) had knowledge about the meaning of futility and orthothanasia. Of this total, 21 (58.3%) preferred the realization of futility; 14 (38.9%), orthothanasia; and one had no opinion on the subject (2.8%). Table 1 shows the choice of participants regarding the futility or orthothanasia, after the explanation of the concept. The variables gender ( $p = 0.5309$ ), age ( $p = 0.7447$ ), education ( $p = 0.0991$ ), marital status ( $p = 0.1797$ ) and religion ( $p = 0.8553$ ) did not influence the patient's opinion when choosing between dysthanasia or orthothanasia.

**Table 1** Option for futility or orthothanasia how to conduct your family

Opcion	Quantity	%
Dysthanasia	122	64,2
Orthothanasia	62	32,6
None	6	3,2
<b>Total</b>	<b>190</b>	<b>100</b>

Source: research questionnaire.

Knowledge about the meaning of terminal status influenced the choice of participants ( $p = 0.0298$ ). Among those who knew him, 44 (70.9%) would choose orthothanasia and 18 (29.1%) for futility. Among those who were unaware, 104 (85.2%) would choose dysthanasia and only 18 (14.8%) orthothanasia. This can be evidenced in Table 2, in which the majority of those who had no knowledge about terminal illness opted for futility, and those

who had, for orthothanasia. After a brief explanation of the term “terminal illness”, it was observed that the total of 71 respondents (37.3%) claimed to be companions of terminally ill patients - a fact that did not influence the choice between dysthanasia or orthothanasia ( $p = 0.33$ ).

**Table 2** Association between knowledge of terminal status and choice of dysthanasia and orthothanasia

Knowledge about terminal illness	Option for orthothanasia	Option for dysthanasia	Total
Yes	44	18	62
No	18	104	122
Did not choose	-	-	6
<b>Total</b>	<b>62</b>	<b>122</b>	<b>190</b>

Source: research questionnaire.  $p=0.0298$  (Fischer Exact).

The study showed that 47 (24.7%) patients had talked to his companions about terminal illness; that 83 (43.7%) patients had not talked and that 60 (31.6%) respondents did not know whether the patient had talked to some other companion, and held that this fact did not influence the choice between dysthanasia or orthothanasia ( $p = 0.45$ ). However, when asked if the hospital had talked to the family health team on conducting intensive treatments (Table 3), 55 (28.9%) said they talked; 69 (36.3%) that it did not talk and 60 (31.6%) did not know whether the patient had spoken. It should be noted that when healthcare professionals had talked about performing intensive treatments with patients, their companions opted for the choice of futility ( $p = 0.0098$ ).

**Table 3** Association between the option and the respondent admitted the family had talked to the medical staff on intensive treatments

	Option for orthothanasia	Option for dysthanasia	Total
Hospitalized family talked with the team	14	41	55
Hospitalized family did not talk to the team	34	35	69
Unaware if the family had talked with the team	-	-	60

	Option for orthothanasia	Option for dysthanasia	Total
Not opted for any procedure	-	-	6
<b>Total</b>	<b>48</b>	<b>76</b>	<b>190</b>

Source: research questionnaire.  $p=0,0098$  (Fischer Exact).

## Discussion

The choice of attitude to take on the impending death of a loved one is one of the most difficult that can occur in an individual’s life<sup>10</sup>. The next period to the death of a family member or dear person is a time of reflection and changes in psychological structure, affective, social and physical of a family or a social group. Thus, it becomes clear the need to produce in-depth analyzes on fears, doubts and fears of people who have owned or have family and friends with some health problem<sup>16</sup>. These reflections are the focus of the present study.

Various aspects - cultural, social and even demographic issues - can interfere with the decision of what action to take before the imminent death of a family member<sup>17</sup>. It is noted in the study a greater tendency to choose the method of dysthanasia, which may have occurred due high economic status of respondents. It is observed that they wish to extend the maximum life of the loved one, considering the availability of skilled and sophisticated treatments of the hospitalized person.

