



Revista Bioética

ISSN: 1983-8042

ISSN: 1983-8034

Conselho Federal de Medicina

Maingué, Paula Christina Pires Muller; Sganzerla, Anor;
Guirro, Úrsula Bueno do Prado; Perini, Carla Corradi
Discussão bioética sobre o paciente em cuidados de fim de vida
Revista Bioética, vol. 28, no. 1, 2020, January-March, pp. 135-146
Conselho Federal de Medicina

DOI: <https://doi.org/10.1590/1983-80422020281376>

Available in: <https://www.redalyc.org/articulo.oa?id=361570650017>

- How to cite
- Complete issue
- More information about this article
- Journal's webpage in [redalyc.org](https://www.redalyc.org)

redalyc.org

Scientific Information System Redalyc
Network of Scientific Journals from Latin America and the Caribbean, Spain and
Portugal

Project academic non-profit, developed under the open access initiative

RESEARCH

Bioethical discussion on end of life patient care

Paula Christina Pires Muller Maingué¹, Anor Sganzerla², Úrsula Bueno do Prado Guirro³, Carla Corradi Perini¹

1. Programa de Pós-Graduação em Bioética, Escola de Ciências de Vida, Pontifícia Universidade Católica do Paraná (PUCPR), Curitiba/PR, Brasil. 2. Programa de Pós-Graduação em Bioética, Escola de Educação e Humanidades, PUCPR, Curitiba/PR, Brasil. 3. Departamento de Medicina Integrada, Universidade Federal do Paraná (UFPR), Curitiba/PR, Brasil.

Abstract

This study aimed at identifying factors that influence the decision-making of health professionals regarding patients in intensive care units. We carried out a quantitative research in two hospitals in Paraná, between March and May 2018. We defined a sample of 45 members of a multidisciplinary team. As results, we identified the interviewees' concern in respecting autonomy, protecting dignity and preserving the quality of life of patients and family members by making shared decision. However, we also observed a tendency of therapeutic obstinacy to fulfill the professional duty, which indicated the need for more discussions and training on palliative care to minimize ethical conflicts.

Keywords: Decision making. Intensive care units. Palliative care.

Resumo

Discussão bioética sobre o paciente em cuidados de fim de vida

O objetivo deste estudo é identificar fatores que influenciam a tomada de decisões de profissionais de saúde diante de pacientes em cuidados de fim de vida internados em unidades de terapia intensiva. Trata-se de pesquisa quantitativa realizada em dois hospitais paranaenses, entre março e maio de 2018, com amostra de 45 integrantes de equipe multiprofissional. Constatou-se preocupação dos entrevistados em respeitar a autonomia, proteger a dignidade e preservar a qualidade de vida de pacientes e familiares por meio da decisão compartilhada. Porém, a tendência de obstinação terapêutica para cumprir o dever profissional mostrou necessidade de mais discussões e formação em cuidados paliativos para minimizar conflitos éticos.

Palavras-chave: Tomada de decisões. Unidade de terapia intensiva. Cuidados paliativos.

Resumen

El debate bioético sobre el paciente en la atención al final de la vida

El objetivo de este estudio es identificar los factores que influyen en la toma de decisiones de los profesionales sanitarios frente a los pacientes terminales que se encuentran en unidades de cuidados intensivos. Se trata de una encuesta cuantitativa realizada en dos hospitales de Paraná, entre marzo y mayo de 2018, con una muestra de 45 miembros de un equipo multiprofesional. Se observó la preocupación de los entrevistados por respetar la autonomía, proteger la dignidad y preservar la calidad de vida de los pacientes y familiares por medio de la decisión compartida. No obstante, la tendencia de la obstinación terapéutica por cumplir con el deber profesional mostró la necesidad de más discusiones y formación en cuidados paliativos para minimizar los conflictos éticos.

Palabras clave: Toma de decisiones. Unidades de cuidados intensivos. Cuidados paliativos.

Technical advances in intensive care units (ICUs) have increased the ability of science to extend life by replacing vital functions of the patient with technology. This feature has added value to medical practice, but also changed the way illness and death are understood^{1,2}. Today it is difficult to recognize and accept finitude, even for health professionals, who often resort to disproportionate measures to avoid the end of life, and thus, prolong suffering. This “therapeutic obstinacy”, is characterized by the adoption of practices not recommended in place of palliative actions².

Therapeutic obstinacy may function as a reaction to the suffering caused by imminent death, or the frustration of professionals trained to fight for life³ or even the lack of knowledge of the multidisciplinary team on palliative care and insecurity in the face of ethical conflicts⁴. Although the number of patients with chronic and limiting diseases admitted to the ICU has grown, the same has occurred to the dissemination of information on palliative care.

