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End of life and dignity: an integrative review

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Abstract

This article aimed to explore the meanings of dignity at the end of life from the perspective of health professionals and to identify care actions that promote it. An integrative review was conducted between March and April 2022, with nine articles selected from databases, all published since 2012. The results indicated that dignity is related to valuing autonomy and that the conduct of health professionals, the care environment, and therapies involving invasive treatments influence its promotion. Among the actions taken by care professionals to foster dignity, the use of tools such as the Patient Dignity Inventory in care planning was highlighted. The conclusion is that health professionals play a key role in promoting autonomy—a fundamental element of dignity for people who are ill—and that both intrinsic and extrinsic factors should be considered when planning care to ensure a good death.

Keywords: Respect. Right to die. Health personnel. Terminal care.

Resumo

Final de vida e dignidade: revisão integrativa

Este artigo buscou conhecer os significados de dignidade no final da vida na perspectiva de profissionais de saúde e identificar ações de cuidado para promovê-la. Realizou-se uma revisão integrativa entre março e abril de 2022, com nove artigos selecionados em bases de dados, publicados desde 2012. Os resultados indicaram que a dignidade está vinculada à valorização da autonomia e que a conduta dos profissionais de saúde, o ambiente de cuidado e a terapêutica relacionados a tratamentos considerados invasivos interferem em sua promoção. Entre as ações de cuidado dos profissionais para promover dignidade, mencionou-se o uso de ferramentas como o Inventário de Dignidade do Paciente no planejamento dos cuidados. Conclui-se que os profissionais de saúde são centrais para promover autonomia, elemento fundamental da dignidade das pessoas em adoecimento, e que devem ser considerados fatores intrínsecos e extrínsecos no planejamento dos cuidados para efetivar a boa morte.

Palavras-chave: Respeito. Direito a morrer. Pessoal de saúde. Assistência terminal.

Resumen

Final de la vida y dignidad: revisión integrativa

Este artículo tuvo como objetivo explorar los significados de la dignidad al final de la vida desde la perspectiva de los profesionales de la salud y identificar acciones de cuidado que la promuevan. Se realizó una revisión integrativa entre marzo y abril de 2022, con nueve artículos seleccionados de bases de datos, todos publicados a partir del año 2012. Los resultados indicaron que la dignidad está relacionada con la valoración de la autonomía, y que la conducta de los profesionales de la salud, el entorno de atención y las terapias que implican tratamientos invasivos influyen en su promoción. Entre las acciones llevadas a cabo por los profesionales para fomentar la dignidad, se destacó el uso de herramientas como el Patient Dignity Inventory en la planificación del cuidado. Se concluye que los profesionales de la salud desempeñan un papel clave en la promoción de la autonomía —un elemento fundamental de la dignidad de las personas enfermas— y que deben considerarse tanto factores intrínsecos como extrínsecos al momento de planificar los cuidados para lograr una muerte digna.

Palabras clave: Respeto. Derecho a morir. Personal de salud. Cuidado terminal.

Research

The authors declare no conflict of interest.

When coping with a disease that threatens the continuity of life, patients experience different phases, and some signs indicate the approach of death. The end of life can be characterized by worsening physical and psychological symptoms, non-compliance with modifying treatment, and limited life expectancy of less than 12 months, among other factors [1]. Accordingly, health care professionals, family members and individuals experiencing this moment need to recognize the transition from illness to the end of life with a view to maintaining dignity.

Collectively, human dignity is conceived as a quality inherent in every person and encompasses precepts of self-determination, protection in relation to the environment and development and, individually, freedom and access to what is basic and fundamental by nature [2]. It can be influenced by personal and cultural experiences and individual factors, and those who are experiencing finitude must have their main needs and desires recognized and their care planned while considering spiritual issues, physical needs and maintenance of relationships [3].

The concept of dignity is still poorly defined; however, a systematic review [4] addressed the current concepts and found an association with innate, individual, relational and social factors. As innate factors, there is a relation with intrinsic values, recognition, inalienation, respect and valorization; individual factors are associated with the control of physical and functional symptoms, personal identity and the maintenance of autonomy; relational factors relate to family ties and receiving support and care; and social factors are linked to the social position occupied by the individual and the relationship with the health care team [4].

