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Nurses' perceptions of advance directives

Ernestina Silva^{a,*}, Maria Neves^b, Daniel Silva^a

^aEscola Superior de Saúde de Viseu, Instituto Politécnico de Viseu, Viseu, Portugal

^bCentro Hospitalar do Baixo Vouga, EPE, Aveiro, Portugal

KEYWORDS

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Terminal care;
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Abstract

Objective: To identify nurses perceptions of Advance Directives (AD) and to analyse the influence of experience with AD on their perception.

Material and methods: Quantitative, descriptive, correlational study conducted in a hospital in central Portugal with a sample of 139 nurses, aged 20-60 and in which 78.4% are women and 74% are under 40 years of age. A questionnaire was applied on nurses' perceptions of AD, their socio-demographic characteristics, and professional experiences with AD.

Results: Nurses with 26-30 years of experience have a more critical position with regards to AD ($P = .03$). Approximately 95% of nurses have no experience of situations where they were given the opportunity for the patient to decide using the AD, nor did they experience situations where the patient has been informed of this right. Most nurses (72.7%) expressed their readiness to reflect with the patient to preparing the AD document and 45.3% would only do so, if the patient or the family requested it.

Conclusion: Nurses have little experience with AD. They are available to respect the patient's will but did not feel able to address the issue on their own initiative. Most agree that the AD can "fail" if the patient does not reevaluate it periodically. Reflection and debate on the ethical issues surrounding AD should be promoted: promoting patient autonomy, care in vulnerable situations, team decisions and conscientious objection.

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*Corresponding author.

E-mail: ernestinabatoca@sapo.pt (E. Silva).

Introduction

Given the current development of medicine and biotechnology, a reflection on whether the application of new technologies suit humanity or not has become necessary.¹ Today it is possible to change the natural course of the disease and to monitor and care for patients in situations of protracted illness. We find ourselves at an impasse between prolonging life and letting natural death occur. On the one hand, the evolution of medicine allows diseases to be cured and life prolonged. On the other hand, one runs the risk of investing too much in saving a life for which there is no possible cure. The end of life and death raise many ethical issues related to quality of life, dignity in the dying process and the autonomy of choices in the final moments of life.²

The right to life is inherent to human beings, which leads us to face its end as something undesirable and objectionable, as it involves universal rights and values which are sometimes particular to a given culture and religion.³ What is sought is the dignity of every human being, not only in life, but also at the time of death. One should appreciate the needs, suffering and issues related to the end of life. Death and dying, pain and suffering are topics constantly debated around the planet.

In Portugal, euthanasia and assisted suicide are considered crimes and do not gather consensus as a means to alleviate suffering in cases of incurable disease. Dysthanasia is also contrary to good practice and raises ethical issues.⁴

Helping patients to die with dignity is a central tenet at the end of life. Dying with dignity is an individual right, legitimized by the right to life. Providing a peaceful death, with the least possible suffering, in which the person remains within their family environment or, at least, not away from it, is an ethical requirement.⁵

In Portugal, strategies and legislation were created in order to safeguard the end of life with dignity, in particular the network of palliative care and Advance Directives (AD), in the form of the Living Will (LW). Law No. 25/2012 of 16 July regulated the appointment of a Health Care Proxy and created the National Registry of the Living Will (RENTEV), which physicians can access online. Through Ordinance No. 104/2014 of May 15, the Ministry of Health approved an AD model. This is defined as a unilateral document which is freely revocable at any time by the party involved, in which people of age and ability, who are not prohibited or disqualified by mental disorder, manifest their conscious will in free and clear writing, with regard to the health care they want to receive or not, if, for whatever reason, they find themselves unable to express their personal will personally and autonomously.

In accordance with Portuguese law, the will expressed in the AD is valid for five years. It is renewable and modifiable in whole or in part at any time. According to the American Bar Association, cited by several authors,⁶ after preparing the LW one should “re-examine your health care wishes every few years or whenever any of the “Five D’s” occur:

- Decade: when you start each new decade of your life.
- Death: whenever you experience the death of a loved one.
- Divorce: when you experience a divorce or other major family change.

- Diagnosis: when you are diagnosed with a serious health condition.
- Decline: when you experience a significant decline or deterioration of an existing health condition, especially when it diminishes your ability to live independently.

LWs that are contrary to good medical practice or compliance with which can deliberately cause unnatural and preventable death shall not be valid.

This legal document also safeguards the right to conscientious objection on the part of health professionals who provide care and the right to non-discrimination to whoever opts for the LW.

Another form of AD is the appointment of a Health Care Proxy through a document conferring powers to make decisions on issues related to the health of the person when they are incapacitated. Unlike the living will, in which the decision about receiving treatment or not is taken in advance, the appointment of a representative allows that person to interpret the supposed will of the represented according to their values and goals.⁷

Nurses, in exercising their professional activity, are guided by respect for human dignity and are stakeholders and participators in all acts that require a human and affective component to alleviate suffering. In providing care, they are dignifying life even in the terminal phase.

