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RESEARCH

Dignified death: the perception of doctors in a teaching hospital

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Abstract

In order to identify the perception of good death by physicians who work at a teaching hospital, a cross sectional study with a convenience sample (100 physicians) is proposed, using the reduced version of the perceived dignified death scale (Brazilian reduced version of Good Death Inventory). All factors of the instrument were considered as highly needed, emphasizing good relationship with the family (98.9%), maintenance of hope and pleasure (97.8%) and not being a burden to others (92.3%). Women prioritized good relationships with family and team; doctors over 45 years old, not being a burden to others; and those without religion, not being a burden to others and having control over the future. The perception of good death presented by physicians valued social aspects such as affectivity and acquaintanceship, by prioritizing these three factors, in addition to showing that age, sex and religiosity influence this perception.
Keywords: Death. Right to die. Personhood. Palliative care.

Resumo

Morte digna: percepção de médicos de hospital de ensino

Com o objetivo de identificar a percepção de morte digna de médicos de hospital de ensino, propõe-se estudo transversal, com amostra por conveniência (100 médicos), utilizando a versão reduzida da escala de percepção de morte digna. Todos os fatores do instrumento foram considerados de alta necessidade, enfatizando-se boa relação com a família (98,9%), manutenção da esperança e do prazer (97,8%) e não ser um fardo para os demais (92,3%). Mulheres priorizaram boas relações com a família e equipe; médicos com mais de 45 anos, não ser um fardo para os demais; e os sem religião, não ser um fardo e ter controle sobre o futuro. A percepção de morte digna dos médicos valorizou aspectos sociais, como afetividade e convivência, ao priorizar esses três fatores, além de demonstrar que idade, sexo e religiosidade a influenciam.
Palavras-chave: Morte. Direito a morrer. Pessoalidade. Cuidados paliativos.

Resumen

Muerte digna: La percepción de los médicos de un hospital de enseñanza

Con el objetivo de identificar la percepción de muerte digna por parte de médicos de un hospital de enseñanza, se propone un estudio transversal, con muestra de conveniencia (100 médicos), utilizando la versión reducida de la escala de percepción de muerte digna. Todos los factores del instrumento fueron considerados como de alta necesidad, con destaque para buena relación con la familia (98,9%), mantenimiento de la esperanza y placer (97,8%) y no ser una carga para los demás (92,3%). Las mujeres priorizaron buenas relaciones con la familia y el equipo; médicos con más de 45 años, no ser una carga para los demás; y los sin religión, no ser una carga para los demás y tener control sobre el futuro. La percepción de muerte digna por parte de los médicos valoró aspectos sociales como afectividad y convivencia, al priorizar estos tres factores, además de demostrar que edad, sexo y religiosidad la influencian.
Palabras clave: Muerte. Derecho a morir. Personeidad. Cuidados paliativos.

Approval CEP-UFSC CAAE 71111317.4.0000.0121

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With the demographic transition underway in the world, and more recently in Brazil, the general life expectancy has increased, also increasing the prevalence of incurable chronic diseases [1], such as cancer and degenerative diseases. Medicine, increasingly specialized and focused on hard technologies, has contributed for individuals affected by these diseases to live longer.

In this context, palliative care has occupied the center of attention in health policies around the world. With the volume of patients in need of such care, the World Health Organization [2] asked member countries, in 2014, to commit to developing cost-effective services, continuing education in the training of health professionals and scientific production to ensure excellence in palliative medicine.

In Brazil, already in 2002, the Ministry of Health [3] launched guidelines on palliative care and pain treatment, establishing that this assistance must be carried out in a coordinated manner at the three levels of health care to ensure comprehensiveness and continuous monitoring. In 2005, the National Academy of Palliative Care [4] was established – which works with the Ministry of Health and the Federal Council of Medicine in professional regulation –, and which established quality criteria and relevant legislation. In 2009, palliative care was included in the Code of Medical Ethics as a fundamental principle [5].

Whether nationally or internationally, these measures aim to facilitate access to quality palliative care, to improve the quality of life and control physical, emotional, spiritual and social symptoms [2-4]. For more adequate care, it is argued that preserving the patient's dignity is one of the most basic ethical principles [6].