When considering dignity in the transition to the end of life, it is necessary to ensure respect for the wishes of the person by means of obtaining consent to the health care actions they wish to receive or not, with a view to expanding autonomy in therapeutic decision-making about their body [5]. It is essential to preserve patient autonomy, promoting relief from existential anxiety, since the fear of loss of dignity or even the desire for its preservation can be perceived [3]. At this time, the process of decision-making on treatments and care is permeated by fears regarding ethics and bioethics, elements that are transversal and fundamental for the maintenance of dignity in the process of dying and in death.

In the care of people with life-limiting diseases, investment in healing, prolongation of suffering and consequent postponement of death are commonly observed. Such measures are inconsistent with the principles of human dignity, at the collective or individual level, being contrary to the principles of good death—that considered painless and without suffering [6]. Based on the fundamental principles of the Brazilian Federal Constitution, dignity is a human right [7]. A dignified end of life can be enabled by orthothanasia, which is defined as a care model centered on death that occurs at the right time, without postponement or hastening [6].

Despite the national and international progress of discussions on and development of palliative care (PC) services, there is still the use of inappropriate end-of-life treatments, such as antibiotic therapy [8], making it difficult to experience death without suffering and limiting the maintenance of a dignified existence [9]. A study showed that physicians with longer training, without specialization in PC, who work in public services are more resistant to the suspension of antibiotic therapy, as they consider antibiotics not as invasive as other measures, thus prolonging the process of dying [8].

Due to characteristics that are inherent to the profession, nurses are considered as professionals capable of promoting death with dignity. Such characteristics include using communication strategies, enabling a safe setting, promoting the occurrence of good death and increasing the quality of life of patients. The promotion of death with dignity, that is, with respect for ethical principles and valuing the human being during the end of life, and the work of the teams, increasing the self-esteem of professionals and patients and the satisfaction of their families, is intrinsically related to nursing care [10].

The lack of discussions about death is a cultural behavior and becomes a hindering factor for the promotion of dignity, since the teams are more prepared to seek vitality and healing [11]. It is observed that the end of life is permeated by fears and challenges for those who face it, because,

in addition to the diagnosis of a threatening disease, there is the prevalence of limitations, especially physical and physiological limitations, which prevent the maintenance of autonomy and independence, thus posing a risk to the maintenance of dignity [12].

Thus, the objectives of this article were to explore, in the national and international literature, the meanings of dignity at the end of life from the perspective of health care professionals and to identify care actions for the promotion of dignity at the end of life.

Method

This is an integrative literature review comprising: 1) definition of the review question; 2) research and selection of primary studies; 3) extraction of data from primary studies; 4) critical evaluation of primary studies; 5) synthesis of review results; and 6) presentation of review results [13].

The research question was developed by the PIO strategy [14], in which: P: population; I: intervention, influence or exposure; and O: outcomes, the synthesis of meanings and actions related to dignity at the end of life. The research was guided by the following questions: what are the perspectives of health care professionals about dignity at the end of life and what actions to promote dignity at the end of life can be identified in the national and international literature?

The study identification and selection stage was conducted between March and April 2022, using the Health Science Descriptors (DeCS) "respect," "right to die," and "death" and the Medical Subject Headings (MESH) "right to die," "value of life," and "death," associated with the Boolean operators "*and*" and "*or*" in the Scientific Electronic Library Online (SciELO) and Medical Literature and Retrieval System Online (MEDLINE) databases, via Pubmed (Chart 1).