Became evident preference for futility among respondents who were unaware of terminal illness (Table 2). The population failed to understand that the terminally ill patient invariably pass away and that for him, the realization of the futility only be a discomfort, suffering the most, besides the fact that it will be exposed and will be away from the society of his family, of their habitat and personal routine<sup>18</sup>. Also complemented the fact that the respondents themselves have reported not knowing the meaning of the terms studied.

Factors such as gender, age, marital status and educational level did not influence the respondent’s decision about what action to take before the terminal phase of life. Thus, it is believed that personal and individual factors are not of relevance or importance, and there is a critical common sense in a given population which serves as the basis for selection. Another point of great importance is the con-

solidated affection throughout the living with the family that, together with the dogma that the function of the physician is always save lives<sup>19</sup>, makes it difficult for families to give up fighting for the life of one, seeking always alternatives in order to maximize their survival.

However, the fact that the civil state does not interfere in that choice is remarkable since this correlation was explicit in several studies<sup>20,21</sup> conducted with people who have marital ties with terminal patients. The condition modifies the choice of spouse, being related to the tendency to opt for orthothanasia, due to the companion put yourself in the position of the terminally ill, their beloved<sup>21</sup>. A lot of unmarried survey respondents may have altered this correlation, since what many do not have the experience of a lasting relationship, with more intense coexistence and mutual dependence, implying that other factors affect your choice.

The religious aspects are of paramount importance for the improvement of general well-being of the terminally ill patient, providing reflections about an "afterlife" and providing an increase in "peace" within the patient<sup>22</sup>. Some studies show that as leading to the choice of treatment of the patient<sup>23</sup> in the present study, no interference factor in the choice of religion or disthanasia orthothanasia observed. This result is important because different religious institutions around the world adopt positions regarding the choice facing the terminal illness of life<sup>24,25</sup>.

The lack of statistical relationship toward religion variable may be due to most participants believe in a religion, confirming the findings of this study in which the population has a preference for futility to believe in healing.

Another factor that may have influenced the choice of companions, was the study was conducted in a general hospital, where the patients' prognosis in most cases is good. Thus, family members have difficulty accepting impending death, clinging to hope that something positive occurs and the patient is able to cure<sup>16</sup>. Different is what occurs in an oncology hospital, where family members are already suffering for some time and may have received a greater preparation in relation to the death of their loved one.

The survey shows the interference of two factors in choosing the theme: understanding the terminally ill loved one and the family had conferred with the health care team on terminal illness of life. Respondents who reported that their family

had talked with the team opted for futility (Table 3). Studies showed that over half of doctors have difficulty speaking with patients about the topic of death<sup>26,27</sup>. Consequently possible in one's own healthcare team with the patient may occur, encouraging him to continue the treatment and extolling the qualities of science in life extension<sup>23</sup>, given the difficulty of accepting death and associate it with failure or error.

A proposed mechanism for reducing dysthanasia is the manifestation of will advance<sup>26-29</sup>. In this, the patient shall inform whether or not to, when you can not cure, what methods of artificial prolongation of life are employed. This mechanism does not yet have one current legislation in Brazil, but a survey showed that<sup>29</sup>. Piccini significant portion of physicians regarding patient choice, even this mechanism showing no legal value, and other research fields and colleagues<sup>30</sup> found that almost all patients and families want to have their wishes respected anticipated. In this context, to fill the legal vacuum, the Federal Council of Medicine (FCM) issued Resolution 1995/12<sup>31</sup>, which established the advance directives of will within the Brazilian medical ethics as an instrument that can contribute to the inhibition of dysthanasia.

This study highlighted the need for further discussion about terminal illness of life that much of the population is unaware. Very discloses and discusses the "euthanasia", due to its strong presence in the media, but the discussions on the topics "medical dysthanasia and orthothanasia" are reduced, not having as much importance as the first<sup>23,32</sup>. This may be occurring by the absence of national federal laws to regulate the practice of orthonasia<sup>27-31</sup>, with only<sup>33</sup> a bill pending before the Committee on Constitution, Justice and Citizenship of the Senate, although the regulation of CFM is in force directed to physicians through the Code of Medical Ethics<sup>10</sup>, article 41, and CFM Resolution 1805/06<sup>34</sup>, which allows the physician to limit or suspend procedures and treatments that prolong the life of the terminally ill.