The concept of dignity was constructed and modified historically [7]. In Antiquity, for example, it was linked to position and social recognition; in turn, stoicism positioned it as a differentiating factor between human beings and other creatures, especially regarding the individual freedom to build and guide their own destiny. Currently, dignity belongs to the scope of the fundamental rights of every human person, an idea that is configured as a supreme value and is included in the Brazilian Federal Constitution of 1988 [8], where it is considered one of the foundations of the Republic.

When the patient is under palliative care, it is crucial to ensure his dignity, even at the moment of death, and one must consider the way the individual thinks he is seen by others is related to his own perception of dignity [9,10]. To provide better care for these patients and promote a dignified end of life, several studies have sought to establish what is "dignified death" [11-14]. This concept includes symptom control, not being a burden for others, having a good relationship with family members and the health team, choosing the place of death and maintaining dignity and control in the process of dying [11-14].

To do so, the dignified death perception scale (EPMD) [12,13], elaborated in Japan and validated and simplified in Brazil, has been used in research that shows it can vary according to the studied population, bereaved family members [11, 12,15], health professionals [16] and students [17,18].

As we understand the importance of ensuring dignified death for patients under palliative care and legitimizing this concept among health professionals, it is proposed to evaluate the perception of doctors who work in a public teaching hospital on the subject. This perception is associated with the demographic profile, the feeling of perceiving oneself as healthy and the previous experience with the death of a relative or patient. It is expected that this evaluation can guide the planning of education and the exercise of medical profession in the country, resulting in safe and efficient palliative care whilst also providing dignified death [6].

Method

This is a cross-sectional study, with an initial convenience sample of 100 doctors and/or medical teachers, out of a total of 300 (33.3% – 100/300), who work in care and/or teaching at the University Hospital of Federal University of Santa Catarina (HU/Ufsc). A standard form with a demographic questionnaire, questions related to the theme and the reduced version of the EPMD was used. From the initial sample, nine participants were excluded for incomplete completion of the instrument, totaling 91 (30.3% – 91/300) participants. To characterize the sample, the independent variables of sex (female and male), age (expressed in absolute numbers), belief in a religion (yes, no; if yes, which) and the answer to each of the three

questions related to previous experiences: "do you consider yourself healthy?", "have you had any recent family losses?" and "did you recently deal with the death of your patient?"

The reduced version of the EPMD was developed and validated by Wanssa [13], after being adapted for the Brazilian context by Wanssa and collaborators in 2012, based on the original scale prepared by Miyashita and collaborators [11] in Japanese. It consists of 24 cofactors (COF) associated with dignified death, which are equally divided into six factors according to the specific domain (*maintenance of hope and pleasure; good relationship with the professional health team; physical and cognitive control; not being a burden for others, good relations with the family and control over future* [19]). The response to each cofactor is expressed and weighted on a Likert-type scale (1 = totally unnecessary; 2 = unnecessary; 3 = something unnecessary; 4 = more or less necessary; 5 = something necessary; 6 = necessary; 7 = totally necessary).

The standard form was applied by three of the five authors and/or by members of the HU/Ufsc Palliative Care Committee, with the consent of the hospital's directorate-general. Participants were recruited from their workplace to respond to the survey between November 2017 and March 2018.

Continuous variables were expressed as medians and percentiles, and categorical variables as absolute numbers and percentages. For association analysis, the independent variables were dichotomized. Non-normal distribution was observed from the application of the Shapiro-Wilk test, complemented by the evaluation of asymmetry and kurtosis and by the analysis of curves and histograms [20]. The "age" variable was divided into two groups (≤44 and ≥45 years), based on the average age of doctors from Santa Catarina (44.2 years) [15].

The scores for each factor were determined by adding the values assigned on the seven-point Likert scale to each of its four cofactors. Thus, they ranged from a minimum of four points to a maximum of 28 (average of the range of score values = 16). For analysis of the association between factors and independent variables, the total scores were dichotomized from the average (16) between low need (4 to 16) and high need (17 to 28) for dignified death.

