

Perception of “dignified death” for students and doctors

Inês Motta de Moraes¹, Rui Nunes², Thiago Cavalcanti³, Ana Karla Silva Soares⁴, Valdiney V. Gouveia⁵

Abstract

Death is the definitive end of life in the body. The technological advances of medicine have made it possible to prolong the process of dying. This study aimed to discover the perception of medical students and medical professionals about a good death, and analyzed the differences between the groups and their correlates based on demographic variables. A total of 398 people, equally divided among medical students and doctors, participated in the study. Most of the participants were male (57.8%), with a mean age of 34.5. They responded to the GDPS (Good Death Perception Scale) and demographic questions. Results indicated that doctors preferred to die in a hospital (74%) and students at home (74%). The latter obtained a higher mean GDPS score ($M = 5.6$, $SD = 0.6$). Despite its limitations, this study allows the consideration of future practices inherent to the conception of a good death by health professionals, improving the doctor-patient relationship.

Keywords: Death-Value of life. Perception. Medicine. Doctors. Students.

Resumo

Percepção da “morte digna” por estudantes e médicos

A morte é a cessação definitiva da vida no corpo. Os avanços técnico-científicos da medicina conseguiram prolongá-la. O objetivo do presente estudo foi conhecer a percepção de estudantes e profissionais da medicina acerca da “morte digna”. Levantaram-se as diferenças entre os grupos e seus correlatos, valendo-se de variáveis demográficas. Participaram 398 respondentes, distribuídos equitativamente entre estudantes e médicos da cidade de Porto Velho, dos quais 57,8% eram do gênero masculino, com média etária de 34,5 anos. Os participantes responderam à chamada “escala de percepção de morte digna” (EPMD) e questões demográficas. Os resultados indicaram que os médicos preferiram morrer no hospital (74%) e os estudantes, em casa (74%); esses últimos tiveram maior média na EPMD ($M = 5,6$; $DP = 0,6$). Apesar das limitações, este estudo favorece a reflexão sobre práticas futuras, inerentes à concepção de morte digna por integrantes da saúde, auxiliando a relação médico-paciente.

Palavras-chave: Morte-Valor da vida. Percepção. Medicina. Médicos. Estudantes.

Resumen

Percepciones de estudiantes y médicos sobre la “muerte digna”

La muerte es la cesación definitiva de la vida en el cuerpo. Los avances técnico-científicos de la medicina lograron posponerla. El objetivo del presente estudio fue conocer la percepción de estudiantes y profesionales de la medicina con respecto a la muerte digna. Se registraron las diferencias entre los grupos y sus correlatos con variables demográficas. Participaron 398 personas divididas equitativamente entre estudiantes y médicos de la ciudad de Porto Velho (RO). Del total, 57,8% eran de género masculino, con una edad promedio de 34,5 años. Estos respondieron la EPMD (Escala de Percepción de Muerte Digna) y preguntas demográficas. Los resultados indicaron que los médicos prefieren morir en el hospital (74%) y los estudiantes en sus casas (74%); éstos presentaron una media mayor en la EPMD ($M = 5,6$; $DP = 0,6$). A pesar de las limitaciones, este estudio propone pensar prácticas futuras inherentes a la concepción de muerte digna de parte de los profesionales de la salud, colaborando en la relación médico-paciente.

Palabras-clave: Muerte-Valor de la vida. Percepción. Medicina. Médicos. Estudantes.

Aprovação CEP Fimca CAAE 0014.0.382.000-10

1. **Doutora** imm1952@gmail.com 2. **Doutor** ruinunes@med.up.pt – Faculdade de Medicina da Universidade do Porto, Portugal 3. **Mestre** thiagomcavalcantii@gmail.com 4. **Doutora** akssoares@gmail.com 5. **Doutor** vvgouveia@gmail.com – Universidade Federal da Paraíba, João Pessoa/PB, Brasil.

Correspondência

Valdiney V. Gouveia – Departamento de Psicologia (CCHLA), Universidade Federal da Paraíba CEP 58051-900. João Pessoa/PB, Brasil.

Declararam não haver conflito de interesse.

Death is an everyday reality in the daily work of health professionals, especially when this segment is compared with the general population¹. Because they deal with processes related to health, disease and death on a daily basis, these professionals are more likely to have psychic and somatic problems², and the occupational routine, the quality of the work environment, as well as the proximity to pain and death, are factors which explain some of the health problems of this population. However, the way of classifying and reporting to death has undergone changes along time, similarly to the profile of health professionals, especially doctors³.

