




Living will from the perspective of nurses caring for terminally ill patients

Testamento vital sob a ótica de enfermeiros que assistem pacientes em situação de terminalidade

El testamento vital en la perspectiva de los enfermeros que atienden a pacientes terminales

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ABSTRACT

Objectives: to know the representation of the living will for nurses working in the care of terminally ill patients. **Methods:** a qualitative study conducted in a high complexity public university hospital located in the city of São Paulo, São Paulo, Brazil. An interview guided by the question "Talk about the living will" was performed with 15 nurses working in the care of terminally ill patients. Data analysis was performed using the Discourse of the Collective Subject. **Results:** three categories that make up nurses' Collective Subject Discourse in relation to living wills were identified: "the nurse before advance directives"; "the nurse before the terminally ill patient's family" and "the nurse before the terminally ill patient's physician". **Conclusion:** from the perspective of nurses, the living will represent the patient's autonomy and right to make decisions in terminally ill situations that must be shared with their family members and health professionals.

Descriptors: Nursing; Hospice Care; Advance Directives; Living Wills; Ethics, Nursing.

RESUMO

Objetivos: conhecer a representação do Testamento Vital para os enfermeiros que atuam na assistência à pacientes em situação de terminalidade. **Métodos:** estudo de abordagem qualitativa, realizado em hospital público universitário de alta complexidade localizado na cidade de São Paulo, São Paulo, Brasil, com 15 enfermeiros que atuam na assistência à pacientes terminais, por meio de entrevista norteada pela questão "Fale a respeito do Testamento Vital". A análise dos dados foi desenvolvida pelo Discurso do Sujeito Coletivo. **Resultados:** identificou-se três categorias que compõem o Discurso do Sujeito Coletivo dos enfermeiros em relação ao testamento vital: "o enfermeiro frente às diretivas antecipadas de vontade"; "o enfermeiro frente à família do paciente em terminalidade" e "o enfermeiro frente ao médico do paciente em terminalidade". **Conclusão:** o testamento vital representa, na perspectiva dos enfermeiros, a autonomia e o direito do paciente pelas decisões nas situações de terminalidade que devem ser compartilhadas com seus familiares e profissionais de saúde.

Descritores: Enfermagem; Cuidados Paliativos na Terminalidade da Vida; Diretivas Antecipadas; Testamentos Quanto à Vida; Ética em Enfermagem.



RESUMEN

Objetivos: conocer la representación del Testamento Vital para enfermeros que actúan en el cuidado de enfermos terminales. **Métodos:** estudio cualitativo realizado en un hospital universitario público de alta complejidad ubicado en la ciudad de São Paulo, São Paulo, Brasil. Se realizó una entrevista guiada por la pregunta “Hablemos del Testamento Vital” con 15 enfermeros que actúan en el cuidado de pacientes terminales. El análisis de los datos se realizó utilizando el Discurso del Sujeto Colectivo. **Resultados:** se identificaron tres categorías que componen el Discurso del Sujeto Colectivo de los enfermeros en relación a los testamentos vitales: “el enfermero frente a las directivas anticipadas”; “la enfermera frente a la familia del enfermo terminal” y “la enfermera frente al médico del enfermo terminal”. **Conclusión:** en la perspectiva de los enfermeros, el testamento vital representa la autonomía y el derecho del paciente a tomar decisiones en situaciones terminales que deben ser compartidas con sus familiares y profesionales de la salud.

Descriptor: Enfermería; Cuidados Paliativos al Final de la Vida; Directivas Anticipadas; Voluntad en Vida; Ética en Enfermería.

INTRODUCTION

Death is a topic that people generally avoid thinking and even talking about. In terminally ill situations, this fact makes decision-making difficult for patients, family members and professionals, and contributes to disagreements about how people want to die and how this actually happens. Given the scientific and technological advances, human life can be prolonged and death can be slow and painful, leading to the loss of autonomy and human dignity, thereby requiring a reflection on limitations of clinical interventions^(1,2).

Throughout history, the time of death has been removed from the family and domestic environment, and transferred to hospital settings, where there are technological apparatus and people capable of prolonging human life. However, this same environment that can provide healing and life can be inhumane for terminally ill patients, who may lose consciousness and decision-making capacity regarding how they want to live the last days of their lives with dignity.