However, most patients continue to receive inadequate care, focused only on healing attempts. The World Health Organization (WHO) concluded that only 14% of those who have an indication for palliative treatment do receive it⁵. This type of assistance aims to bridge the gap between scientific and humanistic knowledge, seeking to rescue the dignity of life and the possibility of dying as desired⁶.

The ICU multidisciplinary team must continually reassess patients’ clinical condition, redefining the treatment goals and consider palliative care, especially when there are limitations to the disease-modifying therapy. We call “end of life care” the situation when the disease is at an advanced stage, with signs that death is near. In such cases, the postponement of death with technological resources would generate high psychological, social and financial losses for all parties involved (patient, family, health professionals and hospital network)^{7,8}.

Interdisciplinarity is absolutely necessary in palliative treatment. Both the care plan, and the therapeutic planning must involve the entire team, always seeking to improve the patients and families’ quality of life^{9,10}. In addition to scientific competence, the training of professionals must include bioethics and the humanities. And to promote welcoming and care, frequent updating is always very important¹¹.

Resolution 1.805/2006¹² of the *Conselho Federal de Medicina* (CFM) [Brazilian Federal Council of Medicine] supports the suspension of futile treatments for patients with incurable disease, if accepted by him/her or a legal representative. The

advance directive will (ADW), foreseen by Resolution CFM 1.995/2012¹³, constitute a resource that guides the doctor to respect the person’s discretion. They allow patients to make their own choices in future treatments, accepting or refusing procedures in advance, in case of inability to communicate or express their will⁸. The resolution states that no one, even in a life-threatening situation, can be forced into treatment clinical or surgical¹⁴, based on the premise that, like life, dignified death is also a right¹⁵.

The technological arsenal currently available in ICUs is so large that the multidisciplinary team may feel obliged to offer all possible therapeutic options, regardless of whether the disease prognosis is limited or not. Thus, professionals often end up keeping a seriously ill organism alive, postponing the moment of death to previously unthinkable limits¹⁶. In fact, for such patients, the most appropriate objective would be to provide conditions for death without pain and suffering, with compassionate care extended to the patient’s relatives¹⁷.

There are many questions about what is technically possible and ethically correct, and even when to continue treatment without harming human dignity. There must be limits to full therapy, as there is a time when it is not appropriate to continue treatment aimed at healing. The individual’s autonomy and the principles of beneficence and non-maleficence must be respected¹⁸.

In view of the unpreparedness in dealing with terminally ill patients, this study seeks to answer the following questions: What is the perception of health professionals about therapeutic obstinacy? What do these professionals, who work in the ICU, understand about this practice? Which ethical conflicts do they face when making decisions that involve patients in end of life care?

Many factors contribute for therapeutic obstinacy as a common practice in ICUs. Among them, there are: growing technicality in health care; professional’s difficulty in understanding the end of human life; feelings of frustration, failure and helplessness; deficient training; and fear of suffering legal processes suited by family members of patients. Such factors, added by others that influence decision making show the immense need for carrying debates in the bioethics field. This is because not only adequate training of professionals is necessary, but also the awareness of the whole society about these issues¹⁹.

One of the methods used by clinical bioethics is deliberative practice, which search for solutions to a given situation based on listening and careful

analysis of the main factors and values involved²⁰. Following such method, this research aimed at identifying elements that influence the decision making of health professionals regarding ICU patients in end of life care, seeking solutions that respect the person's autonomy and guarantee both their quality of life and the right to a dignified death.

Method

This is an exploratory and descriptive research, with a quantitative approach, carried out in the ICU of two general university hospitals located in the city of Curitiba, Paraná, Brazil that serve clinical and surgical adult patients. The study participants are health professionals from a multidisciplinary team constituted by doctors, nurses, physiotherapists, nutritionists, pharmacists, psychologists, social workers and speech therapists dedicated to the care of terminal patients.

The sample included all ICU professionals from the two hospitals that met the following inclusion criteria: participating in the multiprofessional team, working in direct end of life patient care and having completed higher education. Therefore, professionals who were residing were excluded. Finally, 45 participants responded the survey questionnaire (Annex), being 38 female and seven male.

We collected data between February and April 2018 with a questionnaire adapted from Moritz³, replacing the adjectival scale by Streiner and Norman²¹ by the Likert's in order to facilitate the understanding of the responses. The Likert scale we adopted has five points: "Strongly disagree", "disagree", "Undecided", "Agree" and "Strongly agree", corresponding to a score from 1 to 5 respectively. We also included a question about factors influencing the professional's after each clinical case. The cases were based on real decision-making situations regarding the refusal or suspension of treatment, described by Moritz³ in her thesis.