Historically, in the 5th and 6th centuries death permeated everyday life and was perceived in a prosaic manner, with no drama or fear⁴. In the medieval era it was a domestic, romanticized phenomenon⁵, restricted to the circle of family members, friends and neighbors, in addition to the presence of a priest. In this context, it was not common for the doctor to be summoned even to confirm the death, given that this act was considered an incivility.

This was the point when the medical literature began investigating this theme, which started having bibliographic references³, although resignation and the notion of the inescapable fatality of death made the feeling of fear related to it become practically absent. This perspective, which lasted until the 18th century⁶, gave rise to a perception of death in the next century as an event that raises fear⁴.

In the beginning of the 20th century the evolution of medicine and public health allowed for the reduction of mortality rates and the extension of life time expectancy. In this context, death experienced at home in the presence of the family gradually ceased to be acceptable⁷. Medicine itself, with its measures for prevention and social control of diseases, had a crucial role in this phenomenon when it moved death away from the domestic realm and thus hid it, aiming at protecting hospital routines from the crisis represented by the imminence of death⁸⁻⁹.

In this early century a growing tendency to simplify the rituals regarding death is observed, such as faster, more discreet funerals, a notorious growth in the number of cremations and a shorter grief period. In terms of hospital care, the contemporary perspective of death has demanded more technical knowledge on the phenomenon, especially for health professionals who have started to consider the notion of “good death”, or dignified death. This proposal gains more space every day in the health area, stimulating hospitals to acquire

means to allow for more comfort and care for their terminal patients³. This is the scenario upon which the current study is based, so that the perception of medicine students and professionals regarding dignified death be known. Specifically, it is intended to verify to which extent demographic variables are related to this perception.

Dignified death

In addition to bringing benefits to people's health, the technological advance of medicine has facilitated the control of the death process with the artificial maintenance of the operation of organs, even in cases with no perspective of cure. The place of death has been shifted; in other words, if death would in ancient times occur mostly at home, in the presence of family and friends, it is now practically confined to the hospital environment in which the patient is often alone¹⁰⁻¹¹.

As a consequence of this shift, palliative care and the humanization of hospital intervention processes are more and more relevant. Palliative care consists in the management of symptoms and psychosocial support to the patient in order to potentialize the quality of the care and reduce the frequency of use of medical services. However, this type of treatment is generally used belatedly, in advanced stages of the disease, especially with patients who are already committed to a hospital. For this reason such care many times proves to be ineffective to improve the quality of the care that is rendered¹².

Scientific and technological advancements in the medical area have also reached the hospitals, which have shifted from being institutions for sheltering and giving assistance to poor people close to death into a privileged locus for these advancements, with professionals who are apt to deal with the biological aspects of life and carry out procedures involving the most sophisticated technologies. However, in spite of such progresses these professionals still show certain limitations in respect to their relationship with terminal patients¹³.

The execution of therapeutic interventions authorized solely by family members, with no knowledge of the patients, implies the loss of their dignity since they are prevented from making their own choices and cease to exercise their autonomy¹⁴. Each individual idealizes the way they want to die; but in some cases, such as with people with poor prognosis or in terminal stages, this matter becomes

paramount as a factor of imminent death. In such situations it is important that patients participate in their dying process by expressing what they consider essential to their quality of life, because although they are in terminal stages and near death, they are still alive¹⁵.

It is not easy to accept death. Dying is not only an event of medical or scientific interest, but essentially an episode with personal, cultural and religious dimensions. In this sense doctors need to learn how to deal with the situation, starting by thinking about it. In fact, one of the most afflictive cases for health professionals, given their lack of preparation to deal with this matter, is when patients express their desire to die. The feeling of anguish can be accentuated in case the doctor is requested to accelerate the patient’s death in order to shorten their suffering, especially in societies in which this conduct is regarded as criminal and contrary to professional ethics. In these occasions doctors react in several ways, among them to consider that the patients are depressed and not to comply with their request¹⁶.

Euthanasia, dysthanasia and orthothanasia

Euthanasia, also known as “the good death”, occurs when patients know that their disease is incurable or that they can no longer live with dignity, and ask the doctor, who in turn accepts, to abbreviate their lives in order to avoid the continuation of their physical and psychological suffering¹⁷. This practice consists of taking the life of human beings for humanitarian reasons, relieving them from suffering and pain. Discussions about this conduct generally spark intense controversy since they involve individual rights and legal aspects, reuniting in the same environment the patients, their family members, the care team and even the health institution¹⁶.