In a study of 458 individuals admitted to a general hospital in the United States of America (USA) with the purpose to find out how they would like to spend the last days of their lives when approaching dying, most (75.0%) wanted to die at home. However, most of these patients died in a health institution (66.0%)⁽³⁾. This reality might have been different if these individuals could choose how to die and leave this explicit and registered will. Based on this context, emerged the “living will”⁽⁴⁾.

The living will is a legal document and one of the types of advance directives that aims to delimit the types of treatment and medical procedures a patient wants to undergo in case of becoming unable to make decisions^(5,6). The legal concept of living will was proposed in 1969 by Luis Kutner, a lawyer from Chicago (USA), who wrote a document with the express record of the desire of a citizen to refuse treatment in case he would suffer from a terminal illness⁽⁷⁾. Kutner’s thinking started from the principle that the patient has the right to refuse

medical treatment whose objective is strictly to prolong his/her life, in situations where his/her clinical condition is irreversible or if in persistent vegetative state⁽⁷⁾. A few years after its conception, the living will was legally recognized as a legal instrument in 1976, when the State of California approved the Natural Death Act prepared by the Faculty of Law at the University of Yale⁽⁷⁾.

All USA states currently have formalized Living Will statutes, which require the declarant to be capable and over the age of 18, and provide declaration forms containing information about which life supports are accepted or not by the declarant, such as: cardiopulmonary resuscitation, mechanical ventilation through a ventilator, electroshock therapy, dialysis, chemotherapy, transfusion of blood and blood products, installation of catheters, surgical procedures necessary for comfort and pain relief, antibiotic therapy, nutrition and hydration, in addition to specific information for care in pathologies such as cancer, HIV infection (Human Immunodeficiency Virus) and degenerative diseases of the central nervous system⁽⁸⁾.

The declarant of the living will must expressly inform that the registration is a personal desire, voluntary wish, free from influences or coercion, which is guaranteed by law. By doing so, the individual ratifies, in these terms, that the family, attending physicians and all concerned with his/her health are legally absolved for having followed the instructions declared in a document⁽⁸⁾. In this document, there may also be a provision for the appointment of a legally responsible agent who will have powers determined by the declarant and act only when the attending physician communicates the person is not incapable of making decisions⁽⁸⁾.

The living will concept is widely discussed in many countries and part of a process called anticipatory care planning. Brazil has no specific legislation on the subject, and the validity of the living will can be based on the Federal Constitution of 1988: Article 1, III, which deals with the Principle of the Dignity of the Human Person, Article 5, which deals with the Principle of Pri-

vate Autonomy, and Article 5, III, which deals with the constitutional prohibition of inhumane treatment. Specifically in relation to older adults, there is legislation addressing the right to choose, in which the right to choose no treatment is implicit⁽⁹⁾.

In Brazil, the terms “living will” and “advance directives” are synonymous and regulated within the scope of Medical Ethics⁽¹⁰⁾. In 2012, the Brazilian Medicine Federal Council published a resolution that defines the living will as a document drawn up by individual in the enjoyment of their mental faculties with the aim to address the treatments they wish to undergo or not when faced with the diagnosis of a terminal illness and unable to express their will. Among other things, this regulation allows patients to define they shall not to be kept alive with the help of devices nor undergo invasive or painful procedures, and the physician must know, record and respect the patient’s will⁽¹⁰⁾.

In a study conducted in 2017 with cancer patients facing the end of life, 85.0% were unaware of living wills/advance directives, and after being clarified about the meaning of living wills, 62.0% would agree to prepare this type of document. The conclusion in that study was related to the importance of talking about the subject during the training of health professionals, since there is evidence of a lack of knowledge by professionals that consequently leads to patients not receiving the information correctly⁽¹¹⁾.

Another study of 32 undergraduate nursing students conducted in the city of São Paulo corroborates with the need to explore the subject in courses in health areas, as only 25.0% of students adequately answered the definition of the living will, 43.75% responded partially adequately, and 25.0% responded not having knowledge, while 56% of students stated they had not discussed the subject during graduation, which proves the need to talk about the issue⁽¹²⁾.

Despite its relevance, the scientific production on the subject living will in Brazil is incipient, and the aforementioned articles show the lack of knowledge about the subject among professionals/patients/relatives.

In order to identify other constitutions on this subject, searches were carried out in databases such as Medical Literature Analysis and Retrieval System Online (MEDLINE/PubMed), Scientific Electronic Library Online (SciELO) and Google Scholar using the keywords: “Autonomy”, “Advance directives”, “Living will” and “Terminality”. In this context, there was a lack in the production from nurses’ perspective.

