

Advance healthcare directives in hospital care: nurses' perspective

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Abstract

This study aims to understand how nursing assistants from a university hospital would act in cases of end-of-life patients provided with advance directives. This is a qualitative, descriptive and exploratory study conducted with 20 nurses from a public university hospital in the South of Brazil. Data were collected from November 2017 to January 2018, using semi-structured individual interviews, and submitted to discursive textual analysis, from which we established three categories: acceptance of death in the hospital context as prerequisite for complying with the directives; patient autonomy, respecting limits; advance healthcare directives: from (lack of) knowledge to the possibility of professional support. In conclusion, nurses consider that advance healthcare directives facilitate fulfilling patient autonomy, besides offering support to the nursing professional.

Keywords: Nurses. Advance directives. Hospital care. Ethics, nursing. Personal Autonomy.

Resumo

Diretivas antecipadas de vontade na assistência hospitalar: perspectiva de enfermeiros

O objetivo deste estudo é compreender como enfermeiros assistenciais de hospital universitário atuam em casos de pacientes em fase final de vida providos de diretivas antecipadas de vontade. Trata-se de estudo qualitativo, descritivo e exploratório realizado com 20 enfermeiros de um hospital universitário e público do Sul do Brasil. Os dados foram coletados de novembro de 2017 a janeiro de 2018, por meio de entrevistas individuais semiestruturadas, e submetidos a análise textual discursiva, a partir da qual foram elencadas três categorias: aceitação da morte no contexto hospitalar como pressuposto para cumprir as diretivas; autonomia do paciente, respeitando limites; e diretiva antecipada de vontade, do (des)conhecimento à possibilidade de respaldo profissional. Concluiu-se que os enfermeiros consideram que as diretivas antecipadas de vontade facilitam o respeito à autonomia do paciente, além de oferecerem respaldo ao profissional.

Palavras-chave: Enfermeiras e enfermeiros. Diretivas antecipadas. Assistência hospitalar. Ética em enfermagem. Autonomia pessoal.

Resumen

Directivas anticipadas de voluntad en la atención hospitalaria: perspectiva de enfermeros

El objetivo de este estudio es comprender cómo actuarían los enfermeros asistenciales de hospitales universitarios en casos de pacientes en la fase final de la vida provistos de directivas anticipadas de voluntad. Se trata de un estudio cualitativo, descriptivo y exploratorio con 20 enfermeros de un hospital universitario y público del Sur de Brasil. Los datos fueron recolectados de noviembre de 2017 a enero de 2018, a través de entrevistas semiestructuradas individuales. A partir de un análisis textual discursivo, los datos se clasificaron en tres categorías: aceptación de la muerte en el contexto hospitalario como prerequisite para el cumplimiento de las directivas; autonomía del paciente, respetando límites; y directiva anticipada de voluntad, desde el (no) conocimiento hasta la posibilidad de apoyo profesional. Se concluyó que los enfermeros consideran que las directivas anticipadas de voluntad facilitan el respeto a la autonomía del paciente, además de ofrecer apoyo al profesional.

Palabras clave: Enfermeras y enfermeros. Directivas anticipadas. Atención hospitalaria. Ética en enfermería. Autonomía personal.

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Population aging has been causing the overburdening of health services, considering that this phase of the life cycle is characterized by the accumulation of molecular and cellular damage, in addition to chronic diseases that may arise over the years. This increase in life expectancy is associated with the evolution of technology and disease-modifying treatments, especially for progressive and advanced life-threatening diseases¹.

This trend is accompanied by therapeutic obstinacy – the intention of fighting death and prolonging life even if without decent conditions. Such practice, which results in slow and painful death, can be considered degrading and inhumane². As such, Brazil is currently following the worldwide predisposition of affirming the right to autonomy, aiming to allow people to choose the approach they prefer in uncertain and delicate situations³. However, most critically ill patients lose the ability to make complex decisions; in such cases, resolutions are based on family and assistant physician criteria⁴.

