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End of life in intensive care: family members' acceptance of orthotanasia

Terminalidade da vida em terapia intensiva: posicionamento dos familiares sobre ortotanasia

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This study was conducted at the intensive care unit, Hospital Servidor Público Estadual "Francisco Morato de Oliveira" – HSPE-FMO – São Paulo (SP), Brazil.

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ABSTRACT

Objectives: This study aimed to assess family member acceptance of orthotanasia as related to symptom management, patient preference and the influence of the medical team's communication on therapy.

Methods: This was a descriptive one-year study conducted at the adult intensive care unit of the Hospital do Servidor Público Estadual. A structured questionnaire based on the Quality of Dying and Death (QODD 22) instrument and prior informal interviews were used.

Results: Sixty family members were assessed; the mean age was 51.7 + 12.1 years, and 81.7% were female. The patients were hospitalized for a mean of 31 + 26.9 days, and 17.0% of these days were spent in the intensive care unit. Most of the patients had neurological conditions. Most of the patients (53.3%) had discussed their end-of-life care wishes with family members; however, 76.7% of them had not discussed this issue with their doctors ($p < 0.00$). The family members reported being favorable to orthotanasia in 83.3% of the

cases. Most (85.0%) desired the medical team to clearly approach the subject, and 65.0% wished to take part in the quality of end-of-life decision making process. The family members were generally satisfied with information they received from the doctors: 93.3% believed they had received appropriately frequent communications about the clinical conditions; 81.7% were able to clarify their doubts regarding the patient's clinical status; the communication was understood by 83.3% of the respondents; and 80.0% believed that clear and honest information had been provided. Only 43.3% of the respondents wished to be present at the time of their loved ones' deaths. A significant association between family member acceptance of orthotanasia and participation in end-of-life decisions ($p = 0.042$) was observed.

Conclusions: Most of the respondents were favorable to orthotanasia and wished to participate in end-of-life discussions.

Keywords: Family; Critical illness; Intensive care; Attitude to death; Ethics; Communication

INTRODUCTION

Bioethics emphasizes that life support limitation (LSL) should be considered in intensive care unit (ICU) patients for whom maintaining vital signs is only prolonging the death process in irreversible and incurable cases.⁽¹⁾

Worldwide consensus statements designed to improve the care of end-of-life patients have recently been developed.⁽²⁾ Despite the increasing LSL discussions, however, establishing standard procedures is difficult in Brazil. Brazilian intensive care physicians usually prefer "non-resuscitation" approaches, while in the Northern Hemisphere, removing patients from mechanical ventilation is part of routine care.⁽³⁾

End-of-life ICU care is well established in other countries and requires specialized knowledge from physicians and other critical care professionals.⁽⁴⁾ In the United States and Europe, there are clear guidelines for palliative ICU care, such as symptom management strategies, patient/family communication skills, spiritual support, emotional support for the medical team and palliative care education.⁽⁵⁾

The medical team should educate the family members on treatment futility if curative procedures are continued without clinical response. Removing or limiting life support will have no impact on the condition's outcome, and improving end-of-life (orthotanasia) quality is necessary.⁽⁶⁾ This approach allows family members (or their legal representatives) to understand the end-of-life decision making process when the patient is unable to participate (according to articles 24 and 41 of the new Brazilian Medical Ethics Code, which has been in force since 2010).⁽⁷⁾

Several research reports have emphasized the importance of family participation in LSL decisions.⁽⁸⁾ The obstacles to family participation in the end-of-life decision making process are related to defective (and/or superficial) communication between the physician and family members,⁽⁹⁾ particularly failing to provide clear information about the patient's prognosis.⁽¹⁰⁾

Recent studies have shown that, LSL decisions in Brazil are mostly focused on the medical perspective, with limited participation by the family⁽¹¹⁾ and other team members.⁽¹²⁾ Although some intensive care physicians still fear sharing end-of-life decisions with the family,⁽¹³⁾ the medical team should encourage families to become involved in the process.⁽¹⁴⁾

This study aimed to assess the relationship between family member acceptance of end-of-life decisions and their perceptions of the clinical status, their satisfaction with the medical team's communication regarding treatment and the patient's preferences regarding end-of-life quality.

METHODS

After receiving the appropriate approval from the institution's ethics committee (approval document: CEP 004/09), a descriptive study was conducted in the 27-bed adult ICU of the Hospital do Servidor Público Estadual (HSPE-FMO), a tertiary hospital. This ICU receives both medical and surgical patients. The study assessed the orthotanasia knowledge of the family members of all patients admitted to the ICU from April 2009 to April

2010 who had an end-of-life diagnosis and who stayed more than 5 days in the ICU. All of the participants signed a voluntary participation informed consent form. The confidentiality of the patients and family members was assured. Family members were excluded if they continued to expect clinical improvement despite clear communication of the patient's terminal prognosis in the initial interview.