Thus, the question is: do nursing professionals know what advance directives are? What do they represent for nurses?

The aim of the present study is to understand the representation of the living will for nurses working in the care of terminally ill patients.

METHODS

This is a qualitative study conducted in a high complexity public university hospital located in the city of São Paulo, São Paulo, Brazil. Approximately 80.0% of care in this setting is financed by the Brazilian Unified Health System (Sistema Único de Saúde - SUS: Portuguese acronym).

Key informants were nurses working at the institution, who met the following inclusion criteria: having previous experience in assisting terminally ill patients and currently performing direct care activities for terminally ill patients.

Data collection took place in the second half of 2017 according to the availability of participants in a place that allowed the interviewee’s privacy. Statements were recorded with the aid of a recorder. Interviews were carried out by only one researcher, no predetermined duration, and the guiding question was: “Talk about the living will”.

Data regarding sex, length of professional experience at the institution and work shift were collected for the characterization of participants.

The number of professionals was not defined a priori, because, according to the method adopted, the analysis of descriptions was carried out concomitantly with data collection, until reaching the moment of invariance of the investigated phenomenon. From the time the speeches began to be repeated, the descriptions were considered sufficient to unveil the phenomenon.

After transcription of participants’ speeches in full by the same researcher, data analysis was performed using the Collective Subject Discourse Software (CSDsoft) (2005 version, Tolteca Informática, Brazil), which is a program developed based on the Collective Subject Discourse method. The answers of interviewees were included in the system for analysis. After the complete inclusion, started the processing of qualitative analysis using the DSC operators.

The Collective Subject Discourse (CSD) represents a methodological resource that makes it possible to give shape and qualitative visibility to discourses that express collectivity, allowing a social group to be seen as the author and issuer of shared discourses⁽¹³⁾. The technique employs four methodological figures: key expressions (KE); central ideas (CI); anchorage (AC) and the CSD itself. The KE is a follow-up to the statement in which the interviewee’s opinion on the topic under analysis

is clearly expressed⁽¹³⁾. The CI is the name or linguistic expression created by the researcher that reveals and describes in summary the meaning of key expressions present in the statement⁽¹³⁾. The AC is the expression of a given theory or ideology reported by the author of the speech, which is embedded in his/her speech as if it were any statement, ideology or belief⁽¹³⁾.

The most significant excerpts were separated from the transcribed speeches, and they comprise the key expressions. Subsequently, the central ideas were developed, which are a synthesis of the discursive content manifested by interlocutors. These excerpts were organized and written in singular first-person in order to synthesize a single collective discourse composed of key expressions with the same central idea. The anchorage was not envisioned in the testimonies; all the collective subject discourses that emerged in the present study were constituted of key expressions and central ideas. Key expressions are identified with the letter “E” and an Arabic number that corresponds to the interviewee. This strategy was adopted in order to maintain the secrecy of data corresponding to the interviews performed.

The project was approved by the Research Ethics Committee (*Certificado de Apresentação de Apreciação Ética - CAAE*, Portuguese acronym, number 53103216.7.0000.5392). The recommendations of Resolution n.466, of December 12, 2012, of the Brazilian National Health Council were followed in the study. After explaining the objectives and procedures of the study, the informed consent was applied to participants. Those who agreed to participate expressed their decision in writing by signing the aforementioned form.

RESULTS

Fifteen nurses participated, of which 13 were female (86.7%) and two were male (13.3%). The length of professional experience at the institution was less than 6 years for 4 nurses (26.7%), 6-15 years for 8 nurses (53.3%) and more than 15 years for 3 nurses (20.0%). Daily shift work was the most frequent (86.7%). Most nurses have specialization in Cardiology (86.7%).

Three central ideas emerged from nurses: “The nurse before advance directives”, “The nurse before the terminally ill patient’s family”, “The nurse before the terminally ill patient’s physician”, through which the collective subject discourse was built.