The Mann-Whitney U test was applied to assess the association between factors/cofactors and independent variables [21]. The level of statistical significance was set at 5%, with a 95% confidence interval, and the analysis was performed using the Statistical Package for Social Sciences for Windows, version 25.

The research project was approved by the Ufsc Human Research Ethics Committee and followed the guidelines of the National Health Council (CNS) Resolutions 510/2016 [22] and 466/2012 [23], which regulate research involving human beings in Brazil. The informed consent form was provided and signed by everyone who agreed to participate in the study.

Results

Demographic profile, feeling healthy and recent experience with the death of a relative or patient

In a convenience sample composed of 91 doctors from a public teaching hospital, 51.6% of respondents were men and 48.4% were women, with a predominance of the group aged 45 years or older (53.8% vs. 46.2%) and people with religion (75.8% vs. 24.2%), among which most declared themselves Catholic (60.8%), followed by other unspecified religions (24.6%), Spiritist (13%) and Evangelicals (1.4%). Most of them considered themselves healthy (93.4%) and declared that they had no recent family (60.4%) or patient (60.4%) loss.

Factors and cofactors of the reduced version of EPMD vs. independent variables

Participants considered all six factors to be of high need for a dignified death, the most important being "good relations with the family" (98.9%), followed by "maintenance of hope and pleasure" (97.8%), "Not being a burden for others" (92.3%), "good relationship with the professional health team" (91.2%), "control of the future" (90.1%) and "physical and cognitive control" (78%) (Table 1).

Considering each cofactor in the reduced version of the EPMD separately, the medians ranged from 7 (totally necessary) to 3 (somewhat unnecessary). The cofactors with the highest medians were "to count on people who can hear you"; "Enjoy enough time with the family"; "Not to be treated as an object or a child"; and "saying goodbye to loved ones". The lowest median pertained to "not showing your physical and mental weakness to the family".

Table 1. Percentage distribution of factors for dignified death and its need (Florianópolis, Santa Catarina, Brazil, 2019)

Factor	Importance (%)	Need	Median
1. Maintenance of hope and pleasure	97.8%	High*	25**
2. Good relationship with the professional health team	91.2%	High	23
3. Physical and cognitive control	78.0%	High	19
4. Don't be a burden to others	92.3%	High	23
5. Good relations with the family	98.8%	High	25
6. Control over the future	90.1 %	High	22

** High need: scores from 17 to 28; low need: scores from 4 to 16; ** median of scores: median of the sum of scores for the four cofactors that make up the factor on the seven-point Likert scale*

Sex

The medians (M) were higher in the group of women in the evaluation of factors 2 and 5 (respectively, M-women = 23.5, standard deviation (SD) = 3.459, M-men = 21, SD = 4.188, and M-women = 26, SD = 2.317, M-men = 24, SD = 2.416). There was a significant association between females and a greater need for the factors "good relationship with the professional health team" (factor 2, p= 0.009) and "good relationships with the family" (factor 5, p= 0.015) (Table 2). Table 2 expresses results of the Mann-Whitney U test (significance level p<0.05; 95% confidence interval).

Table 2. Relationship between factors for dignified death and demographic profile, being healthy and previous experience (Florianópolis, Santa Catarina, Brazil, 2019)

Factor	Sex	Age	Religion	To be healthy	Recent family loss	Recent patient death
1	0.401	0.268	0.996	0.085	0.192	0.96
2	0.009	0.235	0.520	0.898	0.408	0.006
3	0.641	0.978	0.435	0.676	0.964	0.819
4	0.783	0.033	0.028	0.968	0.832	0.772
5	0.015	0.206	0.973	0.324	0.132	0.997
6	0.309	0.651	0.001	0.653	0.070	0.576

Higher median values were observed for females in the relationship between demographic profile and COF 17 and 23 (respectively, M-women = 6, SD = 1.363, M-men = 5, SD = 1.781, and M-women = 6, SD = 1.311, M-men = 5.49, SD = 1.249). Women considered the cofactors "to have a doctor or nurse with whom to talk about fears of death" (COF 17, p= 0.016) and "to believe that all available treatments were used" (COF 23, p= 0.031) more necessary (Table 3). The other cofactors did not show any significant association with any of the variables.