We applied the IBM SPSS Statistics software (v. 21.0) to perform the statistical analysis. The association among the responses and the gender, profession and work sector of the participants was tested using Fisher's exact test, since some expected frequencies were less than 1. The continuous quantitative variables referring to the characterization of the sample – length of ICU work and working time with terminally ill patients – were tested for normal distribution using the Kolmogorov-Smirnov test. As they did not present a normal distribution in all categories,

these variables were compared with the responses on clinical cases by using the Kruskal-Wallis test.

We performed a post hoc analysis with the Mann-Whitney test to relate the question "Have you ever participated in this discussion in the hospital environment?" to the working time in the ICU. And we assumed the significance level of 0.016 exclusively for this analysis ($\alpha/3$), after Bonferroni's correction. In all other analyzes, we considered a significance level of 0.05 ($\alpha=0.05$). The results were presented as mean, standard deviation (SD), median, minimum, maximum, first quartile (1Q) and third quartile (3Q), absolute frequencies and relative percentages.

Results and discussion

All respondents worked – or had already worked – in the ICU and with patients in end of life care. However, despite having practical experience, most professionals did not have training in palliative care, such as extension, improvement or specialization courses (Table 1).

Table 1. General characteristics of the sample

Characteristics		Freq.	%
Profession	Social worker	1	2.2
	Nurse	9	20.0
	Physiotherapist	22	48.9
	Speech therapist	1	2.2
	Doctor	4	8.9
	Nutritionist	5	11.1
	Psychologist	3	6.7
Marital status	Single	20	44.4
	Separated	2	4.4
	Widow/er	1	2.2
	Live with partner	20	44.4
	Not informed	2	4.4
Religion	Catholic	27	60.0
	Protestant	5	11.1
	Without religion	2	4.4
	Other	5	11.1
	Not informed	6	13.3
Sector in which you work	ICU	20	44.4
	Nursing	5	11.1
	ICU + another sector	6	13.3
	Another sector	11	24.4
	Not informed	3	6.7

continues...

Table 1. Continuation

Characteristics		Freq.	%
Do you work or have worked in ICU?	Yes	45	100.0
	No	0	0.0
Do you work or have worked with end of life patients?	Yes	45	100.0
	No	0	0.0
Are you trained in palliative care?	Yes	6	13.3
	No	39	86.7

Freq.: frequency; ICU: Intensive care unit; %: percentage

We compared responses involving treatment decisions were compared with the interviewees' sex, profession and work sector, but observed no significant association was observed regarding the sex of the participants. As for the profession, the positive response regarding participation in discussions about treatment was greater among doctors, nurses and physiotherapists, professionals who are part of the fixed staff of the ICU multiprofessional team, staying more with patients and family members. Conversely, the other professionals work not only in the ICU, but also in other sectors, remaining more distant from patients and family members.

Shared decisions have a positive impact on care: patients tend to trust more the team and the services provided, and feel more satisfied with the care received¹⁷. However, in many cases patients remains subjected to other's decisions about their lives, in which the power of choice is transferred to the multiprofessional team.

Most of the interviewees who participated in discussions about refusing or suspending treatment work exclusively in the ICU, which demonstrates how common these debates are in this environment. Among those working exclusively in the ICU, only two participants (10%) reported never having collaborated in this type of decision. However

this result can be explained by the fact that these professionals work in the ICU for less than a year.

The other responses showed that professionals working exclusively in the ICU talk more about death with their family members. The respondents also stated that they would not like to be resuscitated in case of serious illness - even in good health, but at an advanced age – and that they would not resuscitate relatives who did not have such desire. In their daily lives, health professionals face pain, loss and death, experiencing internal conflicts, fragility, vulnerability, fears and uncertainties that they are not always able to share²².

Conflicts between the multiprofessional team are frequent, and most of them involve disagreements about prognosis and treatment plan. Issues related to the terminality of life tend to be the focus of disagreement and exhaustion among professionals, affecting care and often causing delay in decision making²³.

We also investigated the association between sex and profession regarding responses about clinical cases. A significant association was only observed in relation to the gender of the interviewees in Clinical Case 3, question 16, which deals with an elderly patient, with an unfavorable prognosis and no response to treatments, dependent on mechanical ventilation and vasoactive drugs, as shown in Table 2.

The question asked whether or not the professionals would talk to this patient to find out his opinion regarding resuscitation techniques, preceding a possible cardiorespiratory arrest. Most women (84.2%) responded "Strongly agree", while among men most of the responses were divided between "Strongly disagree" (28.6%) and "Strongly agree" (42.9%). The situation shown by these figures is that it is more difficult among male respondents to maintain effective communication with patients. This problem is serious, for regardless of the area of basic training, health professionals have human relations as the basis of their work and, therefore they need to improve their communication skills.