To safeguard the patient's autonomy under these conditions, advance directives (AD) emerged, encompassing documents such as the living will and durable power of attorney for healthcare⁵. According to Dadalto⁶, ADs were first proposed in a text by North-American human rights lawyer Luis Kutner, in 1969. Upon publishing the first article on the topic, Kutner created a document named "living will," which contained the premises of the advance directive. In 1991 the document became law in the United States with the Patient Self-Determination Act (PSDA), which in its second section provides for the Advanced Healthcare Directives⁶. After the North-American PSDA, Europe started legalizing ADs in the 1990s; in Latin America, only Argentina and Uruguay regulated them in 2009⁶.

It is important to emphasize that the living will and ADs are distinct concepts, although many studies wrongly treat them as synonyms⁴. These directives enable patients to exercise their right to freedom and autonomy⁷ and aim to ensure respect for human dignity⁵. They can be recorded in a living will and/or durable power of attorney for healthcare. The living will is written by people in full possession of their mental faculties, foreseeing a situation in which

they cannot freely manifest their will. Its aim is to provide information about care, treatments and procedures – such as cardiopulmonary resuscitation, mechanical ventilation, artificial diet, medications, intravenous fluids, etc. – to which the patient may or may not wish to be submitted in the case of a progressive and advanced life-threatening disease, without therapeutic possibility of cure⁴. Durable powers of attorney for healthcare, in turn, aim to appoint a health attorney, who will be responsible for deciding on the patient's behalf when the patient cannot do so⁶.

Despite its importance and recurrence in daily medical activities, Brazilian health professionals generally have little familiarity with ADs³. In 2012, the Federal Council of Medicine⁸ issued Resolution 1,995, which regulates the application of ADs, defining them as the set of wishes previously and expressively declared by the patient about care and treatments they do or not want to receive if unable to freely and autonomously express their will. The resolution thus preserves patients' autonomy, who can refuse treatments or prolong their life by artificial means⁷. ADs, however, have no legal backing – which does not mean that it is illicit.

In other countries, the practice has been in place for decades, and although difficulties regarding its application, it has been observed that ADs are well accepted by the population in general, patients and health professionals⁹⁻¹¹. Its importance was highlighted by an analysis of the scientific production on AD applied to terminally ill patients, which also showed the viability of the instrument when properly used in the patient-family-professional relationship, considering respect for autonomy and human dignity¹².

In this context, nurses stand out, since these professionals stay longer with patients and their family members, interacting with the entire multiprofessional team. This enables qualified communication both to guide and to spark reflections and discussions about AD¹³.

The Code of Ethics of Nursing Professionals¹⁴ mentions advance directives and establishes that they must be respected, but nurses who feel insecure about the absence of specific legislation on the topic are supported by its article 22, which describes the right to refuse

to perform activities that do not offer safety to the professional. The lack of legal protection creates uncertainty in applying the instrument. Added to this is the deficient approach to the topic of end-of-life in the academic life of these professionals, which ends up emptying the role of the directives, disregarding their relevance in guiding therapeutic decisions¹⁵.

Based on this, we consider that the application of AD can support nurses in ethical dilemmas and conflicts¹² – especially when medical decisions are not explicit, such as in do-not-resuscitate orders. Thus, this study investigates the perspective of nurses from a university hospital on the possibility of assisting patients who have registered advance directives, seeking to understand how they would act in this situation. More specifically, nurses were asked how they understood their performance before end-of-life patients with AD.

Method

This is a qualitative, descriptive and exploratory study, developed in two medical clinic units (CM I and CM II), one surgical clinic (CC) and one adult intensive care unit (ICU) of a large public university hospital in the South of Brazil. At the time of the research, CM I had 10 nurses; CM II, 11; the surgical clinic, 17; and the ICU, 11¹⁶. CM I treats patients with pathologies related to nephrology or oncology; CM II, patients hospitalized due to complications of chronic-degenerative diseases; in the surgical clinic are patients who will undergo surgical procedures; and, finally, the ICU receives patients in severe conditions, requiring intensive care¹⁶.

The selection of nurses was intentional, following the inclusion criteria: being a nurse at CM I, CM II, CC or ICU and working for at least one year in the unit (minimum period that, presumably, would allow nurses to acquire more comprehensive experiences). Besides professionals who did not meet the inclusion criteria, those who were on sick leave or away from work were excluded. Inclusion of participants in the sample and data collection were based on saturation – that is, when the data began to repeat and the proposed goals could be achieved, no new interviews were

conducted. Of the 22 professionals invited before the sample was closed, two did not agree to participate, stating they were unaware of the topic. Before data collection, we made a pilot test to evaluate the interview script, which proved to be adequate.