Table 3. Relationship between factors for dignified death and demographic profile, being healthy and previous experience (Florianópolis, Santa Catarina, Brazil, 2019)

Cofactor	Sex	Age	Religion	To be healthy	Recent family loss	Recent patient death
5	0.900	0.046	0.53	0.235	0.944	0.728
8	0.553	0.015	0.131	0.987	0.724	0.255
9	0.563	0.846	0.029	0.881	0.949	0.299
11	0.650	0.736	0.034	0.103	0.501	0.932
12	0.125	0.280	0.117	0.08	0.096	0.352
17	0.016	0.951	0.630	0.606	0.937	0.255
18	0.606	0.215	0.003	0.655	0.154	0.824
19	314	0.280	0.219	0.711	0.135	0.035
23	0.031	0.882	0.266	0.739	0.621	0.126
24	0.902	0.017	0.066	0.908	0.877	0.679

Age

People aged 45 years or older (M≥45 = 24, SD = 3.907) considered it more necessary than younger people (M≤44 = 22, SD = 3.608) "not to be a burden for others" (factor 4, *p*= 0.033). "Counting on people who can hear you" had a significant association with the group of up to 44 years of age (COF 5, *p*= 0.046; mean≤44 = 6.6, SD = 0.798, vs. mean≥45 = 6.33, SD = 0.899, with a value of M = 7 for both age groups), while the group above 45 years of age considered it more necessary "not to be a burden for family members" (COF 8, *p*= 0.015; M≥45 = 6, SD = 1.685, vs. M≤44 = 5, SD = 1.55) and "do not bring problems to others" (COF 24, *p*= 0.017; M≥45 = 6, SD = 1.58, vs. M≤44 = 5, SD = 1.473).

Religion

Participants who have no religion considered it more necessary to "not be a burden to others" (factor 4, *p*= 0.028) and to have "control over the future" (factor 6, *p*= 0.001) than those who had a religious belief (respectively, M without religion = 25, SD = 2.819, vs. M with religion = 22, SD = 3.97, and M without religion = 24, SD = 3.23, vs. M with religion = 21, SD = 3.953).

There was also a significant association between lack of religion and the co-factors "being prepared to die" (COF 9, *p*= 0.029); "Being mentally capable of making decisions, being lucid" (COF 11, *p*= 0.034); and "controlling the life span, as through euthanasia" (COF 18, *p*= 0.003). The medians were higher in the group without religion for these three cofactors (respectively, M = 7, SD = 0.944; M = 7, SD = 1.601; M = 6, SD = 1.826 for those without religion vs. M = 6, SD = 1.39; M = 6, SD = 1.313; M = 4, SD = 1.753 for those with religion).

Feeling healthy

There was no statistically significant association between the variable "feeling healthy" and each of the six factors. However, people who considered themselves healthy perceived as necessary "to be calm, relaxed" (COF 12, *p*= 0.008), with a median value higher than those who did not consider themselves healthy (respectively, M yes = 6, SD = 0.808, vs. M no = 5.5, SD = 1.941). There was no association between factors or cofactors of the reduced version of the EPMD and the independent variable "recent family loss".

Recent patient death

Participants who recently dealt with the death of a patient considered "a good relationship with the professional health team" more necessary (factor 2, *p*= 0.006). In addition, this variable showed a positive association with "having a nurse with whom you feel comfortable" (COF 19, *p*= 0.035), with a higher mean value (mean yes = 5.78, SD = 1.312 vs. mean no = 5.07, SD = 1.654) but with the same median (M yes and M no = 6)

As for the high or low need for dignified death, the bivariate analysis related to the factors and the independent variables showed no statistically significant difference (chi-square test or Fisher's test).

Discussion

The perception of the participants in this research was comprehensive when considering the six factors of the reduced version of the EPMD as being of high need for dignified death. Among these, the most frequent factors were "good relations with the family" (98.9%), "maintenance of hope and pleasure" (97.8%) and "not being a burden for others" (92.3%). The first and the last were also associated with sex, age and religion.