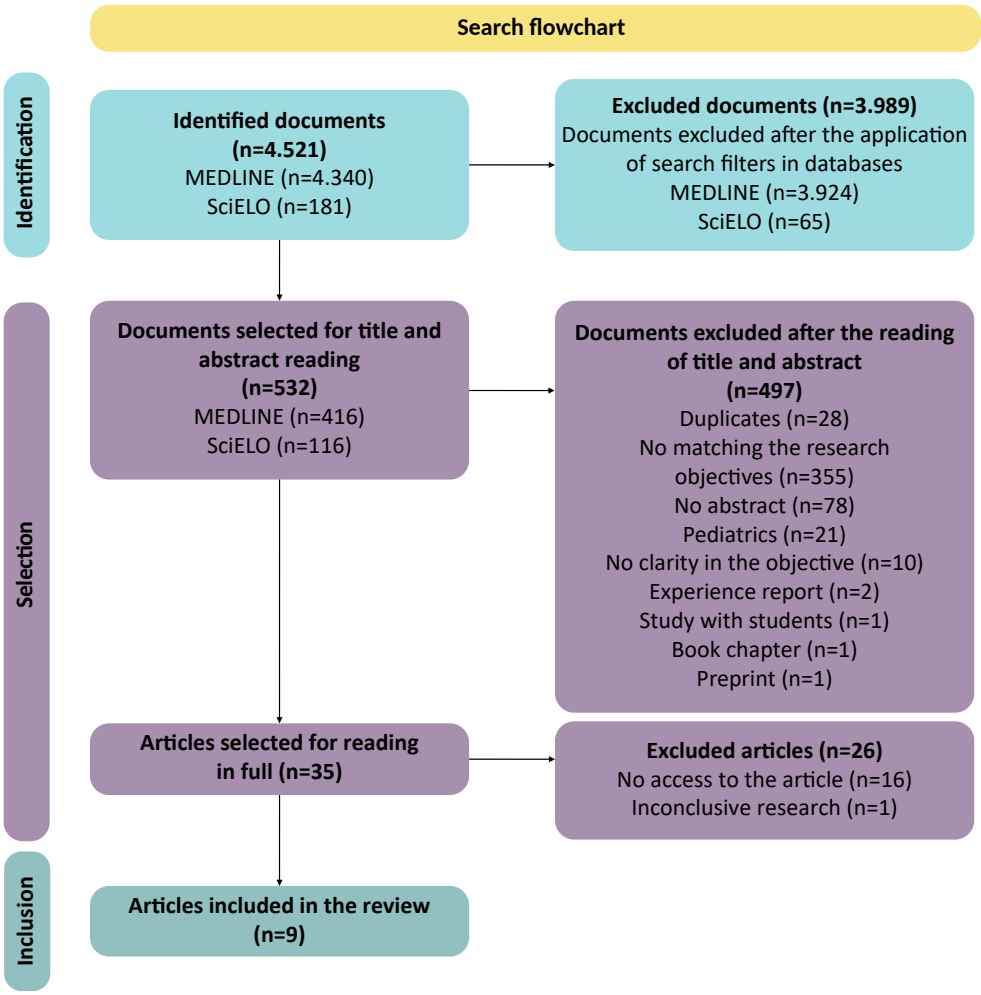
Chart 1. Research search strategies

Database	Associations
SciELO	(respect) *AND* (right to die)
	(respect) *AND* (death)
MEDLINE	("right to die"[MeSH Terms] *OR* ("right"[All Fields] *AND* "die"[All Fields]) *OR* "right to die"[All Fields]) *AND* ("value of life"[MeSH Terms] *OR* ("value"[All Fields] *AND* "life"[All Fields]) *OR* "value of life"[All Fields])
	("right to die"[MeSH Terms] *OR* ("right"[All Fields] *AND* "die"[All Fields]) *OR* "right to die"[All Fields]) *AND* ("death"[MeSH Terms] *OR* "death"[All Fields] *OR* "deaths"[All Fields])

We found 181 documents in SciELO and 4,340 in MEDLINE. The inclusion criteria were: original articles, reviews and theoretical essays in Portuguese, English and Spanish, published from 2012, available in full via the CAPES journal portal, which included issues involving dignity at the end of life in adults. The exclusion criteria were: experience report, dissertations, theses, abstracts and monographs, studies focused on the concepts of euthanasia, dysthanasia, orthothanasia, misthanasia, assisted suicide and suicide, which had as a setting intensive care units, addressed the donation and capture of organs and tissues, which did not have abstracts or specific objectives and incomplete studies.

Thus, search filters were applied, leaving 116 articles in SciELO and 416 articles in MEDLINE, totaling 532 articles. Subsequently, the duplicates were eliminated, leaving 518, and, after reading titles and abstracts, 35 articles were selected for full reading. In total, nine articles composed the empirical material of analysis. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [15] was used to prepare the flowchart of the searches (Figure 1).

Figure 1. Search flowchart



Source: adapted from PRISMA Flow Diagram [16].

For data organization and management, we used free tools from the *Rayyan* [17] application and Google's spreadsheet management platform. The review results were grouped by similarity between the themes, based on their repetitions.