In Brazilian law euthanasia is not legal as an act from a third party who deliberately puts an end to someone’s life with the intention of ending a situation that is considered unbearable. Euthanasia is not agreed and, although not absolute, the right to life is a legal asset generally unavailable for third parties. Therefore, even when requested by the patient, this act constitutes a crime of murder as determined by the Brazilian Criminal Code¹⁸.

It is important to point out that, in Brazilian criminal law, for an act to be characterized as a crime three factors must concur: typicality, unlawfulness and culpability. In euthanasia, the patient’s consent does not eliminate the unlawfulness of the medical

conduct, and for this reason it is not disqualified as a homicide since this consent is not seen by the law as a cause of exclusion of the typicality of the conduct. A doctor who could have acted otherwise and avoided an unlawful conduct is culpable¹⁹.

Medicine has evolved, and as a result it is able to artificially extend human life. However, there must be sufficiently clear criteria and norms to guide doctors on how to deal with this situation²⁰. It is fundamental that they know how to distinguish between euthanasia *stricto sensu* and the suspension of the so-called extraordinary, futile and disproportionate means of treatment. These situations bring about ethical dilemmas and, in western societies, the use of these disproportionate resources is considered an inadequate medical act, or dysthanasia. When patients in terminal stages wish to suspend their treatment doctors must respect their will, provided that what is at stake is the suspension of useless and disproportionate treatment²¹. This will thus materialize the principle of individual autonomy, which is a pillar of contemporary bioethics²².

Dysthanasia means “bad death”, that is, the exaggerated extension of the life of a patient in critical condition. This term may be used as a synonym for useless treatment, and denotes a medical attitude which, on behalf of “saving the life” of terminal patients, ends up submitting them to excessive suffering. This procedure does not extend life, rather the dying process²³. In Europe there is the term “therapeutic obstination”; in the United States, “medical futility”. Popularly, the question may be posed in the following terms: To what extent should the dying process be extended when there is no more hope of reverting the situation?²⁴

Arising from the growing medicalization of health and the exaggerated use of medical technologies, dysthanasia is under constant bioethical debate due to the impact it causes on the patients’ quality of life, as well as that of their family members and caretakers. This practice does not take into account the well-being or individual preferences²⁴. It means, fundamentally, a slow death accompanied by anxiety and much suffering. However, this “therapeutic obstination” or “aggressive therapy” is rejected by most specialists in ethics and bioethics because it is contrary to a person’s dignity¹⁶.

The 1988 Brazilian Constitution ensures that the dignity of a human being is one of the foundations of the State. Therefore the right of dying with dignity is also therein included, and this right must be guaranteed to patients with no chance of cure. One of the ways to ensure them to this right

is by means of orthothanasia, which means “correct death”, in its due time, not submitting patients to inhuman and degrading treatment aimed only at extending their dying process²⁵.

Therefore, orthothanasia has the sense of death in its due time, with no disproportionate extension of the dying process. It is different from euthanasia since it is sensitive to the process of humanization of death and pain relief, and does not incur in abusive extension by means of the application of disproportionate means which only impose additional suffering²³. On this note, a study has investigated terminal patients, their family members and medical teams about what a good death means²⁶. It concludes that for most participants it was understood as the capacity of having 1) good control over pain and symptoms; 2) a good relationship with the family and environmental well-being; and 3) a good relationship with the medical team. Another research has determined that family members of terminal patients committed to the ICU notice that end-of-life care includes dignity, support, reflection, peace and control of the patients, and these are important elements to define a good death in the hospital context²⁷. Another study carried out with ICU nurses has verified that these professionals consider the presence of family members important in the final stage of the dying process, as well as the availability of spiritual support whenever possible, thus respecting the needs of the patients²⁸. And what do medical students and doctors in Brazil think about this? Could their perception be influenced by their demographic characteristics? These were the motivating aspects of this study, which has attempted to learn where these individuals stand in respect to the matter of dignified or good death.

Method

Participants

The study had 398 respondents, equitably divided into medicine students and professionals. Out of that total, 57.8% were male, with a mean age of 34.5 years (SD = 12.9; amplitude from 19 to 75 years of age). Specifically, students were mostly male (52.3%) with a mean age of 25.47 years (SD = 4.5); as for doctors, 63% were male with a mean age of 43.2 years (SD = 12.3).