"Good relations with the family" demonstrates the importance of family support and coexistence and its relationship with dignified death, which is also found in previous research conducted in China[16], South Korea[24] and Germany[18]. However, in Japanese[25,26] and American[27] studies, family presence was not considered the main factor, but factors such as being free from pain, being at peace with God[12], being valued as a person[25] and trusting the doctor[26]. While in Brazilian culture and in Asian countries the family occupies a central place, in the United States (USA) and in other western populations individualism is more valued, which justifies the physical and cognitive control at the end of life being more important for them[26]. On the other hand, in this research, the least considered factor of high need was precisely "physical and cognitive control".

The cultural influence on the perception of dignified death ranges from the difference in core values to the preference for the place of death[27]. Even in the same country, different ethnic groups may have different perceptions and desires, as pointed out by Steinhauser and collaborators[27] when demonstrating that Afro-descendant Americans give more importance to receiving all available treatments – which may be related to the low belief in white medical culture. In this study, an association was observed between the female sex and "good

relationship with the family" and "with the professional health team". This result corroborates the study by Meffert and collaborators [18], which shows that women medical students place greater value on having a family for whom they can express themselves, be reconciled with people and have people who listen to them, cofactors related to the "good relationship with the family" factor.

Understanding the role of gender in decision-making and preferences at the end of life is important to adapt the approach and communication, since men and women have different perceptions, as, historically, they live different contexts and roles in society and family [28]. It is also worth noting, in terms of health, that women have a longer life expectancy, but higher morbidity (physical and mental) [29], in addition to notably using more health services than men [30].

Another fundamental factor in understanding gender roles is the difference in communication and interaction between doctor and patient [30,31], in which women, when patients, tend to question their doctors more [32,33] and have longer consultations [34]. At the other end of the relationship, doctors seem to dedicate more time to psychosocial counseling, perform more preventive care and have higher levels of satisfaction for their patients [30]. Therefore, it is important to consider gender – as well as its social implications, communication profile, doctor--patient relationship and preferences at the end of life – in the perception of dignified death, so that the approach with patients can be individualized.

Age has also been shown to be a significant variable in the association with factors, since individuals see death in different ways throughout life [35]. In addition, epidemiological [36,37] and demographic [1] changes have influenced the causes of death and, consequently, life expectancy [37].

In our study, an association was observed between age greater than 45 years and "not being a burden for others", while the youngest (≤44 years) considered it more important to "have people who can listen to you". In South Korea, Yun and collaborators [24] found a similar result, both in the perception of health professionals and in that of cancer patients and caregivers. In this case, those over 50 years of age were associated with "not being a burden to others", while the younger ones considered the importance of the family's presence.

These differences between age groups can be explained in part by the fact that, for the youngest, death is distant both temporally and by the smaller number of experiences related to it [18]. The elderly, in general, have already had more contact with the end of life and experienced health problems, which makes them closer to finitude, even if still figuratively and even unconsciously [18,38].

According to Freud [38], in order to deal emotionally with death, the human being creates ways to deny his terminality, which seems to be corroborated by the association between older age and "not being a burden for others" – a factor that refers to the desire to remain self-sufficient, without causing problems for the family [13]. On the other hand, younger people emphasized family contact and support, which seems to be related to the need for help on the emotional impact that death causes in this age group.

In addition to the relationship between demographic profile and the perception of dignified death, there was also an association with religiosity, which is contemplated in the literature [18,27,39,40] and also in medical practice [39,40]. People without a religious belief were more concerned with "not being a burden to others" and "controlling the future", revealing materialistic orientation, guided by personal principles [13]. Steinhauser and collaborators [27] also associated time and place of death and not having a religion in a study with patients, family members and doctors in the USA. In Germany, medical students who did not practice any religion considered it more important not to cause problems to others; be independent; live as always; and controlling time as by euthanasia [18], cofactors that relate to "not being a burden to others" and "control of the future", as corroborated by this study.