Results and discussion

Chart 2 presents the general characterization of the empirical material for analysis.

Chart 2. Empirical material for analysis

Authorship; year	Title	Objectives	Study approach
Sampaio C, Renaud I, Leão PP.; 2020 [18]	*"A montanha-russa da insuficiência cardíaca": a percepção de dignidade pelas equipes de enfermagem*	Understand what it means to live with advanced heart failure from the point of view of patients, nurses and family members and understand the factors that constitute and affect dignity and can contribute to quality nursing care for this specific group of patients.	Qualitative

continues...

Chart 2. Continuation

Authorship; year	Title	Objectives	Study approach
Li YC, Feng YH, Chiang HY, Ma SC, Wang HH. 2020 [19]	*The effectiveness of dignity therapy as applied to end-of-life patients with cancer in Taiwan: a quasi-experimental study*	Determine the effectiveness of dignity therapy as applied to end-of-life patients with cancer.	Quantitative
Horn R, Kerasidou A. 2016 [20]	*The concept of dignity and its use in end-of-life debates in England and France*	Explore the meaning of the term dignity in England and France by comparing public debates and legislation on end-of-life-related issues.	Qualitative
Pols J, Pasveer B, Willems D. 2018 [21]	*The particularity of dignity: relational engagement in care at the end of life*	Explore the potential of the concept of dignity to support care practices, presenting a pragmatic approach and unveiling how dignity in care is understood in the literature, to then analyze how it is put into practice in end-of-life care.	Qualitative
Guo Q, Chochinov HM, McClement S, Thompson G, Hack T. 2018 [22]	*Development and evaluation of the dignity talk question framework for palliative patients and their families: a mixed-methods study*	Develop a self-administered intervention called Dignity Talk to facilitate meaningful conversations between palliative patients and their families and describe the development of Dignity Talk, assessed by a group of palliative patients, family members and health care professionals.	Mixed methods
Stängle S, Büche D, Häuptle C, Fringer A. 2021 [23]	*Experiences, personal attitudes, and professional stances of Swiss health care professionals toward voluntary stopping of eating and drinking to hasten death: a cross-sectional study*	Assess the experiences, personal attitudes and professional stances of Swiss health care professionals towards voluntary stopping of eating and drinking.	Quantitative
Antiel RM, Curlin FA, James KM, Sulmasy DP, Tilburt JC. 2012 [24]	*Dignity in end-of-life care: results of a national survey of U.S. physicians*	Examine data from a national survey of physicians to find their views on the usefulness and meaning of the concept of dignity and examine their judgments about a clinical scenario in which dignity may be relevant, understand how clinical attitudes toward the case scenario could be explained by physicians' divergent understandings of the concept of dignity, and how both may be related to differences in their religious characteristics.	Quantitative
Ho AHY, Chan CLW, Leung PPY, Chochinov HM, Neimeyer RA, Pang SMC, Tse DMW. 2013 [25]	*Living and dying with dignity in Chinese society: perspectives of older palliative care patients in Hong Kong*	Examine the generalization of the dignity model to older Chinese palliative patients and explore cultural influences on the conception of dignity under a different ethical context.	Qualitative
Fink-Samnick E.; 2016 [26]	*The evolution of end-of-life care: ethical implications for case management*	Discuss historical milestones of the death with dignity movement, provide legislation, reimbursement, and programming updates, discuss the influence of shared decision-making, and explore the ethical implications of the evolution of end-of-life care for case managers.	Qualitative

Research

Most participants were health care professionals [18,21,23,24], followed by patients [19,25], and a single study [22] included health care professionals, patients and family members. Two studies [20,26] do not mention the participants. Study settings included hospital setting [18,21,25], oncology outpatient clinic [19] and palliative care outpatient clinic [22], primary health care (PHC) [18] and nationwide studies in the following countries: United States of America [24,26], England and France [20] and Switzerland [23]. The years of publication were: 2020 [18,19], 2018 [21,22], 2016 [20,26], 2021 [23], 2013 [25] and 2012 [24]; the countries of publication were: United States [20,26], Brazil [18], Taiwan [19], Netherlands [21], England [22], Germany [23] and Hong Kong [25].

The analyses led to four main categories in relation to dignity: concepts and definitions; factors that influence the promotion or maintenance of dignity; therapy; and care actions to promote dignity. They are addressed below.