The nurse before advance directives

Collective Subject Discourse: *Advance directives constitute a document that the person leaves to say what he wants to be done with him in the last moments of his life,*

what the person wants in his treatment, what he wants to happen at the time of his death, what are his last wishes when he is no longer aware and cannot decide, cannot express his wishes. This document must be registered at the registry office, while the person is fully aware and capable of making decisions. If possible, the document must be made available to family members and health professionals and be attached or recorded in the patient’s medical record. It is a document that, in the end, the patient’s desire must prevail. I have to respect... I want to respect... I have to try to respect the patient’s will. I would be very frustrated not to fulfill the patient’s wish. (E3, E8, E7, E9, E10, E11, E12)

The nurse before the family of the terminally ill patient

Collective Subject Discourse: *It is important to explain the patient’s prognosis to the family and report that the patient made a living will that expresses his position in the situation when decisions are not possible. Most patients do not talk to the family about advance directives, transferring this function to the medical or nursing team. Therefore, the health professional must encourage family members and patients to discuss the issue, provide a joint dialogue with the multidisciplinary team to explain the patient’s health condition and the paths to follow, the possible interventions and palliative care. The decision for the patient’s comfort and not for curative measures can put relatives in conflict, because it is difficult to accept there is no possibility of cure. I have to respect that. I respect the family’s decision even knowing that it is not the patient’s will.* (E1, E2, E5, E6, E8, E9, E15)

The nurse before the terminally ill patient’s physician

Collective Subject Discourse: *Physicians are somewhat afraid of talking about the end of life with patients and their families. Some people think they have to do everything to save the patient’s life. If the medical team is against the wishes expressed by the patient, the nursing team should try to speak, explaining this is not the patient’s will and that he has the right to decide. The nurse can try to talk it out, but physicians will decide. I cannot go against them. If I could refuse, I would. It is often an immediate decision, something that has to be done in the moment. Unfortunately, I only follow what the physician advises. The physician knows about teamwork, but many work with authoritarianism. If the medical team does not do what the patient wants, unfortunately it is frustrating for me, as part of the team.* (E1, E2, E4, E10, E13 e E14)

DISCUSSION

The difficulty of individuals in dealing with the theme of death is a reflection of the society's unpreparedness to deal with this theme and its consequences⁽¹⁴⁾. In this context, studying the phenomenon of death has the purpose of promoting reflections that help in daily living with it⁽¹⁵⁾. Further discussions on the subject in the hospital environment are needed so that the theme of living will becomes part of everyday life and is treated assertively by nursing professionals⁽¹⁶⁾.

When expanding the discussion about the will, emerges the need to discuss the theme of death and its circumstances⁽¹⁷⁾. Nursing professionals who work with terminally ill patients experience the impact of the patient's death on their families, and need to learn to deal with and live with the psychological weight of the theme "death" and its proximity. The uncertainties and unpredictability surrounding the death-die binomial compel human beings to live with its presence from the beginning to the final stage of its development⁽¹⁸⁾.

Nursing professionals go through stressful situations in their work environment, which result from limitations in their ability to act and their personal conceptions regarding the process of death and die⁽¹⁹⁾. Situations like this are evidenced in nurses' collective discourse, when there is a lack of respect for the patient's will by the medical team or medical professional. The nurse has a prominent role in the action of maintaining the patient's wellbeing, acting in the process of death and dying, therefore, they can suffer intensely when the patient's will, which is aimed at one's own well-being, is disrespected.

With the caveat that the terms "advance directives" and "living will" are treated as synonyms by participants of this study, in the central idea "The nurse before advance directives", a clear understanding of participants is evident regarding the living will being a document that records what the individual wants in the final moments of life, and that it must be signed when patients have cognitive conditions to make their decisions.

Advance directives are means capable of instrumentalizing the patient's desires⁽⁸⁾ based on the principle of individual autonomy. This principle concerns the ability to exercise self-determination until the end of one's life, preserving freedom over the individual's choices even in the final moments^(20,21). One of the ways of expressing advance directives is the living will, in which the person establishes in a document the medical treatments that one intends to undergo, in the event of a terminal illness or irreversible damage to health, and when no longer enjoying the conscience for the exercise of autonomy in the face of desires. The living will does not guarantee

that the will of the patient will be respected, but only that the wish expressed by the patient is true, and even though it is not legalized in our country, it has validity requirements⁽²²⁾.

The patient's death is more acceptable when the prognosis is negative, i.e. whether older adult or with diseases considered terminal, the advance directives and wishes are more easily accepted⁽²³⁾. However, consideration must be given to the possibility of having difficulties in putting the desire into practice when it is a young patient, moreover, the lack of legal support and the deficient approach to academic training limit the function of the living will stands out⁽²³⁾.

The weakness of legal support is also pointed out by the category of physicians. A study of 32 doctors in a Hospital Emergency Service found that most professionals (81.3%) are aware of advance directives, 87.5% were in favor of their use and considered the patient's will as a determinant, but, at the same time, 84.4% consider that legislation is needed for better decision-making regarding the patient⁽²⁴⁾.