In addition to influencing the perception of dignified death, religiosity seems to affect medical practice in some way in terms of caring for end-of-life patients. Cohen and collaborators [39] indicate that doctors with religious beliefs have a harder time accepting decisions not to treat, use therapies that can accelerate death and administer potentially lethal drugs. However, in practice these same individuals exercised some of these actions, that is, the ethical and humanistic character helped to relativize their decisions, and perhaps they themselves did not face their beliefs imperatively.

Likewise, Seale [40] showed that doctors without a religion were more likely to agree with euthanasia or measures that could accelerate death. Thus, it is clear that religion affects the perception of dignified death, in addition to influencing the clinical practice of medicine. However, despite this impact [18],

it should be considered that religious beliefs do not appear to imperatively affect medical work [39].

The medical professional culture and the experience in the profession modify the perception of death [41] and generate discrepancies between doctors and the general population, although the literature points out that both share most preferences and priorities [24,27,41,42]. To improve medical training and adapt professional practice to the needs of patients, it is necessary to understand and explore these differences, and physicians are expected to have a biomedical view of death [41] due to academic training.

According to Payne, Langley-Evans and Hillier [42], doctors place greater importance on painless death, while patients value dying while sleeping and dying peacefully. Other authors [25] observed that doctors, caregivers, family members and patients agreed to more than 50% of their perception of dignified death. However, more than doctors, patients valued being mentally capable, planning their funeral, feeling that life was complete, not being a burden to others, being able to help others and being at peace with God [25].

In research in South Korea, while cancer patients prioritized not being a burden to others and family presence, doctors considered it more important to feel that life was significant (related to the maintenance of hope and pleasure factor) and family presence [24]. These findings deny the strictly biomedical character of the perception of death as they bring a more humanistic view, which differs from American research, in which the most important is to be free of pain [27]. In the sample studied, the results were similar to the Korean study, which is probably due to the cultural similarity of family valuation. Thus, it can be inferred that social beliefs and customs influence the individual's understanding of dignified death more than professional culture.

Despite this, because it is a cross-sectional study that addresses a specific population of doctors, the data in this research cannot be extrapolated to the general reality of Brazilian professionals. Above all, one must consider the continental character of the country and the cultural differences between the regions. Selection bias should also be considered because it is a convenience sample. It is possible that the humanistic character of the participants' perception of dignified death was influenced by exercising their work in a teaching hospital, where service and teaching are integrated. In addition, the recent curricular change in medical training focused on a human and integral approach [43] may also have influenced the outcome.

It is essential to highlight that research that deals with dignified death uses different methods and / or scales, which makes it difficult to compare the results, and addresses different populations in countries with different cultures. For example, there are studies that used a version of the Miyashita and collaborators scale [12] adapted or reduced by other researchers, generating different factors and cofactors.

Final considerations

The literature on dignified death is scarce, especially from the point of view of medical perception and the South American and Brazilian context. This study contributes to the discussion by demonstrating that the results obtained are close to the vision of Asian countries, while distancing themselves from the individualism characteristic of the USA and the Western world in general.

Considering the influence of personal, cultural values and previous experiences [16], it is difficult to find a universal concept of dignified death. Therefore, health professionals need to understand this individuality, taking into account values that influence it and respecting the plurality of desires and preferences. The medical society, regulatory authorities and the government can provide adequate conditions for this plurality to be made possible, guaranteeing a dignified death for everyone [25,44].

The analysis of the data in this research showed that the doctors' perception of dignified death valued social aspects, such as affectivity and coexistence, when prioritizing the factors "good relationship with the family", "maintenance of hope and pleasure" and "not being a burden for the others ". In addition, it was found that age, sex and religiosity can alter the perception on the topic, pointing to the importance of a more plural approach with patients near the end of life, understanding their needs case by case.

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Participation of the authors

Fernanda Naspolini Zanatta and Ana Maria Nunes de Faria Stamm were responsible for the writing, final revision and analysis and interpretation of data collected by Saskia Pereira Teixeira and Fernanda Wolff da Silva Arruda. Lara Patricia Kretze participated in the conception and design of research and data analysis.

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