Table 2. Association between responses of clinical cases with respondents' gender

Clinical case/question	Response options	Gender		p
		Female	Male	
Case 1	Strongly disagree	20 (52.6%)	5 (71.4%)	0.869
	Disagree	3 (7.9%)	0 (0%)	
	Undecided	4 (10.5%)	1 (14.3%)	
	Agree	4 (10.5%)	1 (14.3%)	
	Strongly agree	7 (18.4%)	0 (0%)	

continues...

Table 2. Continuation

Clinical case/question	Response options	Gender		p
		Female	Male	
Case 2 Question 10	Strongly disagree	11 (28.9%)	5 (71.4%)	0,103
	Disagree	6 (15.8%)	0 (0%)	
	Undecided	3 (7.9%)	1 (14.3%)	
	Agree	5 (13.2%)	1 (14.3%)	
	Strongly agree	13 (34.2%)	0 (0%)	
Case 2 Question 12	Strongly disagree	6 (15.8%)	3 (42.9%)	0.469
	Disagree	4 (10.5%)	0 (0%)	
	Undecided	5 (13.2%)	0 (0%)	
	Agree	5 (13.2%)	0 (0%)	
	Strongly agree	18 (47.3%)	4 (57.1%)	
Case 3 Question 14	Strongly disagree	9 (23.7%)	4 (57.1%)	0.101
	Disagree	6 (15.8%)	0 (0%)	
	Undecided	9 (23.7%)	0 (0%)	
	Agree	7 (18.4%)	0 (0%)	
	Strongly agree	7 (18.4%)	3 (42.9%)	
Case 3 Question 16	Strongly disagree	1 (2.6%)	2 (28.6%)	0.018*
	Disagree	0 (0%)	1 (14.3%)	
	Undecided	1 (2.6%)	0 (0%)	
	Agree	4 (10.5%)	1 (14.3%)	
	Strongly agree	32 (84.2%)	3 (42.9%)	
Case 3 Question 18	Strongly disagree	0 (0%)	0 (0%)	0.591
	Disagree	0 (0%)	0 (0%)	
	Undecided	2 (5.3%)	1 (14.3%)	
	Agree	7 (18.4%)	1 (14.3%)	
	Strongly agree	29 (76.3%)	5 (71.4%)	
TOTAL		38 (100%)	7 (100%)	

*Statistical significance; Fisher's exact test ($\alpha=0.05$). For a statement of the cases and questions, see Appendix.

People who work with terminally ill patients must know not only what to say, but when and how, but knowing also when to shut up⁶. Patients need to be heard during decision-making²⁴, and *health professionals have a duty to respect their autonomy, (...) allowing death to occur at the place, time and company of whomever the patient wants*²⁵.

We observed significant associations with profession for responses to Clinical Case 2, which refers to an elderly woman, in good health, who wishes to die. Respondents were asked whether or not they would call the resuscitation team if she presented cardiopulmonary arrest belonging to their family. Most doctors (50%), nurses (44.4%) and nutritionists (60%) responded "Strongly disagree", while physical therapists (40.9%) responded "Strongly agree". Even when dealing with a family member who has already manifested a desire to die suddenly, professionals demonstrated doubts about calling the resuscitation team or respecting

the patient's autonomy, which reveals conflicts in relation to decisions of this type.

Disagreements in health teams are not usually about the facts themselves, but about their interpretation and representation. There are no pure facts, as they are interpreted considering the values attributed to them. As argumentations are within the scope of values²⁶, which are morally binding, it is common for elderly patients affected by unexpected illnesses to undergo futile resuscitation treatments or efforts, simply due to lack of consensus or more effective communication between professionals, even when patients have previously manifested their will²³.

There was also a significant association between profession and the responses to question 12 of Clinical Case 2, which asks, still about the elderly patient who wants to die: "If you belonged to the resuscitation team, would you initiate resuscitation techniques?" Higher percentages of the "Strongly agree" response were found among nurses (44.4%), nutritionists

(40%) and physical therapists (63.6%). But responses varied among doctors and other professions. When it comes to the patient, and no longer the relative, the respondents agree to initiate resuscitation, following the legislation, even though disrespecting the patient's autonomy. The responses show the concern of professionals in relation to healing with the ethical obligation of not neglecting care.

We noticed that *health professionals often end up performing some procedures because they fear the risks of exposing themselves to possible civil or criminal lawsuits, if they record their decisions*²⁷. This shows that, even dealing with the end of life frequently, it is common for professional to be unaware of the legal consequences of indicating or suspending therapies in terminally ill patients. All other responses, although not statistically significant, demonstrated that most professionals agree that, before making a decision, it is necessary to talk to the patient, who must be the most interested in this choice²⁸.