Concepts and definitions of dignity

The concept of dignity was related to respect and autonomy, in the sense that the person must be seen and respected as such. It is essential to recognize this autonomy in older people, recovering their identity and providing individualized care focused on the main needs, in order to promote dignity [18].

Another study [20], carried out in England and France, found that, in the first country, dignity is understood as respect for autonomy, such that the two terms are equivalent and, therefore, redundant, which makes it a priority that the person be seen as autonomous and can pursue their own goals until the end of their life. In France, dignity is related to the collectivity and can be understood as a form of respect for humanity, while individual interests are secondary [20].

Thus, there is the recovery of the definition of autonomy: the capacity of the individual to control their life and self-govern according to their own wills to maintain their integrity, with no disrespect to their rights in the social sphere [27]. In the end-of-life period, this autonomy is associated with dignity and subject to care support, the work of the health care team, current legislation and psychological, social, physical and spiritual support.

Corroborating the findings, a study [28] with health care professionals showed that the maintenance of dignity through autonomy at the end of life can occur through the inclusion of the family in care support, improving connections; through interaction by dialog, to understand individual aspects; and through the inclusion of the person in decision-making about their treatment. The health care team is responsible for sharing correct information among the members, sharing the decision-making process and, when possible, requesting the opinion of a specialized professional, in addition to recognizing the nurse's leadership to defend the person's autonomy in the end-of-life period. According to the authors, these conducts guarantee respect and autonomy with a view to maintaining dignity, since some situations may compromise it [28].

Another study [21] identified four categories of dignity: dignity as a principle; dignity as a state or situation; dignity to describe social differences; and dignity as personal meaning. The first considers that all human beings have intrinsic dignity that must be preserved to protect humanity, which, for being understood as something inherent, is subject to violation. From this perspective, health care professionals cannot offer dignity to the person, but they can try to ensure humanized care that preserves it until the moment of death.

The second category understands dignity as something concrete and related to the state of health, which can be violated in situations considered precarious. The third category understands that dignity is granted to some, that is, those privileged by the position they occupy in society, and therefore relates directly to social influences and the idea of meritocracy, showing that people of lower social classes have less dignity than those rising to upper social classes. In the fourth category, dignity comprises individual values and is identified when the person is included in their own health care, having their opinion and values considered [21].

The concept of dignity is broad and follows transformations in society resulting from technical-scientific development and globalization. In Stoicism, it was seen as equal for all human beings and differentiated them from other living beings. In addition, since classical Antiquity, dignity would be related to the position that

the person occupied in society or their degree of recognition [29].

Returning to the findings of this review, a study [24] conducted with 1,032 physicians linked dignity to a condition transferred by a transcendent to each person. In addition, most professionals believed that there was no difference in dignity between people after this transfer process. It was also related to the individual ability to make one's own choices, and some participants expressed that, during the process of dying, the person loses some of it (43% of respondents), loses it totally (36%) or does not lose it at all (21%). Of these respondents, those who were considered religious believed that dignity was equal for all and that it could not undergo loss.

Finally, a study [25] mentioned that, in the Eastern context, dignity is related to spirituality, a relation that is decisive in promoting quality of life and in the context of PC. This statement is justified by the holistic approach, which reestablishes dignity through spiritual care in the last moments of life. In this context, dignity is considered a spiritual value that is inherent to human beings, which is manifested in self-determination and self-responsibility, implies respect for others, and must be respected by society [30]. Therefore, it is important that health care professionals promote spiritual care and facilitate religious rituals according to patient will so as to enable a dignified and quality end of life. From this perspective, it is understood that comprehending the spiritual dimension and preserving it allows the humanization of care, which can thus be offered with enhanced comprehensiveness in end-of-life scenarios [31].

Factors that influence the promotion or maintenance of dignity

The quality of care was directly related to the maintenance of dignity. Not making judgments, respecting personal values, religion and spirituality, supporting decisions and offering care to the main needs are conducts directly related to a more dignified death [18]. It is considered that knowledge of oneself and of the other is one of the pillars of care and that it is important to analyze the patient's situation in order to understand human nature in its complexity [32]. The professionals' spirituality and positive thinking can assist in the provision of care and thus influence the comfort offered to patients and promote a humanized death through dignified care [33].