Instruments

Participants responded to an instrument named “escala de percepção de morte digna”

(dignified death perception scale - EPMD), made up of 24 items distributed in 6 factors: 1) maintenance of hope and pleasure; 2) good relationship with the professional health team; 3) physical and cognitive control; 4) not being a burden to others; 5) good relationship with the family; 6) control of the future. This version is the result of a survey made with medicine students and professionals who belong to the general population of Rondônia, and was submitted both to exploratory and confirmatory analyses to attest to its metric adequation, that is, factorial validity and internal consistency²⁹. Participants had to indicate to what extent the content expressed in each item was necessary or unnecessary to guarantee a dignified death by choosing a number on a 7-point response scale which varied from 1 (totally unnecessary) to 7 (totally necessary) (See Annex).

Another instrument used was the demographic questionnaire, with social and demographic questions to characterize the sample by gender, age, marital status, if affected by any illness, place of residency and where the person would like to die, at home or at a hospital.

Procedure

This study deals with a correlational research. Among the medicine students, data collection was carried out in a collective context, at a classroom or at hospitals of the Porto Velho public health network, but with individual participation. In the first case, authorization by the coordinators of the medicine courses from the private and public institutions was granted. Specifically, two surveys were presented requesting the voluntary collaboration of the students and indicating that there was no need for identification, given the anonymous and confidential character of the survey.

The same surveyors introduced themselves to the clinical director of a children’s hospital and to the internal medicine chief of service at a general hospital, requesting their approval for the participation of the students who were doing their academic training at said institutions. Voluntary participation was also informed, with the clarification that no identification of the participants was necessary.

In regard to the doctors’ sample, the selection was based on the list of doctors registered at the Conselho Regional de Medicina de Rondônia (Rondônia’s Regional Medicine Council). The surveyors had their addresses and attempted an initial contact in order to schedule a date for filling in the instrument. At the time the professionals were informed that although it would not offer immediate

Table 1. Correlation between the EPMD factors and demographic variables

	Doctors					Students				
	Where to die	Having disease	Having work	Health	Marital status	Where to die	Having disease	Having work	Health	Marital status
Factor 1	-0.13	-0.11	-0.39	-0.70	0.36	0.79	0.33	-0.55	-0.21**	-0.43
Factor 2	0.38	-0.24	0.74	0.14*	0.16	-0.11	0.29	-0.11	-0.20**	0.30
Factor 3	-0.15*	-0.95	0.11	-0.11	0.30	0.04	0.97	-0.11	-0.72	0.55
Factor 4	-0.20**	0.54	0.13*	-0.36	0.20**	-0.05	0.81	0.37	-0.88	0.27
Factor 5	0.11	-0.11	0.78	0.37	-0.04	0.18	0.70	0.03	-0.13*	-0.11
Factor 6	-0.16	0.38	0.13*	0.61	-0.91	-0.42	0.39	0.11	-0.61	0.77

Notes: * $p < 0.05$; ** $p < 0.001$

benefits to the participants, the survey would allow for a better knowledge of the doctors' preferences and their daily professional conduct.

The study was submitted to the Comitêe de Ética em Pesquisa Involving Human Beings of the Faculdade Integradas Aparício Carvalho (Aparício Carvalho Integrated Colleges - Fimca) in Porto Velho. In this respect, all ethical procedures complied with the standards established by Resolution 466/2012³⁰ of the Conselho Nacional de Saúde (National Health Council), which deals with the norms of research involving human beings. The potential participants of the survey were duly explained about its voluntary, anonymous and confidential character, and those who accepted to collaborate signed an informed consent form. Each participant had the option to fill in the instrument and deliver it immediately, or do it at a later date and schedule a time for its delivery. It took them an average of 15 minutes to conclude their participation in the survey.

Data analysis

The PASW 18 software was used for data tabulation and analysis. Descriptive statistics (frequency distribution, measurements for central tendency and dispersion), correlations and differences between averages (t test) were used.

Results

To facilitate the reader's comprehension, the presentation of the results was structured into main topics. Initially, a general description of the profile of the survey participants is given. Then, an attempt is made to show the dignified death correlates, separating the doctors from the students. Finally, comparisons between the averages of doctors and

medicine students on dignified death factors are shown.

Characterization of the participants

Out of the students who took part in the survey 82% were single, 36.2% lived with their parents and 86.4% said they were unemployed. Almost all of them lived in urban areas (99.5%). Health status was considered by them as excellent or good (93.5%) and only 1.5% admitted to having health problems. When asked about where they would prefer to die, 74% opted for dying at home.