We also compared the responses with the respondents' working time with this type of patient in the ICU, to investigate whether opinions varied. The question regarding the participation in discussions on the treatment of terminally ill patients was the only one that showed a significant difference in relation to the working time in the ICU. In the post hoc analysis, using the Mann-Whitney non-parametric test, a statistically significant difference was observed between the responses "Strongly disagree" and "Strongly agree" ($p=0.009$). The median for working time in the ICU among those who never participated in this type of discussion was nine months, while the median of those who claimed to have participated was 48 months.

Discussions on the treatment of terminally ill patients are regular within the multidisciplinary teams, and could even be more frequent, as they increase knowledge and decrease conflicts. They are important to resolve doubts and minimize divergences, since uncertainty regarding common ethical dilemmas due to the advancement of technology and treatment options generates stress for everyone involved²³. In order to preserve patients, health professionals often end up making a kind of pact of silence with them. In contrast, in palliative care programs, it is possible to discuss procedures collectively in order to share information and feelings²⁹.

In order to identify values in decision making, we asked the respondents about which factors most influenced their responses in all clinical cases. As these questions were open and provided discursive

responses, it is not possible to present all of them here. We grouped and categorized such responses, so that we could quantify them.

In Clinical Case 1 – young patient, with multiple organ failure, unfavorable prognosis, with no response to treatment, and who, after 60 days of hospitalization in the ICU, presented cardiorespiratory arrest –, we asked the interviewees: "Do you think this patient should be resuscitated?". A total of 28 participants (62.2%) responded "Strongly disagree" or "Disagree", among which 15 (53.5%) pointed out the "unfavorable prognosis", in isolation, as the most relevant factor for decision making. In responses indicating more than one justification, eight other participants declared "unfavorable prognosis" as an element taken into account: unfavorable prognosis and impaired quality of life (4), unfavorable prognosis and prolonged hospitalization, (2) unfavorable prognosis, impaired quality of life and family issues (2). In all, 82.1% of the justifications contained "unfavorable prognosis". Lifetime prognosis is one of the most discussed criteria today. It is customary to establish the limit of six months of life expectancy as a criterion for indicating palliative care. However, WHO recommends that, since diagnosis, every patient with severe, progressive and incurable disease has the option of receiving palliative treatment associated with curative therapies. Measures to prolong life – and therefore the suffering of all people involved – should be avoided, aiming to maintain the person's comfort and dignity, as some physical symptoms – such as pain, fear, shortness of breath, anxiety and depression – associated with emotional and spiritual suffering, may be strong enough to make life intolerable^{6,30}.

In Clinical Case 2 – elderly, in good health, who would like to die suddenly and has cardiopulmonary arrest – we asked the interviewees if, being the patient a family member, they would call the resuscitation team. The most frequent responses were "Strongly disagree" and "Disagree", summing up 22 participants (48.9%), among which 19 (86.4%) justified the decision as "respecting the will previously manifested". A number of 18 professionals (40%) responded "Strongly agree" or "Agree", of which 12 (66.6%) explained the option for the "previous clinical condition of the patient" and three (16.7%) for the "family bond". The other three (16.7%) presented varied justifications.

Although they must define treatments based on facts and values, health professionals do not always discuss this matter. This makes them end

up deciding based on clinical facts and on their own point of view, disregarding the patient's, whose inclusion in decision making is a moral and ethical obligation that, when fulfilled, improves health care. Thus, it is necessary to give space to conversations about values²⁶, maintaining clear and objective communication that makes the patient the protagonist of the deliberations^{30,31}.

Still in Clinical Case 2, participants were asked whether or not they would initiate resuscitation techniques if they belonged to the resuscitation team. A number of 27 professionals (60%) responded "Strongly agree" or "Agree", among which nine (33.3%) justified the response due to the patient's previous clinical condition. The other justifications varied.

When functional capacity declines and it is known that, even with good previous health conditions, the patients' recovery will never take them to the previous level, palliative actions are imperative, instead of invasive and painful treatments that would only prolong the suffering uselessly²⁶. In these circumstances, the multiprofessional team has the obligation of ensuring medical ethics and the patients' rights, so that their wishes are considered independently of the professionals' personal values³².

Since the 1960s, there has been a worldwide movement to value patients' autonomy, especially in end of life care. This concern has been materialized in documents of manifestation of will, among which are the ADW. It is very important that patients are aware of this possibility and encouraged to prepare the document, attesting in advance their wishes about palliative care if they are unable to express themselves¹⁴.