The place where the person is experiencing their last moments is another factor that influences dignity. It is considered that, in the hospital setting, mainly, the person is distant from their routine and there are restrictions in the care provided by the professionals due to the limited time offered to patients, in addition to the workers exhaustion due to excessive workload [18].

Another study [21] showed that, in the Netherlands, an inappropriate place for death would be the intensive care unit (ICU), because the technological support of the setting is considered life-sustaining treatment and incompatible with dignity. Also, it is mentioned that the hospital would not be an appropriate place for death, as this setting is geared toward curing diseases. Although dying at home is considered the best choice for the majority in the Netherlands, home care provided by local health care services is advocated, noting that these services would need to be coordinated with other reference services so as to promote dignity [21]. In contrast, a Canadian study [26] found that 70% of the population believes that the hospital is the setting that provides end-of-life care, and even most people who prefer to die at home die in the hospital.

To discuss the findings of this review, we found a study [34] with 71 caregivers of already deceased patients who had been followed-up by a PC team. It found that 86.7% of the respondents were satisfied with the fact that the family member had died at home, and 13.2% preferred the occurrence of death in the hospital. When asked about the possibility of the family member dying at home before the follow-up of the team and the beginning of the treatment, 56.6% considered it impossible and 43.4% already knew about the possibility, and all reported having had support from the health care team at the time of the death of the family member. The same study observed that dying at home with family preparation and adequate symptom control is also the preference among health care professionals [34].

After diagnosis of a life-limiting disease, in order to enable the promotion of dignity, it is necessary that health care professionals provide patients

with humanized care and talk about comfort care they wish to receive and preference for place of death. A study [35] evaluated the most frequent place of death among the Brazilian population and found that the hospital was prevalent (66.71%) compared to the home (21.43%). As a justification, the authors noted that the preference for the hospital is due to receiving appropriate care and reducing the burden on family members/caregivers, while the choice of home is due to the desire to spend more time with the family [35,36].

In another study [37], with 400 older adult patients, 52.2% of respondents mentioned preferring to die at home, and 47.8% preferred it to be in some institution, including the hospital. A study with physicians [38] found that most believe that the patient should choose the place of death, as this allows the preservation of autonomy and dignity. However, it is argued that it is essential to offer support to family members, as keeping the patient supported is a difficult task given the modification in the family routine and the need to adapt the setting [38].

Finally, there was mention of the issue of level of dependence or loss of independence and their relation with the loss of dignity, due to reduced or limited functional capacity to follow a normal routine [25]. Disease-related concerns, such as physical and psychological distress, resulting from death anxiety, and the existence of physical symptoms, such as pain, fatigue and inappetence, also interfered with dignity. The authors note that, although pain is an uncomfortable symptom, it is fundamental to maintain dignity as experiencing it means vitality and strengthening of spirituality and morality. Excessively reducing it could negatively interfere with the spiritual growth generated by the experience of suffering [25].

The same study shows that reducing concerns about the future and seeking spiritual comfort to find peace, improve family connections and improve life prospects are factors that promote existential integrity and help promote dignity in people who are at the end of life and receive PC [25]. In addition, issues related to lack of privacy and social support, reduced level of care and concerns related to the disease undermine the dignity of these people. It is considered that residents of institutions suffer due to the lack of space and feel constrained by institutional care, because in many cases health care professionals are not trained in PC to provide it to them [25].

The provision of PC is considered one of the main approaches to maintain dignity. However, there are still gaps in the training of professionals with a view to its practical application, and it would be relevant to expand the study on this approach. There is also a lack of quality services and trained professionals, as not every one of them is trained to deal with death naturally. Thus, maintaining patient autonomy during the end of life poses a challenge [38,39].

Concerning privacy, corroborating the findings, a study [40] shows that offering it ensures greater patient satisfaction and that demonstrating sensitivity and presence and looking into the eyes positively influences the treatment. The preservation of autonomy is directly related to dignity, as it is important that the person is able to independently perform routine and self-care activities. When there are hindrances to this, there is a reduction in the sense of dignity, and it is essential that health care professionals identify the main needs and promote comfort measures [40].