As for the doctors, 65.3% said they were in a stable relationship and 7.1% were divorced or had lost their spouses. Most informed that they lived in urban areas (97.5%) and 67% said they lived only with their spouses, or spouses and children. A significant part of them declared their health status as being excellent or good (85.4%). As for work, 92.5% said they were employed. Upon being asked to respond about the best location to die, 74.3% chose the hospital.

Correlates

The proposal was to get to know the correlations between the EPMD factors and the set of demographic variables considered. To gain knowledge on the consistency of these correlations, the calculations were performed taking the two sample groups into account separately. Table 1 below summarizes the main findings.

Factor 1 refers to the *maintenance of hope and pleasure* and points out the positive aspects of life, the feeling of attributed hope and the sensation that life is worth living. Factor 2, named *good relationship with the professional health team*, expresses the concern with interpersonal relationships, specifically with the people who are the main caretakers in the context

of the disease. Factor 3, *physical and cognitive control*, measures the importance of being independent in daily activities (for example feeding and personal care habits), the fear of demonstrating weakness and the decision-making capacity. Factor 4, regarding *not being a burden to others*, depicts the fear of being dependent of equipment and/or other people. Factor 5, corresponding to *good relationship with the family*, evaluates the importance of family support, comfort and the enjoyment of interacting with one’s relatives. Lastly, Factor 6, called *control of the future*, has to do with knowing the amount of time one still has to live, being prepared to die and, mainly, the disposition of saying goodbye to dear ones.

In regard to the doctors, it could be verified that no variable correlated with the factor *maintenance of hope and pleasure*. However, the factor *good relationship with the professional team* was associated with the health status ($r = 0.14$; $p < 0.05$). *Physical and cognitive control* correlated with the location for dying ($r = 0.15$; $p < 0.05$). *Not being a burden* was negatively correlated with the location for dying ($r = -0.20$; $p < 0.001$), being employed ($r = 0.13$; $p < 0.05$; 1 = Yes and 2 = No). It was verified that there is a correlation between the factor *control of the future* and being employed ($r = 0.13$; $p < 0.05$; 1 = Active and 2 = Unemployed).

In regard to the medicine students, health status (1 = Excellent to 5 = Terrible) showed a correlation with *maintenance of hope and pleasure* ($r = 0.21$; $p < 0.001$), the *good relationship with the professional health team* ($r = 0.20$; $p < 0.001$) and the *good relationship with the family* ($r = -0.13$; $p < 0.03$).

Differences between doctors and students

Independent *t* tests were carried out to verify if there were differences between doctors and students in the EPMD factors and demographic variables. Statistically significant differences were determined in the scores of five of the six dignified death factors, and students invariably showed higher scores than the doctors, respectively, as indicated below:

- *Maintenance of hope and pleasure*: $M = 6.5$ and 6.1 ; $t(395) = 5.48$; $p < 0.001$
- *Good relationship with the professional health team*: $M = 6.1$ and 5.5 ; $t(394) = 6.49$; $p < 0.001$
- *Physical and cognitive control*: $M = 5.4$ and 4.9 ; $t(395) = 4.76$; $p < 0.001$
- *Good relationship with the family*: $M = 6.3$ and 6.1 ; $t(395) = 2.95$; $p < 0.05$

- *Control of the future*: $M = 4.9$ and 4.6 ; $t(395) = 2.27$; $p < 0.05$

The only factor that showed no difference was *not being a burden to others*: $t(395) = 0.53$; $p > 0.05$. In this sense, the students showed a higher average in the total EPMD score ($M = 5.7$; $SD = 0.61$) than the doctors: $M = 5.3$; $ST = 0.61$; $t(395) = 5.57$; $p < 0.001$.

Discussion

From the results it can be shown that most doctors, about 75%, would rather die at a hospital, practically the same proportion of students who choose to pass away at home. Contact with death during the professional practice may justify that preference, since death may have become natural, or in other words, may have become a commonplace thing, to be treated technically, which would characterize the emotional “hardening” of the professionals.