Data collection took place from November 2017 to January 2018, and initially we applied an instrument to collect sociodemographic data from participants. Later, the nurses received an AD model and, based on this document, the individual semi-structured interview began. The guiding questions encompassed: knowledge on ADs; experiences with ADs in the hospital context; action when faced with a patient who refuses to undergo extraordinary procedures and treatments; compliance by the nursing team with the patient's wishes; behavior in cases of conflict between the patient's, family members' and health professionals' decisions; and the importance of nursing in the context of ADs.

Interviews were conducted individually by one of the researchers and mostly took place in the nurses' work environment, in private rooms, to ensure privacy and confidentiality, according to convenience and availability, without interfering with the progress of care activities. They were recorded for later transcription, totaling 610 minutes of audio, with an average duration of approximately 30 minutes per interview.

The same researcher who collected the data, transcribed the statements. The information was organized in Microsoft Excel and submitted to discursive textual analysis, which aims to deconstruct and reconstruct the researcher's understanding so that new concepts emerge from the investigated phenomena. This analysis involves three steps: 1) unitarization, which consists in deconstructing the corpus texts; 2) categorization, which establishes relationships between the unitary elements; and 3) capture of the new, in which emerging understanding is recorded and validated¹⁷.

With unitarization, we analyzed the interviews in detail so that constituent units of the phenomenon could be identified¹⁷. This phase, in turn, also followed three steps: 1) fragmenting the texts and coding each unit; 2) rewriting each unit so as to recognize a meaning in it; and 3) assigning a title to each unit.

In the next step (categorization), the units of analysis were organized and grouped to create categories that established relationships between the elements¹⁷. In the third phase, related to new understandings of the topic, metatexts (descriptive and interpretative texts) were produced from the units of analysis and categories. This process resulted in a renewed understanding of the collected data¹⁷.

The ethical aspects described in Resolution 466/2012 of the National Health Council¹⁸ were also observed. Participants were identified with alphanumeric codes formed by the acronym "PN," "participant nurse," followed by the order number of the interviews.

Results and discussion

Twenty nurses, 16 women and 4 men, participated in the study, comprising the age groups 20 to 30 years (7 participants), 30 to 40 years (12 participants) and more than 40 years (1 participant). Among the units surveyed, CC had more participants, with 6 nurses, followed by the ICU and CM II, with 5 participants each, and CM I, with 4 participants. Regarding length of experience in the hospital studied, 11 participants have been working as nurses for between 5 and 10 years; 3 for more than 10 years; and 6 for less than five years. Three categories emerged from the data analysis, representing how nurses would act, hypothetically, when caring for end-of-life patients with AD.

Acceptance of death in the hospital context: a prerequisite for complying with advance directives

As for fulfilling the AD, the nurses' behaviors and reactions relates to the issue of finitude, since they reported the experience of accompanying the death of a patient. We observed in the interviews that death and advance directives are accepted more naturally when patients have an advanced chronic disease:

"Terminality, it exists from the ER [emergency room] to the sixth floor [pediatrics], including for me and for you. But the idea of doing what the

patient left written, seems to be easier when it happens with an older patient, who already has a long-term illness and is suffering" (PN2).

We can infer that when the team accepts death there is greater consensus regarding fulfilling the AD; if the patient has a negative prognosis, following such directives seems more acceptable to professionals. On this aspect, a study with nurses found that the death of older patients or terminal patients were more easily accepted by professionals, since in these cases death was seen as the expected outcome¹⁹. This attitude, however, can be seen as a way of protecting oneself against the inevitable, since it changes when the team feels the patient's death as a break in the natural life cycle¹⁹.

Such conclusion is corroborated in our study, because even though they live with patients' terminality daily, nurses find it difficult to face the death of young patients, which can hinder fulfilling ADs:

"It's difficult to deal with the death of young patients. We are more used to face the death of a chronic patient, an older adult, who is going through the [final] stage of a disease. This is different from a young patient who suffers a polytrauma; he leaves us extremely shaken, because we are human. (...) In these cases, it would be more difficult to comply with the directives" (PN11).