### Final Considerations

It was observed that even with the strong disclosure in the media on the subject of end-of life, most of the interviewees unaware of its basic concepts and reflections, and highlights the need for a broader approach to the entire health care team aims to elucidate the possible doubts about the patient's situation.

Most respondents opted for realization of futility against the possible impending death of the family. It was found that this choice did not undergo intervention of the factors sex, age, marital status, education, and religious aspects. However, the study showed significant interference in relation to family possess knowledge about the meaning of terminal illness as well as the prior existence of dialogue about end of life, between the patient and his family. Other works should be carried out to fill the gaps left by this research, analyzing, for example, other environments such as public hospitals, specific age groups etc.

The data found in this research can contribute to improve care, psychosocial care and support to both inpatients about family involved with terminally ill patients. The information gathered can help im-

prove health services, advising managers and staff on how to improve the care of their patients.

The work also allowed establishing that there is need to better prepare health teams to host of relatives and friends of a terminal patient. This finding proves to be especially pertinent in relation to doctors, whose graduation teaches combat death, including pressure or legal fears. There, in certain cases, graduation and other levels as in residency, lack of education on how to drive and react in case of impossibility of treating and curing terminal patients.

Finally, there is urgent need to bring the topic for discussion in society, informing people about what is futility and orthotanasia, and sensitizing them to understand that the prolongation of life in hardship may ultimately become a burden for the patient and for society.

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#### Participation of authors

All authors have participated in the development and revision of the article. Luis Eduardo Almeida de Souza and Luísa Carvalho Silva in data collection and writting. Renan Kleber Costa Teixeira in the critical analysis and writting. José Antônio Cordero da Silva has oriented the reseach and made a critical revision.

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**Appendix**  
**Research questionnaire**

1 Age: \_\_\_\_\_

2 Sex:  
 Men's  
 Female

3 Status:  
 Married  
 Single  
 Widowed  
 Divorced

4 Schooling:  
 Illiterate  
 Fundamental incomplete  
 Fundamental complete  
 Incomplete secondary education  
 High school  
 Incomplete higher education  
 Full Higher Education  
 Master or PhD

5- Race / Color:  
 Black  
 Brown  
 White  
 Indigenous

6 Do you have knowledge about medical futility and orthothanasia?  
 You know what that means?  
 Yes  No. What is it?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

6.1 If the answer was "Yes" to question 6, how you acquired knowledge about this subject?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

7 If it were possible, which would you opt to be taken as conduct your family? How come?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

The 8-(a) you (a) have no idea what is a terminal illness?  
 Yes  No  
 If so, what is the meaning

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

9-Do you own or have owned a terminally ill family?  Yes  No

10-What is / was the diagnosis of your family?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

11-What is your spiritual orientation / religion?

Roman Catholic  
 Orthodox Catholic  
 Protestantism  
 Judaica  
 Buddhist  
 Islamic  
 Spiritualism  
 Other, which?

\_\_\_\_\_

12- His religion has some guidance on the approach to be used in case of terminal patients?  
 Yes  No

12.1 If yes, what behaviors would be?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

13-You follow this advice?  Yes  No

The 14-patient that (a) you (a) received accompanies visit from a member of the church / religion you belong to?  
 \_\_\_\_\_ Yes  No

14.1 If yes, how do you think the patient reacted to visit? Guide to give a score between 0 to 10, where "0" would Terribly and "10" would Perfectly. The note "5" represents very well. Note: \_\_\_\_\_



The 15-patient ever talked to you about terminally life?  
( ) Yes ( ) No

The 16-patient revealed / talked to you about your wishes for treatment against aggravating factors - eg, resuscitation, intensive care, invasive treatment (surgery)?  
( ) Yes ( ) No

The 17-patient revealed / talked with the doctor / medical staff about their desires treatment against aggravating factors - eg, resuscitation, intensive care, invasive treatment (surgery)?  
( ) Yes ( ) No ( ) Do not know