The change in place to die from the residence to the hospital happened due to several historical and social factors¹⁰. Although the students from the health area have a theoretical education concerning death⁴, the daily contact with this phenomenon is probably responsible for changing their perception. In the case of doctors, the option of the majority for dying at a hospital is due to the fact that they work, on a daily basis, in an environment in which technical and scientific knowledge are shown to be useful and effective, and sometimes represent the only possibility of dealing with death. In addition, familiarity with the environment and with other professionals who work in it may reinforce confidence. Confirming the previous statements, the doctors showed negative correlations between the place where they prefer to die and the factors *physical and cognitive control* and *not being a burden to others*, which did not happen with the students.

Additionally, the other correlates indicate the importance that health professionals give to controlling death, pointing out their concern about not being a burden to others. This last finding must be considered, since doctors, due to living with the disease process, go through situations in which the patient may generate a burden to the family, albeit involuntarily. Thereby, this experience may directly influence the concern by these professionals about not becoming a burden to their family members. This perception may also take place due to the fact that the group of doctors shows a higher mean age

than the group of students and, consequently, more life experience, both in the personal and the professional realms, a factor which may interfere in the manner how one deals with that matter.

It is also necessary to highlight the fact that other psychosocial factors may influence the preference for dying at home. For example, the presence or absence of financial difficulties, the attachment to the family environment and possible fear of the hospital environment favor that choice³¹. It is possible that human values also play a role as an explanatory factor. People who prioritize social values opt to die close to their friends and family; they are individuals geared for interaction, companionship with others and observance of social norms. By contrast, those who prioritize personal values, that is, the ones who are more geared towards themselves, their individual accomplishments, desires and goals, choose the hospital as the best place to die³².

Finally it should be pointed out that the literature on the perception of death considers, above all, patients¹⁴, and work focused on health professionals is scarce. This study has attempted to fill in this gap and contribute to shed some light on the perception of death by medicine students and professionals. In this respect, the results presented herein allow for designing new studies focused, for example, on the differences between the genders about the perception of dignified death, evaluating the impact of education time and its possible relationship with the medical advice given to patients and with the professionals' acceptance of the choices made by the patients when they do not coincide with what the doctors would do.

Final considerations

The goal of this study was to get to know the demographic correlates of the perception of

dignified death considering medicine professionals and students. Based on the results, it is believed that this goal has been reached. However, as in any scientific enterprise, the study is not exempt of limitations such as: 1) the sample was not probabilistic (by convenience); 2) there was homogeneity in the sample regarding the geographic reach of the study since it did not include participants from all geopolitical regions in Brazil; 3) only self reporting measures (pencil and paper) were used, so the respondents' answers may be biased by social desirability; 4) it did not take into account the difference between public and private institutions. It is necessary to point out, however, that these factors do not compromise the findings of the study, and that its results have at least a heuristic value, allowing to know the way how people committed with promoting health “react” when faced with death, and mainly how they conceive dignified death.

It is important to investigate to what extent the choice of location where one wishes to die may be explained by individualistic or collectivist tendencies, especially when the horizontal and vertical dimensions are considered. Perhaps “*not being a burden to others*” is a typical thought of vertical individualists, focused on success, on the achievements of life, while the choice of home, together with the family, may represent an option that is more typical of horizontal collectivists who prioritize family relations. These are, certainly, matters that must be contemplated in the professional practice and in the education of these health professionals, since they may help the relationship process among doctor, patients and their family members, especially by making them recognize that others may not have the same comprehension of death as they do, since they are so used to facing this dilemma of end of life.

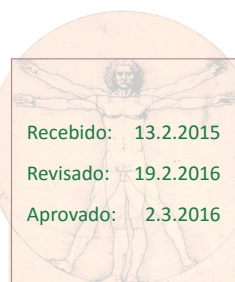
Referências

1. Kovács MJ. Morte e desenvolvimento humano. São Paulo: Casa do Psicólogo; 1992.
2. Nascimento AMD, Roazzi A. A estrutura da representação social da morte na interface com as religiosidades em equipes multiprofissionais de saúde. *Psicol Reflex Crit*. [Internet]. 2007 [acesso 28 maio 2015];20(3): 435-43. Disponível: <http://www.scielo.br/pdf/prc/v20n3/a11v20n3.pdf>
3. Kovács MJ. Educação para a morte. O homem diante da morte: ensaios de compreensão do trabalho de Philippe Ariès. São Paulo: Casa do Psicólogo; 2008.
4. Aquino TAA, Alves ACD, Aguiar AA, Refosco RF. Sentido da vida e conceito de morte em estudantes universitários: um estudo correlacional. *Interação Psicol*. [Internet]. 2010 [acesso 28 maio 2015];14(2):233-43. Disponível: <http://bit.ly/1QRXdD6>
5. Ariès P. História da morte no Ocidente. Rio de Janeiro: Francisco Alves; 1977.
6. Aquino TAA, Serafim TDB, Daniel H, Silva M, Barbosa EL, Araújo E *et al*. Visões de morte, ansiedade e sentido da vida: um estudo correlacional. *Psicol Argum*. [Internet]. out-dez 2010 [acesso 28 maio 2015];28(63):289-302. Disponível: <http://bit.ly/1LK2VZ5>