In Clinical Case 3 – elderly with an unfavorable prognosis, unresponsive to treatments and dependent on mechanical ventilation and vasoactive drugs – we asked the interviewees whether or not, in the event of cardiopulmonary arrest, they would resuscitate the patient. A total of 19 respondents (42.2%) indicated "Strongly disagree" or "Disagree", and in 13 responses (68.4%) the justification was

"unfavorable prognosis". Once again, the discussion on palliative care and the renouncement of techniques that prolong suffering are brought up.

Still in the Clinical Case 3, we asked the interviewees whether or not they thought they should talk to the patient to find out his/her opinion. A total of 40 professionals (88.9%) responded "Strongly agree" or "Agree". Among them, 23 (57.5%) reported "respect for the patient's autonomy/their right to choose /their will" as the main reasons for the decision.

Finally, we questioned whether or not they considered it necessary to talk to the patient's family members in advance in order to know their opinion. A number of 42 (93.3%) responded "Strongly agree" or "Agree". The most frequent justifications were: "The opinion of family members must be respected" (8 responses, 19%); "Family members must be aware" (5 responses, 11.9%) and "The opinion of family members must be considered, even if the patient's will is sovereign" (5 responses, 11.9%); "It is necessary to prepare the family regarding the clinical evolution of the patient" (3 responses, 7.1%); "Communicating is important to define advanced life support" (3 responses, 7.1%); and "It is an ethical and humanistic issue" (3 responses, 7.1%).

Final considerations

Considering the results presented, it is clear that professionals are concerned with respecting the autonomy of patients and family members. In circumstances of unfavorable prognosis, we found that care was taken to protect dignity and guarantee the quality of life by shared decision. However, we also detected a certain tendency towards therapeutic obstinacy to fulfill professional duty, which reveals the need to discuss decision making and intensify training in palliative care, minimizing ethical conflicts. Finally, it is worth pointing out as a limiting factor the difficulty of getting professionals to adhere to the research.

References

1. Alvarez CB. Limitation of therapeutic effort: when less is more. *Colomb Med (Cali)* [Internet]. 2015 [acesso 9 ago 2019];46(1):1-2. Disponível: <https://bit.ly/2FMD1DT>
2. Gómez-Sancho M, Altisent-Trota R, Bátiz-Cantera J, Ciprés-Casasnovas L, Gándara-del-Castillo Á, Herranz-Martínez JA *et al.* Atención médica al final de la vida: conceptos y definiciones. *Gac Méd Bilbao* [Internet]. 2015 [acesso 9 ago 2019];112(4):216-8. Disponível: <https://bit.ly/2Np8C2R>
3. Moritz RD. O efeito da informação sobre o comportamento dos profissionais de saúde diante da morte [tese] [Internet]. Florianópolis: Universidade Federal de Santa Catarina; 2002 [acesso 9 ago 2019]. Disponível: <https://bit.ly/2NpFLvb>