"If it is and older patient with a terminal illness, who already has a weakened quality of life, it seems easier to accept to respect what they have left written, what they would like to be done for them. If it is a young patient, who lacks a clear diagnosis and dies, then we end up suffering a little more and would be at risk of disrespecting [the AD], because we don't know what will actually happen" (PN12).

Patient autonomy: respecting limits

The nurses pointed out that complying with the AD is a way of respecting end-of-life patients' autonomy:

"The patient must have autonomy to choose the type of treatment, in the case of a serious pathology, in the case of a terminal patient, for example, whether a surgery will be performed or not, as happens in some cases here" (PN8).

"We have to respect it, because it's the patient's will. There have been situations where patients did not want to undergo treatment; nobody is obliged to do it. If this expressed will exists, I think it has to be respected" (PN15).

In the complex relationship between patient and healthcare team, we should find balance between individual power and other powers; the better this relationship, the better the decisions taken as to not cause harm to patients, respecting their autonomy at all times²⁰. In this sense, the professionals emphasized that the will expressed in advance directives can be guaranteed if the determinations are in accordance with the unit's and institution's routines:

"From the moment a patient has the instrument [AD] in hand, on my part, I would respect it as much as possible, within the unit's routines. But we always make sure that the patient's will prevails" (PN3).

In a study conducted in another university hospital in the South of Brazil, the professionals interviewed also highlighted the importance of respecting patients' autonomy, but said they felt insecure in following ADs because there is no legislation to safeguard them¹⁵. Another study revealed that most respondents (nurses, doctors and pharmacists) declared they would respect the will expressed in ADs if they were legally guaranteed²¹.

In this sense, the lack of legal support and the deficient approach to terminality in medical schools – traditionally focused on techniques and cure – generate insecurity and limit the role of AD, treated as mere additional information, without much relevance to direct therapeutic behaviors¹⁵. Although they recognize the importance of knowing the patient's will, professionals feel the need to protect themselves from possible judicial problems.

We also identified statements that emphasize patients' right to choose which treatments and care they do or do not wish to receive. This autonomy needs to be understood by the nurse, so the decisions expressed can be respected, even if they do not correspond to the professional's wishes:

"I know that there are professionals who want to argue with the patient, that they have to do it and that's it. But that is not how it works. You have the right to choose about your body, your care, your treatment; we have to learn to respect that, even though we do not agree with the document [AD] that the patient wrote" (PN13).

This study with nurses, physicians and pharmacists showed that most respondents considered that discussing end-of-life decisions with the patient is an ethical and acceptable action, leading to the interpretation that health professionals tend to respect patient autonomy and support a dignified death²¹. In our study, the statements suggest that autonomy is considered important and should be respected, even if the patient's wishes are not recognized as the most appropriate from the professionals' personal perspective.

However, terminality is marked by doubts, anxieties, fears, and apprehensions. It is important that professionals recognize and accept death, communicating this situation to patients and family members as to promote changes in attitudes towards death. The desire to respect their wishes is not enough if professionals cannot accept the end of life. In this sense, the professional's feeling of powerlessness limits the implementation of ADs and favors therapeutic obstinacy²².

Advance healthcare directives: from (lack of) knowledge to the possibility of professional support

As the interviewees' statements show, some professionals are unaware of ADs, attributing this gap to the lack of courses on this topic during undergraduate studies. But the nurses point out that, although they do not use the nomenclature, the choices expressed by the patients are respected in the hospital:

"In college we do not learn about this, it is not talked about, and neither here in the hospital. I understood what it is about, but until then I did not know what could be done and everything, by the patients themselves, or even to have a healthcare proxy, because we come across these situations, but these terms of the directives were never used" (PN5).

The result corroborates a study conducted in the district of Kaunas, Lithuania, which found a low level of knowledge about ADs: only 16.7% of respondents said they knew the meaning of “advance directives” – among them, physicians were more familiar with the term than nurses and pharmacists²¹. In the present study, the lack of knowledge seems to be related to limitations in academic training, which, focused on the preservation and permanence of life, does not adequately discuss death, treating it as failure. Undergraduate experiences are also not always sufficient to prepare health professionals to deal with ADs and work with patients and family members who are going through the death process²³⁻²⁴.