7. Luper S. A filosofia da morte. São Paulo: Madras; 2010.
8. Ariès P. O homem perante a morte. Lisboa: Europa-América; 2000.
9. Menezes RA. Reflexões em torno da morte e o morrer. In: Santos FS, Incontri D, organizadores. A arte de morrer: visões plurais. 2ª ed. São Paulo: Comenius; 2009. p. 229-36.
10. Medeiros MM. Concepções historiográficas sobre a morte e o morrer: comparações entre a *ars moriendi* medieval e o mundo contemporâneo. Outros Tempos (Dossiê Religião e Religiosidade). [Internet]. 2008 [acesso 11 jun 2015];6(5):152-72. Disponível: <http://bit.ly/1VJNhip>
11. Howell DA, Roman E, Cox H, Smith AG, Patmore R, Garry AC *et al.* Destined to die in hospital? Systemic review and meta-analysis of place of death in haematological malignancy. BMC Palliat Care. [Internet]. 2010 [acesso 11 jun 2015];9(9):1-8. DOI: 10.1186/1472-684X-9-9
12. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VAJ, *et al.* Early palliative care for patients with metastasis non-small-cell lung cancer. N Engl J Med. [Internet]. 2010 [acesso 27 fev 2016];363(8):733-42. Disponível: <http://bit.ly/YAEhCR>
13. Melo HP. O direito a morrer com dignidade. Lex Medicinæ: Revista Portuguesa de Direito da Saúde. 2006;3(6):69-73.
14. Borges RCB. Eutanásia, ortotanásia e distanásia: breves considerações a partir do biodireito brasileiro. Migalhas. [Internet]. 4 abr 2005 [acesso 12 jun 2015]. Disponível: <http://bit.ly/1RP09Aw>
15. Kovács MJ. Autonomia e o direito de morrer com dignidade. Bioética. [Internet]. 1998 [acesso 12 jun 2015];6(1):[s.p.]. Disponível: <http://bit.ly/1pGSmM8>
16. Taboada PR. El derecho a morir con dignidad. Acta Bioeth. [Internet]. 2000 [acesso 12 jun 2015];6(1):89-101. Disponível: <http://www.scielo.cl/pdf/abioeth/v6n1/art07.pdf>
17. Cesarin AS. Breves considerações sobre eutanásia e ortotanásia e o respeito ao princípio da dignidade no momento da morte. Anuário da Produção Acadêmica Docente. 2008;12:30-47.
18. Brasil. Lei nº 7.209, de 11 de julho de 1984. Altera dispositivos do Decreto-Lei nº 2.848, de 7 de dezembro de 1940, Código Penal, e dá outras providências. Diário Oficial da União. Brasília, v. 348, nº 9, p. 10217, 13 de jul 1984. Seção 1. Parte geral, Título 1, Da aplicação da lei penal.
19. Dodge REF. Eutanásia – aspectos jurídicos. Bioética. [Internet]. 1999 [acesso 24 jun 2015];7(2):[s.p.]. Disponível: <http://bit.ly/1o96Kvj>
20. Nunes R. Proposta sobre suspensão e abstenção de tratamento em doentes terminais. Rev. bioét. (Impr.) [Internet]. 2009 [acesso 24 jun 2015];17(1):29-39. Disponível: <http://bit.ly/1UnxkPI>
21. Nunes R, Melo HP. Testamento vital. Coimbra: Almedina; 2011.
22. Morais IM. Autonomia pessoal e morte. Rev. bioét. (Impr.). 2010;18(2):289-309.
23. Dallari DA. Bioética e direitos humanos. In: Costa SIF, Oselka G, Garrafa V, coordenadores. Iniciação à bioética. Brasília: CFM; 1998. p. 231-41.
24. Diniz D, Costa S. Morrer com dignidade: um direito fundamental. Brasília: Letras Livres; 2004. (Série Anis, nº 34).
25. Bomtempo TV. A ortotanásia e o direito de morrer com dignidade: uma análise constitucional. Revista Internacional de Direito e Cidadania. [Internet]. 2011 [acesso 24 jun 2015];9:169-82. Disponível: <http://reid.org.br/arquivos/00000236-14-09-bomtempo.pdf>
26. Hirai K, Miyashita M, Morita T, Sanjo M, Uchitomi Y. Good death in Japanese cancer care: a qualitative study. J Pain Symptom Manage. [Internet]. 2006 [acesso 24 jun 2015];31(2):140-7. DOI: 10.1016/j.jpainsymman.2005.06.012
27. Mularski RA, Heine CE, Osborne ML, Ganzini L, Curtis JR. Quality of dying in the ICU: ratings by family members. Chest. [Internet] 2005 [acesso 24 jun 2015];128(1):280-7. DOI: 10.1378/chest.128.1.280
28. Santana JCB, Dutra BS, Baldansi L, Freitas RHF, Martins TCO, Moura IC. Ortotanásia: significado do morrer com dignidade na percepção dos enfermeiros do curso de especialização em unidade de terapia intensiva. Revista Bioethikos. [Internet]. 2010 [acesso 24 jun 2015];4(3):324-31. Disponível: <http://www.saocamilo-sp.br/pdf/bioethikos/78/Art09.pdf>
29. Wansa MCD, Morais IM, Gouveia VV, Miyashita M, Nunes R. Briefed version of the good death inventory (GDI-B): evidences of its validity and reliability in Brazil [no prelo]; 2012.
30. Brasil. Ministério da Saúde, Conselho Nacional de Saúde. Normas e diretrizes para pesquisa envolvendo seres humanos. [Internet]. CNS; 2012 [acesso 8 mar 2016]. Disponível: http://bvsms.saude.gov.br/bvs/saudelegis/cns/2013/res0466_12_12_2012.html
31. Baidier L, Surbone A. Patients’ choices of the place of their death: a complex, culturally and socially charged issue. Onkologie. [Internet]. 2007 [acesso 24 jun 2015];30(3):94-5. DOI: 10.1159/000099371
32. Morais IM. A escolha do lugar onde morrer por estudantes e médicos: valores humanos e percepção de morte digna [tese]. [Internet]. Porto: Faculdade de Medicina, Universidade do Porto; 2012 [acesso 5 mar 2016]. Disponível: <http://bit.ly/1Ut6jY>