The interviews were conducted by a single investigator, in a separate and private area. After the family structure (father, mother and children) and understanding of the disease history, clinical status, and prognosis were briefly assessed, the participant was asked to complete the questionnaire.

This structured questionnaire was based on the Quality of Dying and Death questionnaire (QODD 22)⁽¹⁵⁾ instrument and consisted of 22 questions. The questionnaire had been previously validated by having 10 family members complete it and verifying their full understanding of the questions.

The questionnaire was divided into 4 parts. The first part focused on assessing knowledge of the patient's clinical and emotional status, along with the emotions related to several aspects of the treatment. The second part analyzed family satisfaction with the medical information provided. The third part contained questions related to end-of-life quality, such as whether the family members would like to discuss end-of-life care, participate in the decision making process (e.g., whether to intubate) or had discussed the patient's preferences with the physician or among themselves. Before proceeding to the third part, the questionnaire presented a short explanation of orthotanasia and provided information to which the participants could express either agreement or disagreement. Finally, some room was provided for comments and reporting the emotions evoked by various aspects of the survey. The fourth part addressed background information, such as the family members' socio-demographic characteristics.

The study results were analyzed using the SPSS version 17.0 statistical software package. The descriptive statistics consisted of the usual measures of central trend and dispersion, in addition to absolute and relative frequency calculations. A 95% confidence interval was used. The Chi-squared test was used to assess the association between the family members' opinion on orthotanasia and their demographic data, their satisfaction with the information provided to family members by the medical team and the discussion of and participation in the end-of-life care.

RESULTS

From a total of 75 irreversible patients seen during the study period, only 60 families consented to participate in the study. The most common diagnoses were stroke (31.7%), chronic obstructive pulmonary disease (COPD) with supplemental oxygen dependency (23.3%), metastatic cancer (20.0%), multiple organ dysfunction (13.3%) and prolonged cardiorespiratory arrest (11.7%). The mean patient age was 77.2 + 12.5 years, 53.3% were male and 70.0% were catholic. The mean ICU stay was 17.5 + 11.9 days (Table 1). All of the patients were receiving opiates. Table 1 show the demographic characteristics of the family members who consented to participate. Most of the family members were the patients' children (65.0%), catholic (63.3%) and had a college education (35.0%).

In the investigation of the family members' perceptions of the patients' overall condition, 58.3% considered pain

Table 1 – Family member and patient demographic characteristics

Variables	N (%)
Patients' characteristics	
Gender	
Male	32 (53.3)
Female	28 (46.7)
Age (years)	79.5 min-max
Religion	
Catholic	42(70.0)
Families' characteristics	
Gender	
Male	11 (18.3)
Female	49 (81.7)
Age (years)	51.7 ± 12.1
Age (years)	53.0
Religion	
Catholic	38 (63.3)
Educational level	
Elementary	9 (15.0)
High school	16 (26.7)
College degree	21 (35.0)
Relationship to the patient	
Son/Daughter	9 (15.0)
Consort	16 (26.7)
Grand child	21 (35.0)
Lives with the patient	
Yes	36 (60.0)
No	24 (40.0)

Results expressed as number (%) or median (min-max or 25-75%).

to be appropriately managed, and 71.7% believed that the patient's dignity was preserved (Table 2). Most of the patients (88%) were receiving mechanical ventilation, and 90.0% of the family members felt that the patients didn't breathe comfortably.

Most of the family members were unable to assess the patient's fear of dying (55%) or whether the patients felt peaceful during their final days in the ICU (43.3%),

Table 2 – The respondents' perceptions of the medical and psychological status of terminal patients

Variables	N (%)
Appropriate pain management	
Yes	35 (58.3)
No	8 (13.3)
Don't know	17 (28.3)
Control of what is going on	
Yes	10 (16.7)
No	44 (73.3)
Don't know	6 (10.0)
Comfortable breathing	
Yes	5 (8.3)
No	53 (88.3)
Don't know	2 (3.3)
Perception of "feeling peaceful"	
Yes	23 (38.3)
No	26 (43.3)
Don't know	11 (18.3)
"Fear of dying"*	
Yes	9 (15.0)
No	18 (30.0)
Don't know	33 (55.0)
Preserved dignity	
Yes	43 (71.7)
No	4 (6.7)
Don't know	13 (21.7)
Large portion of time with the family	
Yes	25 (41.7)
No	34 (56.7)
Don't know	1 (1.7)
Feeling lonely	
Yes	17 (28.3)
No	17 (28.3)
Don't know	26 (43.3)
Mechanical ventilation	
Yes	54 (90.0)
No	6 (10.0)
Don't know	0 (0.0)

Results expressed as number (%). *"fear of dying" - patient's perception of finitude of life.

most likely because the patients were not responsive and were perceived by most of the respondents (73.3%) to have no control over the situation.