A study with nursing students found greater acceptance of AD as semesters progressed, with significant progression in knowledge and personal attitudes towards this instrument²⁴. The result shows how important it is for future professionals to be exposed to the topic. After all, it is an instrument that, as the interviewees point out, promotes respect for the wishes expressed by incapable patients:

“It is an instrument that only brings benefits, both to the patient and the family, because it respects the patient’s will in those most difficult moments, of pain, of suffering” (PN3).

The statements describe the directives as a facilitating tool, since with them patients make their will explicit so that their autonomy is respected¹⁷. Autonomy is the pillar of the process that distances itself from paternalism by reframing the relationship between patient and healthcare team, allowing people to act effectively in their own treatment and enabling a new form of care²⁴. Important in this process, the AD also allow the family to be freed from the burden of having to decide on treatments that often do not cure the disease, but rather fall into therapeutic obstinacy:

“Many times, we do not know what the patient’s will is and we have to guess. And even family members, it is even an emotional matter of responsibility sometimes, because they think they need to try everything. Even the family member, knowing what the patient would like to do, would take a weight off their conscience” (PN6).

We also identified statements about AD regarding the need for multiprofessional participation, not only to put them into practice, but also to clarify information that may be in the document, to verify if the expressed wills are actually feasible:

“We get into a topic that I believe involves not only nursing; the other categories have to explain to the patient the pros and cons of undergoing treatment” (PN2).

“We need a team that knows what to say to the patient if he wants to do use this document, because otherwise he can write something that is not possible later on for the professional to accept” (PN11).

The nurses also emphasized that an AD would support the team’s actions to respect patient autonomy even if the family has an opposite view:

“The instrument gives the patient the possibility, while lucid and guided, if applicable, to choose. So, I believe it gives that person autonomy to say what he would like to be done. This provides the professional with support, because many times it’s the patient’s wish, but the family does not understand” (PN5).

Most respondents agreed that AD would help harmonize responsibility-sharing between healthcare staffs and patients. The nurses’ statements also refer to the idea that relationships with the patient’s family can become conflicting when the team follows the AD, since the expectation of family members may be contrary to the patient’s will. As a rule, however, the AD subject physicians and relatives to the patient’s will, since the latter was informed of all therapeutic possibilities and was mentally lucid when he recorded his wills^{7,13,20}.

In this category, points were listed regarding the lack of knowledge on AD, its importance as a facilitating tool for the team and family members, and multiprofessional participation. We conclude that it is necessary to increase the discussions about death and the ethical issues that surround it. Among the strategies, continuing education actions with the health

team stand out, especially with nurses, as the professionals closest to the patient, often establishing strong bonds. It is also indispensable that these discussions are included in the training of future professionals, preparing them for situations they may experience in practice.

Final considerations

In general, the respondents accept death naturally when it occurs to patients with chronic illnesses and tend to respect, hypothetically, the fulfillment of ADs. Some nurses, however, are still unaware of this tool and report following the patient's decisions only if they do not deviate from the unit's and institution's routines. After all nurses consulted an AD template, they recognized it as a facilitating tool to record the patient's expressed wills.

In the statements, we identified challenges that nurses foresee if they are to comply with ADs. Among them is the fear of lawsuits due to the absence of legislation regarding advance directives. Here we note the importance of nurses feeling secure so that advances in the professional/patient/family relationship can be consolidated. In this sense, it is essential that the entire multiprofessional team knows the AD, helping in its elaboration, clarifying information

that can be included in the document according to the specificities of each treatment, and, finally, putting the instrument into practice.

Advance directives offer support to professionals who comply with them; the topic, however, is little addressed during training, especially in nursing. Thus, it is essential to include AD in the training process, so that future professionals can help their patients to use such directives and then follow them without apprehension. Similarly, further studies on the topic are needed, aiming to contribute to a more clear and natural view of death by nursing professionals.

The data collection scenario - a single university and public hospital - and the fact that the nurses were interviewed in their workplace, which may have distracted them from the topic, are the main limitations of this study. The research revealed demands related to fulfilling advance directives, an instrument generally unknown to the health team. In this sense, the nurse's role is essential. Nurses must be sensitive and understand the individual ADs, ensuring that the whole team preserves the rights and autonomy of the patient. The nursing professional must perceive deficiencies and correct them whenever possible, contributing to an ethical approach to end-of-life patients and their families.

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