4. Silva CF, Souza DM, Pedreira LC, Santos MR, Faustino TN. Concepções da equipe multiprofissional sobre a implementação dos cuidados paliativos na unidade de terapia intensiva. *Ciênc Saúde Coletiva* [Internet]. 2013 [acesso 21 set 2017];18(9):2597-604. DOI: 10.1590/S1413-81232013000900014
5. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* [Internet]. 2015 [acesso 8 out 2018];373(8):747-55. DOI: 10.1056/NEJMr1404684
6. Carvalho RT, Parsons HA, organizadores. Manual de cuidados paliativos ANCP. 2ª ed. São Paulo: Academia Nacional de Cuidados Paliativos; 2012.
7. Oliveira ABF, Dias OM, Mello MM, Araújo S, Dragosavac D, Nucci A, Falcão ALE. Factors associated with increased mortality and prolonged length of stay in an adult intensive care unit. *Rev Bras Ter Intensiva* [Internet]. 2010 [acesso 23 set 2018];22(3):250-6. DOI: 10.1590/S0103-507X2010000300006
8. Coelho CBT, Yankaskas JR. New concepts in palliative care in the intensive care unit. *Rev Bras Ter Intensiva* [Internet]. 2017 [acesso 11 nov 2018];29(2):222-30. DOI: 10.5935/0103-507X.20170031
9. Santos FS. Cuidados paliativos: diretrizes, humanização e alívio de sintomas. São Paulo: Atheneu; 2011.
10. Vianna MLGS, Silva DSN. Existem cuidados paliativos sem interdisciplinaridade? In: Corradi-Perini C, Esperandio MRG, Souza W, organizadores. *Bioética e cuidados paliativos*. Curitiba: Prismas; 2016. p. 65-80.
11. Bertinato CB, Wrzesinski JT. Interface dos princípios dos cuidados paliativos com os fundamentos da bioética clínica. In: Corradi-Perini C, Esperandio MRG, Souza W, organizadores. *Bioética e cuidados paliativos*. Curitiba: Prismas; 2016. p. 41-61.
12. Conselho Federal de Medicina. Resolução nº 1.805, de 9 de novembro de 2006. Na fase terminal de enfermidades graves e incuráveis é permitido ao médico limitar ou suspender procedimentos e tratamentos que prolonguem a vida do doente, garantindo-lhe os cuidados necessários para aliviar os sintomas que levam ao sofrimento, na perspectiva de uma assistência integral, respeitada a vontade do paciente ou de seu representante legal. *Diário Oficial da União* [Internet]. Brasília, nº 227, p. 169, 28 nov 2006 [acesso 16 out 2018]. Seção 1. Disponível: <https://bit.ly/2RbCz7G>
13. Conselho Federal de Medicina. Resolução nº 1.995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. *Diário Oficial da União* [Internet]. Brasília, nº 170, p. 269-70, 31 ago 2012 [acesso 16 out 2018]. Seção 1. Disponível: <https://bit.ly/30j68s7>
14. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. *Rev. bioét. (Impr.)* [Internet]. 2013 [acesso 16 out 2018];21(3):463-76. DOI: 10.1590/S1983-80422013000300011
15. Paiva FCL, Almeida JJ Jr, Damásio AC. Ética em cuidados paliativos: concepções sobre o fim da vida. *Rev. bioét. (Impr.)* [Internet]. 2014 [acesso 13 set 2017];22(3):550-60. DOI: 10.1590/1983-80422014223038
16. Siqueira JE, Pessini L, Siqueira CE. Olhar bioético sobre a terminalidade da vida e os cuidados paliativos. In: Porto D, Schlemper BR Jr, Martins GZ, Cunha T, Hellmann F, organizadores. *Bioética: saúde, pesquisa, educação*. Brasília: CFM; 2014. p. 245-63.
17. Siqueira JE, Zoboli ELCP, Sanches M, Pessini L, organizadores. *Bioética clínica: memórias do XI Congresso Brasileiro de Bioética, III Congresso Brasileiro de Bioética Clínica e III Conferência Internacional sobre o Ensino da Ética*. Brasília: CFM; 2016.
18. Dadalto L, Affonseca CA. Medical, ethical and legal considerations regarding end-of-life decisions in pediatric patients. *Rev. bioét. (Impr.)* [Internet]. 2018 [acesso 12 jan 2019];26(1):12-21. DOI: 10.1590/1983-80422018261221
19. Silva FS, Pachemshy LR, Rodrigues IG. Percepção de enfermeiros intensivistas sobre distanásia em unidade de terapia intensiva. *Rev Bras Ter Intensiva* [Internet]. 2009 [acesso 31 ago 2017];21(2):148-54. DOI: 10.1590/S0103-507X2009000200006
20. Gracia D. Pensar a bioética: metas e desafios. São Paulo: Loyola; 2010.
21. Streiner DL, Norman GR. Health measurement scale: a practical guide to their development and use. 3ª ed. Nova York: Oxford University Press; 2003.
22. Pessini L, Bertachini L, organizadores. *Bioética, cuidado e humanização*. São Paulo: Loyola; 2014.
23. Azevedo R, Oliveira RA. Reflexões éticas em medicina intensiva. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2018.
24. Kovács MJ. Atendimento psicológico em unidades de cuidados paliativos. *Rev Bras Med*. 1999;56(8):786-96.
25. Ribeiro DC. Autonomia: viver a própria vida e morrer a própria morte. *Cad Saúde Pública* [Internet]. 2006 [acesso 20 set 2017];22(8):1749-54. p. 1753. DOI: 10.1590/S0102-311X2006000800024
26. Zoboli E. Bioética clínica na diversidade: a contribuição da proposta deliberativa de Diego Gracia. *Bioethikos* [Internet]. 2012 [acesso 13 out 2018];6(1):49-57. Disponível: <https://bit.ly/36Qnvmd>
27. Siqueira JE, Pessini L, Siqueira CE. Op. cit. p. 255.
28. Menezes MB, Selli L, Alves JS. Distanásia: percepção dos profissionais da enfermagem. *Rev Latinoam Enferm* [Internet]. 2009 [acesso 15 set 2017];17(4):443-8. DOI: 10.1590/S0104-11692009000400002
29. Oliveira RA, coordenador. *Cuidado paliativo*. São Paulo: Conselho Regional de Medicina do Estado de São Paulo; 2008.