Participation of the authors

All of the authors have collaborated equally for the elaboration of this paper.



Annex

Short version of the “escala de percepção de morte digna”
(dignified death perception scale - EPMD)

Statements	Totally unnecessary	Unnecessary	Somewhat unnecessary	More or less necessary	Somewhat necessary	Necessary	Totally necessary
1) Living as if you were at home	1	2	3	4	5	6	7
2) Not changing your appearance	1	2	3	4	5	6	7
3) Knowing how long you have to live	1	2	3	4	5	6	7
4) Reconciling with people	1	2	3	4	5	6	7
5) Counting on people who will listen to you	1	2	3	4	5	6	7
6) Not showing physical or mental weakness to the family	1	2	3	4	5	6	7
7) Being able to be at your favorite place	1	2	3	4	5	6	7
8) Not being a burden to family members	1	2	3	4	5	6	7
9) Being ready to die	1	2	3	4	5	6	7
10) Not being dependent on medical equipment or tubes	1	2	3	4	5	6	7
11) Being mentally able to make decisions, being lucid	1	2	3	4	5	6	7
12) Being calm, relaxed	1	2	3	4	5	6	7
13) Living positively	1	2	3	4	5	6	7
14) Enjoying enough time with the family	1	2	3	4	5	6	7
15) Having the feeling that living is worth it	1	2	3	4	5	6	7
16) Living in peaceful circumstances	1	2	3	4	5	6	7
17) Having a doctor or nurse with whom to talk to about your fears of death	1	2	3	4	5	6	7
18) Controlling life time by means of euthanasia	1	2	3	4	5	6	7
19) Having a nurse with whom you feel comfortable	1	2	3	4	5	6	7
20) Not being treated as an object or as a child	1	2	3	4	5	6	7
21) Being independent in your daily activities	1	2	3	4	5	6	7
22) Saying goodbye to dear ones	1	2	3	4	5	6	7
23) Believing that all possible treatment has been used	1	2	3	4	5	6	7
24) Not creating problems to others	1	2	3	4	5	6	7