Regarding the family members' satisfaction with the medical information provided, 93.3% felt they had received appropriately frequent communication from the physicians, 81.7% had their questions on the patient's clinical condition clarified, and 83.3% of the communication was understood; 80.0% felt they had received clear and honest communication. In the discussions of end-of-life care (Table 3), 76.7% of the respondents reported that the patients had had no previous discussions with their physicians on end-of-life quality, but 53.3% had discussed it with their family members ($p < 0.001$). Regarding family participation in the end-of-life decision making process, 65% wished to participate and 85% desired the medical team to clearly approach the issue. Overall, 83.3% of the respondents reported to be favorable to orthotanasia. Most of the respondents showed awareness of the orthotanasia concept (85%); 56.3% mentioned that it was related to not prolonging their loved one's suffering, while 26.7% added no comments. Of the 16.7% family members who were opposed to orthotanasia, 6.7% added no comments, 5% referred to their religious beliefs and 5% wished to further discuss the subject.

Table 3 – The respondents' assessment of end-of-life quality

Variables	N (%)
Patient discussed end-of-life care with the doctor	
Yes	6 (10.0)
No	46 (76.7)
Don't know	8 (13.3)
Patient discussed end-of-life care with the family	
Yes	32 (53.3)
No	21 (35.0)
Don't know	7 (11.7)
Family took part of end-of-life care discussions	
Yes	39 (65.0)
No	16 (26.7)
Don't know	5 (8.3)
Family discussed end-of-life care with the medical team	
Yes	51 (85.0)
No	5 (8.3)
Don't know	4 (6.7)
Family wishes to be present when the patient dies	
Yes	26 (43.3)
No	19 (31.7)
Don't know	15 (25.0)

The family members' position on orthotanasia was significantly associated with their participation (having knowledge and being able to express an opinion) in the end-of-life decision making process ($p = 0.042$). No significant associations between the family members' acceptance of orthotanasia and gender ($p = 0.499$), education level ($p = 0.955$) or religion ($p = 0.364$) were found. No significant associations between communicating the clinical status to the family members and the frequency of information ($p = 0.343$), opportunities to have their treatment questions clarified ($p = 0.852$), clarity and honesty ($p = 0.843$) or understanding of the information were found ($p = 0.887$).

DISCUSSION

In this study of the family members of end-of-life ICU patients, we identified their willingness to take part in LSL decisions, their perception of the severity of clinical conditions and their knowledge of the patient's preferences regarding end-of-life quality. In addition, medical team communication was considered to be satisfactory.

Although there have been relatively few investigations into family acceptance of orthotanasia, this study is consistent with previous studies showing that most of the family members are favorable⁽¹⁶⁻¹⁸⁾ and that this position is significantly associated with their participation in the LSL decision making process. We noticed that family preferences regarding end-of-life decisions have changed; currently, family members question maintaining life support for terminal patients. As has been shown in some previous studies, family participation in LSL decisions is not particularly encouraged by most of medical teams, probably due to their own difficulties dealing with end-of-life dilemmas.⁽¹⁹⁾

Family members perceive LSL to be measures taken in the patient's best interest and, therefore, to be acceptable. Life-maintenance paradigms are questioned when family members appreciate irreversibility and the prolongation of suffering. Death is seen as a relief or rest that frees the patient from pain, famine, thirst and helplessness.^(20,21) In addition to mitigating suffering, fulfilling the family's regarding life support limitation preferences also preserves the patient's dignity, as has been shown in other studies.^(18,22,23)

This study suggests that prior discussion of end-of-life care preferences with patients may reduce their influence

on limiting and withholding life support, as has been shown in another study.⁽²²⁾ However, this study also found that the patients did not discuss their end-of-life care with their physicians. Recent research conducted in a number of Brazilian hospitals has shown that in cases where patients are unable to take part in end-of-life care discussions due to their clinical condition, most physicians are less likely to disagree with nurses and family members.⁽²⁴⁾ This conclusion agrees with that of another study that was conducted in the US.⁽²⁵⁾

Several studies have stressed the relevance of medical team and patient/family member communication.⁽²⁶⁻²⁹⁾ Published articles have described training programs to improve communication skills.^(9,28) In addition to appropriately addressing the patients' symptoms, families expect the medical team to address some of the families' specific needs, such as providing attention, honest information, comfort, respect for their emotions and spiritual support, in addition to responding to their doubts. Satisfaction with medical team communication contributes to end-of-life decision making.