30. Pessini L, Bertachini L, organizadores. Humanização e cuidados paliativos. 5ª ed. São Paulo: Loyola; 2011.
31. Cook D, Rocker G. Dying with dignity in the intensive care unit. N Engl J Med [Internet]. 2014 [acesso 28 set 2017];370(26):2506-14. DOI: 10.1056/NEJMra1208795
32. Pellegrino ED, Thomasma DC. Para o bem do paciente: a restauração da beneficência nos cuidados da saúde. São Paulo: Loyola; 2018.

Participation of the authors

Paula Christina Pires Muller Maingué conceived the research, analyzed and interpreted the data and wrote the article. Carla Corradi Perini helped to interpret the data and, together with Anor Sganzerla and Úrsula Bueno do Prado Guirro, reviewed the manuscript

Correspondence

Paula Christina Pires Muller Maingué – Rua Deputado Heitor Alencar Furtado, 1.661, Mossunguê CEP 81200-110. Curitiba/PR, Brasil.

Paula Christina Pires Muller Maingué – Master – paula.muller@pucpr.br

 0000-0003-2485-1478

Anor Sganzerla – PhD – anor.sganzerla@gmail.com

 0000-0001-8687-3408

Úrsula Bueno do Prado Guirro – PhD – ursulaguirro@gmail.com

 0000-0003-4879-3057

Carla Corradi Perini – PhD – carla.corradi@pucpr.br

 0000-0002-9340-8704

Received: 5.19.2019

Revised: 12. 9.2019

Approved: 12.11.2019



Appendix

Demographic data

Age: _____

Gender: () Female () Male

Marital status: () Single () Widow/er () Separated () Lives with a partner

Religion: _____

Ethnic origin: () Portuguese () German () Asian () African () Italian () Others

Which? _____

Profession: _____

Hospital sector where you work:

() Previously worked in the ICU () Currently work in the ICU

Time: _____ years

() Works with end of life patients () Worked with end of life patients

Time: _____ years

Do you have any training in palliative care?

() No () Yes

Which?

Decisions about refusing or stopping treatment

Have you ever participated in this discussion in the hospital environment?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

If you agreed

1. Name which professionals were involved in the debate.

2. Who do you think should participate in this debate?

() Patient () Psychologist () Family

() Doctor () Social worker () Nurse

() Religious () Nursing technicians and assistants

() Others

Who?

In the home environment

3. Have you ever talked at home with your family members, especially the elderly, about death and decisions about dying?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

4. If you had a serious and irrecoverable illness and had a cardiopulmonary arrest, would you like to be resuscitated?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

5. If you were 85 years old, in good health for your age, and suddenly had a cardiopulmonary arrest, would you like to be resuscitated??

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

6. If a relative of yours, facing old age or a serious illness, showed the desire not to be resuscitated, and in those circumstances suffered a cardiopulmonary arrest, you would start cardiopulmonary resuscitation (CPR)?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

7. How would you like to die?

() Suddenly () After a consumptive illness () Other

How?

Clinical cases

• Case 1

This is a 16 year old female patient case. She presented history of esophageal stenosis after ingestion of caustic soda when she was four years old and was admitted for surgical correction due to recurrent pneumonia. She evolved in the postoperative period with mediastinitis, maintaining a septic condition without the prospect for further surgical treatment and had no improvement with clinical treatment. Her condition progressed to multiple organ failure and the patient had cardiopulmonary arrest on the 60th day of hospitalization.

8. Do you think this patient should be reanimated?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

9. Which factors you believe most influenced your decision?

• Case 2

An 86-year-old woman who lives with her family and has good health conditions for her age, and she had repeatedly told family members that she would like to *die suddenly*. Then one day she presented a sudden loss of consciousness and cardiopulmonary arrest.

10. If she were your family member, would you call a health team and start cardiopulmonary resuscitation?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

11. Which factors you believe most influenced your decision?

12. If you belonged to the resuscitation team, would you initiate resuscitation techniques?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

13. Which factors you believe most influenced your decision?

• Case 3

Male patient, 63 years old, diagnosed with heart failure due to ischemic cardiomyopathy, with an ejection fraction of 20%. He was interned in the ICU, in a medical center without conditions for heart transplantation and presented no response to clinical treatment, being dependent on dobutamine and mechanical ventilation for 30 days. If this patient had cardiopulmonary arrest:

14. Would you initiate resuscitation techniques?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

15. Which factors you believe most influenced your decision?

16. Before this fact, during hospitalization, do you think you should talk to the patient to find out what his opinion is?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

17. Which factors you believe most influenced your decision?

18. Before this fact, during hospitalization, you think you should talk to the patient's family to find out what your opinion is?

1	2	3	4	5
Strongly disagree	Disagree	Undecided	Agree	Strongly agree

19. Which factors you believe most influenced your decision?