Therapy

As for therapy, in a study [18] that evaluated patients with advanced heart failure, there was the emergence of questions related to the interruption or not of life support. The question was about contribution to dignity *versus* prolongation of suffering, since patients with cardiac implants have higher chances of complications when submitted to certain therapies [18]. It is discussed that the maintenance of dignity can be compromised when patients are submitted to invasive procedures and interventions considered unnecessary, which focus on cure and, therefore, for people with incurable diseases, only prolong suffering. Because it is difficult for health care professionals to accept death, such measures become routine in health care practice [41].

Other study analyzed in this review [20] reports that, in England, patients are primarily responsible for decisions and have the right to refuse treatments according to the principle of corporal integrity, provided that they are informed and demonstrate understanding of their decision. France established

Law 303/2002, which provides for patients' rights and allows the refusal of treatments; however, some professionals are not sure if this refusal includes life-sustaining treatments. Thus, also in France, Law 370/2005, on patients' rights and the end of life, stipulates that patients have the right to refuse any treatment, including clinically-assisted nutrition and hydration. This law specifies that physicians must respect the patient's wishes and desires; however, if there is risk to life, physicians are responsible for "convincing" patients to continue treatment, which configures duality about the patient's ownership of their rights and wishes, since the professionals are considered responsible for the decisions [20].

Thus, patient autonomy is directly related to freedom to make choices, including decisions about end of life, including the refusal of treatment, in respect of what they consider as good life and good death. Therefore, when this autonomy cannot be exercised, for physical or cognitive reasons, it is possible that someone else decides instead. To develop dignity with autonomy, it is necessary that the individual can choose the course of treatment and deal with its consequences. The Brazilian legislation established as legal the medical practice of orthothanasia, that is, the cessation or impediment of the beginning of treatments that will not lead to cure, but rather prolong suffering. This practice is considered as promoting dignity in the face of suffering by not hastening the end while accepting death naturally [42-44].

As for the promotion of dignity, other study [21] included in this review demonstrated the professionals' perception that, if the patient refused treatment, even if it were their own desire or that of family members, there would be risk to their own dignity. That is, the maintenance of patient dignity would be conditioned to the professionals of the medical team. The care offered by the nursing team included patient hygiene, music therapy and prayers, in addition to comfort measures with oxygen therapy.

Another notable result concerns the physicians' opinion on voluntarily stopping nutrition and hydration in a Swiss study [23]. Some professionals believe that such interruption is part of natural death, while others claim that it is passive euthanasia, since some family members accepted such measures and did not oppose life-sustaining measures. This practice was compared to physician-assisted suicide or suicide proper. However, deaths that occurred through voluntary interruption of nutrition and hydration treatment were considered dignified, since there was supervision by professionals when patient suffering was considered unbearable.

Considering this finding, it is argued that the voluntary interruption of hydration and nutrition at the end of life understands the person's need to end their suffering, hence they decide to refuse the offer. However, in Brazil, this practice is uncommon and can be confused with interruption for other reasons, such as impossibility/difficulty in swallowing, inappetence, among others, that is, cases with evident difficulty in maintaining treatment, and it is not clear whether it is an option to hasten death. Health care professionals believe that such strategy should be considered as a last resort and that it is essential that the case be evaluated by a PC specialist and that the opinion of the family be considered [45].

Care actions to promote dignity

As for the care actions adopted to promote or maintain dignity, a study [19] mentioned the use of the Patient Dignity Inventory, consisting of 25 questions that assess existential and psychological suffering, loss of autonomy and symptoms reported by patients at the end of life. In addition to this inventory, we used the 24-item Demoralization Scale, which assesses feelings of demoralization, including loss of purpose, discouragement, feeling of failure and helplessness; and the 9-item Patient Health Questionnaire, which assesses the severity of depression in patients in the previous two weeks. The study concluded that all groups that received these interventions had increased dignity and reduced depression and feelings of demoralization.

These tools direct the planning of care offered to patients with advanced disease so as to facilitate the work of health care teams during care, as they are practical and applicable. A study [46] performed the psychometric validation of the Patient Dignity Inventory (PDI-Br), an instrument composed of 25 items and three domains: the first is related to physical and emotional symptoms; the second,

to dependence; and the third, to existential suffering. This inventory was based on other patient assessment tools, and the results of its validation demonstrate that dignity is directly related to physical symptoms, anxiety, depression, functional capacity, spirituality and quality of life.