Not all family members are ready to decide on end-of-life issues. Family members who did not take part in the study commented that they were aware of the patient's irreversibility but were unable to participate. One study has shown that family members with a passive role in the decision making process manifest anxiety and depression symptoms.⁽³⁰⁾

It could be said that each family has a particular reaction to terminality. These reactions may be influenced by several factors, such as life history, culture, ideology, myths regarding the beginning and end of life, religion and other issues. All of these factors may aid efforts to understand different families' perceptions of LSL measures.

The complexity of life and death discussions has led to the legalization of LSL decisions. In the US and some European countries, terminal patients are legally allowed to previously state their wishes on end-of-life decisions.⁽¹⁷⁾ In Brazil, the Brazilian Federal Medical Council's has stated that respecting the patient's wishes is mandatory (the new Medical Ethics Code, April 2009).^(5,14) In special cases, the family, as the patient's legal representative, can assume this right. Some studies have shown that life support limitation is increasing in several Brazilian regions, although it is not uniform.⁽²⁾ Brazil, along with certain other Latin-American countries, is still discussing the recommended LSL steps.⁽³⁾

This study suggests that medical teams should include families in the end-of-life decision making process if

they desire it. Because this practice is both legally and ethically supportable, medical teams have no reasons to fear sharing end-of-life decisions.

Death and the dying process are no longer simple events in which the dying person organized his/her own ceremony.⁽³¹⁾ The life extension provided by technological advances favors discussions such as those mentioned in this paper.

Although the adapted QODD questionnaire was easily understood by the participants, this study has several limitations, such as the limited sample size and population and the lack of validated instruments for collecting the data. In addition, the data interpretation may have been biased by the investigator herself, in spite of training in this area. Even with these possible methodological biases, the data were sufficiently consistent to achieve the study aims. Future research could compare acceptance of orthotanasia based on family characteristics using a multi-center and multidisciplinary approach.

CONCLUSION

Most of the participants were favorable to orthotanasia. They expressed their willingness to take part in discussions related to end-of-life quality.

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RESUMO

Objetivos: O objetivo deste estudo foi avaliar o posicionamento dos familiares sobre a ortotanásia, ao considerar controle dos sintomas, preferência do paciente e influência da satisfação da comunicação do tratamento informado pela equipe médica.

Métodos: Foi realizado um estudo descritivo na unidade de terapia intensiva geral adulto do Hospital do Servidor Público Estadual durante o período de um ano. Utilizou-se um questionário estruturado, baseado no *Quality of Dying and Death* (QODD 22) e entrevista informal prévia.

Resultados: Foram avaliados 60 familiares, com 51,7 ± 12,1 anos, sendo 81,7 % do sexo feminino. Os pacientes estavam internados em média por 31 ± 26,9 dias, sendo que 17,0% dos dias na unidade de terapia intensiva. A maioria apresentava doença neurológica. A maioria dos pacientes (53,3%) discutiu o desejo de cuidados de final de vida com a família, mas 76,7% dos pacientes não discutiram com seu

médico ($p < 0,00$). Os familiares responderam a favor da ortotanásia em 83,3 %; a maioria (85,0%) gostaria que a equipe médica discutisse claramente o assunto e 65,0% desejavam participar do processo de decisão de qualidade de final de vida. Quanto à satisfação dos familiares em relação às informações médicas: 93,3% consideraram ter adequada frequência na comunicação do estado clínico; 81,7% conseguiram tirar as dúvidas sobre o estado clínico do paciente; em 83,3% a comunicação foi compreendida e 80,0% consideraram terem recebido as informações com clareza e honestidade. Somente 43,3% dos

familiares gostaria de presenciar o momento da morte de seu ente querido. Houve associação significativa do posicionamento dos familiares sobre ortotanásia e participação na decisão de final de vida ($p = 0,042$).

Conclusões: A maioria dos familiares entrevistada foi a favor da ortotanásia, e gostaria de participar da tomada de decisão de qualidade de final de vida.

Descritores: Família; Estado terminal; Cuidados intensivos; Atitude frente a morte; Ética; Comunicação

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