According to the Code of Ethics for Nursing Professionals, Resolution of the Brazilian Federal Nursing Council number 564/2017, in article 46, it is the duty of nursing professionals to respect people's or their legal representative's right to exercise the autonomy in making a free and informed decision about their health and treatment, including respect for one's advance directives regarding decisions about care and treatments that they want or not to receive when they are unable to express their will freely and autonomously⁽²⁵⁾.

Patient aware of his/her situation becomes empowered and demands clear and complete information about his/her health condition. By being informed, he/she participates in the decision-making process about treatment options and procedures that may be adopted as a result of each treatment. The living will is a way of making the person's wish known. This document reflects the person's desire in advance and not just at the end of life, when he/she will no longer be able to decide and freely express his/her choice⁽²⁶⁾.

The collective discourse around the central idea "The nurse before the terminally ill patient's family" highlights the importance of the care team, acting as a connection in the dialogue between patient and his/her family members. The care team has the role of communicating the patient's prognosis to the family, and informing about the treatment plan. Furthermore, patient must previously inform the family of his/her wishes in relation to treatments he/she should or should not undergo, and about the existence of a document in which his/her wishes are left in writing. When the family has not

been communicated by the patient about the existence of guidelines, it is up to health professionals to dialogue with the family in a clear way regarding the prognosis of the disease and clarify about interventions that may cause unnecessary suffering at the end of life, in a scenario where there is no possibility of curing the disease or reversing the clinical condition. Professionals working directly with palliative care are better prepared to fulfill the patient's wish⁽²⁶⁾.

Since this is something new within the context of care and little discussed in Brazil, interviewees emphasize that although the living will is a right of patients to make choices regarding treatment, if it is not an institutional routine, it can cause conflicts⁽¹⁾. According to the Brazilian Federal Council of Medicine, the patient's will must prevail⁽²⁷⁾. Respecting the autonomy implies recognizing that the individual must deliberate and take actions according to his/her life plan⁽²⁸⁾, making use of his/her freedom in order to choose to suspend treatments that prolong suffering. Nurses face the absence of a definitive position in the legislative area, which contributes to increase professionals' insecurity in following patients' determinations⁽²⁹⁾. Although there are no explicit laws on advance directives and the living will, in Brazil, the fundamental principles of the Code of Ethics for Nursing Professionals direct the nursing professional to perform their duties with responsibility, respect for life, dignity and rights of the human person.

Two factors can cause implications in the medical conduct that may bring tension in the multidisciplinary team or conflicts in relation to the patient's will: a) lack of knowledge or little knowledge of the legal instruments used to document the patient's will that constitute the advance directives; b) conflict situations and changes in the physician-patient relationship related to the concept of the right to life⁽²⁸⁾. Nurses can seek dialogue and bring elements to contribute to reverse the first factor, but, in relation to the second, they can do little from a practical point of view, which can lead to frustrations in the face of the situation. Thus, the understanding of health professionals, including the medical team, about what advance directives are, and about the regulation of the document through specific legislation is evidently important, since this helps in the decision of care teams and family members in relation to respect for the patient's decisions⁽²⁾.

In this context, it is important to implement institutional Ethics Committees and include this topic on the agenda of these instances with the purpose of creating and guiding institutional actions in relation to advance directives, in addition to actions of continuing education in health.

This study did not intend to exhaust the theme thus, it has the limitation of approaching only one of the nursing categories that assist terminally ill patients. Studies that also address nursing technicians and assistants are recommended. In addition, information on participants' previous experience with living wills in terminally ill patients was not collected.

CONCLUSION

From nurses' perspective, the living will represents the expression of a patient's autonomy and rights in end-of-life situations, and should be shared with their family members and health professionals. In the context of the health team, nurses are co-responsible for intermediating with the family in order that patients' wishes are respected.

Nurses may experience conflicts in situations where the desire expressed through this document is not respected, either by family members and/or physicians. The perception of limitation of their performance in these conflict situations generates a feeling of frustration before the impossibility of meeting the patient's desire.

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CONFLICT OF INTERESTS

None.

AUTHORS' CONTRIBUTIONS – CRediT

FCBRM: conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; resources; software; writing – original draft and writing – review and editing.

MJS: supervision; validation; visualization; writing – original draft and writing – review and editing.

FLPS: visualization; writing – original draft and writing – review and editing.

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