Other study in this review [22] mentioned the use of Dignity Talk, a tool whose objective is to promote conversations between family members and relationships in general to reinforce values and dignity as a means to improve connections, promote interaction between family members, and deal with unfinished issues. End-of-life patients say it is a great opportunity to revisit memories, talk about personal matter and resolve issues. It also allows family members to reflect on the guidelines and information about the patient's life.

It was found that Dignity Talk is a great opportunity to improve family relationships, working as a starting point for conversation and support for caregivers, providing personal valorization and promoting dignity. It is a tool to transmit memories, life lessons, promote emotional interactions and facilitate the grieving process, helping the end-of-life person to die without regrets and with well-established family relationships [22].

Communication is an essential element in the health care field, especially with regard to PC, as only communication enables understanding the wishes of patients and family members. It is essential that professionals implement strategies aimed at effective communication to promote trust, strengthen bonds and preserve the dignity of patients in this context. Adequate and effective communication enables patients to express their distresses and wishes, given the freedom to communicate what ails them [38].

Communication is understood as the exchange of information between stakeholders, classified as verbal or non-verbal, and in PC it can be established by quality listening, attention, empathy and understanding. It also enables professionals to plan care to meet the main needs of each person, preserving their autonomy. Here, the nursing team's work is noted, since nurses are the main providers involved in exchanges of information about patient health condition due to the direct interaction, thus being able to trace demands and issues due to communication [38,47].

In Brazil, there was cultural adaptation of the Health Communication Assessment Tool (HCAT), which was developed by American researchers and consists of 22 statements and an open-ended question that assesses the establishment of bonds, the encouragement of autonomy, the training and empathy based on the behavior of health care professionals and students. The open-ended question is part of the category on language used with patients in care and enables professionals or students to identify the use of scientific terminology in care. The use of this tool can contribute to the quality and safety of care and facilitate the definitions of proposed health care treatments, preserving the patients' understanding of their condition and their autonomy, as they participate in decision-making [48].

Finally, issues related to end-of-life counseling as a strategy for maintaining dignity were noted. A U.S. study [26] demonstrated that private initiative plans benefit care planning because, in their hiring, they provide qualified professionals, including nurses and specialized physicians, who discuss cases individually to implement advanced health care.

These services enable the allocation of resources for the establishment of evidence-based PC with a focus on patient autonomy. They also aim at shared decision-making as a means of strengthening bonds with patients and families, through patient participation in decision-making about treatment and interventions they want to receive, aware of possible damages and benefits. They consist in a collaborative process between professionals, family members and patients, considering cultural, social and individual aspects, with health care professionals ensuring the dignity of the person at the end of life [26].

In Brazil, the 2019 Atlas of Palliative Care shows that, although PC services are predominantly public (50%), through the Brazilian Unified Health System (SUS), there are private services (36%) and mixed services (14%). According to the data, 22.4% of Brazilians who need PC access them in private services, for health care follow-up and advice, and the remaining Brazilians (77.6%) benefit from the public health care network [49].

In PHC, care planning by family health strategy teams enables including patients in decision-making about treatment, as they fully understand the individual, valuing their participation through access

to services, as well as their family [50]. In the final stage of life, it is essential to facilitate the patient's participation in their dying process according to their understanding of what is most appropriate for them. The bond and continuity of care must occur in a humanized manner, thus allowing the incorporation of effective PC in therapy and a dignified death [51].

Final considerations

This review enabled learning about the meanings of dignity at the end of life from the perspective of health care professionals and about some actions they adopt to promote dignity in care. It was found that the meaning is broad and varies depending on context, cultural characteristics, personal issues and professional issues.

For end-of-life care to be effective and comprehensive, the concept of dignity should be recovered and incorporated as a fundamental element in the approach to each person, focusing on a good death. It is also necessary to learn about the intrinsic and extrinsic characteristics that constitute the dignity of each person, preserve their autonomy and wills, include them in decision-making, allowing them to be an active subject in the various phases of life, including the end of life.

Health care professionals are mainly responsible for promoting and encouraging the autonomy of people in illness, because, like patients, they are central in care. For persons to have their wishes met, care planning should include factors that promote dignity. Thus, holding discussions in health care services about dignity is considered necessary so as to relativize the professionals' choices and views about patients and families. Recognizing, valuing and incorporating PC in health care practice is a possibility to enable such movements towards recovering the autonomy of human persons in the face of death.

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