We know that decisions pertaining to limiting or withdrawing care are taken after a considered multidisciplinary decision, involving the patients themselves, respecting their autonomy. In this process, the every professional’s decision takes into account the scientific knowledge which supports their professional practice and the intervention they will provide. Thus, nursing care to the patient at the end of life raises ethical issues for nurses.

Nurses should be knowledgeable of AD and have the role of informing, respecting, monitoring and caring for the terminally ill and cannot be oblivious to the whole process of planning, designing and complying with it. In this context, we consider it essential to identify nurses’ perception of AD and analyze the influence of nurses’ experiences with it in their perception of it. We intend to raise nurses’ awareness on this issue and contribute to the reflection on the ethical issues associated with the end of life.

Material and methods

This is a descriptive, correlational and cross-sectional study with a non-probabilistic sample of 139 nurses from the Intensive Care Services, Intermediate Surgical Services Care, the Emergency Room, Pneumology and Infectiology, Medicine I, II and III, at a hospital in central Portugal held in February and March, 2013.

The questionnaire was distributed and collected in a sealed envelope and included questions on nurses’ perception of AD, formed by a scale of 31 items developed from Law No. 25 of 2012, with five category Likert-type responses (from 1 “Strongly disagree” to 5 “Strongly agree”) as well as questions about their socio+demographic characteristics, and their experiences as professional nurses with AD. The questions were assessed by an expert in bioethics at the Portuguese Catholic University.

Table 1 Dimensions and number of items corresponding to the Likert scale

Dimensions		Items	Cronbach α
1.	Nurses' information on AD	4, 7, 8, 11, 12, 14, 16, 17, 20, 21, 24, 25, 26, 30	0.720
2.	Decision-making	1, 2, 3, 6, 9, 10, 23, 28	0.737
3.	Criticism of AD	5, 13, 15, 29, 31	0.627

The scale reveals an internal consistency with a Cronbach's alpha of 0.765. Previously the adequacy of the data to apply this technique by statistical analysis with Kaiser-Meyer-Olkin (KMO = 0.805) and Bartlett's sphericity test ($P < .001$) was studied. By analyzing the MSA value, obtained by anti-image correlation, items 19 and 22 ($MSA < 0.5$), were removed from the final scale. By principal component analysis using the Varimax method and given that item 18 presents a factorial load less than 0.3, it was also removed from the factor analysis. Based on the scree plot analysis, we found the existence of three factors.⁸ In interpreting the items for each factor, they were classified into three dimensions: 1) Information on AD; 2) Decision-making; 3) Criticism of AD. The dimensions are presented in Table 1 with the items that constitute each one. Analysis was performed with SPSS® Version 21.0 for Windows. The level of statistical significance was set at 5%.

Results

Of the 139 participants 39.6% are aged between 20 and 30 and 5.8% are over the age of 50. 78.4% are female and 51.8% is married/in a civil union. 71.9% only have basic/initial nursing education (diploma or bachelor degree), 15.1% also have a Master's degree and 12.9% a specialization course.

Approximately 42% have been practising their profession for between 5 and 10 years and 79% of the nurses for 5 to 25 years. The professionals work mostly in the Medicine Department (34.5%), followed by Emergency Room (23.7%) and Intermediate Surgical Care (12.9%).

According to Table 2, we find that only 3.6% of respondents said they had experienced a situation in which the admitted patient had been told they were entitled to decide on death and the LW or AD could be enacted, and 5.0% reported having had some experience in that the patient was given the possibility of deciding on AD.

Nurses with experience in information about LW/AD and those who have had experiences of situations in which the

patient was given the possibility of resorting to AD, had higher scores in the dimension of Decision-making.

Nurses mostly agree that information should be given to the patient on the use of this method and that decision-making and patients' wishes are rights which must be expressed in an AD document. The nurses showed willingness to reflect with the patient about its creation but agree that the entire process surrounding the AD can and should be improved.

In the relationship between the socio-demographic variables and perception of AD, we can verify that it is individuals aged between 51 and 60 who have better mean scores in the dimension Nurses' Information on AD and Decision-making, while in Criticism of AD, it is individuals aged between 41 and 50. Although female nurses have better scores on Nurses' Information on AD, there were no statistically significant sex and age differences on the Perception of AD. We observed no differences between individuals with between 26 and 30 years of experience as compared to individuals with 0-5 years ($P = .005$) and 16-20 years ($P = 0.017$) in the dimension Criticism of AD.

Discussion

The results obtained allowed us to validate a scale on the nurses' perception of AD, where three dimensions emerged related to information, decision-making and criticism of AD. Inferential analysis with socio-demographic characteristics and professional nurses' experiences with AD was performed for each.

We find that there are statistical differences in the group with 26-30 experience years for the dimension Criticism of AD. This led us to analyze the responses in this group in order to find out their level of professional/academic training and the type of concordance on indicators of the dimension Criticism of AD and observed that it is the holders of the Master's degree and Specialists. Professional and academic training coupled with a professional maturity allows them to take a more critical position.

Table 2 Sample distribution according to experience in information on LW/AD and experience of decision appealing to the AD

	Yes		No		Total	
	N	%	N	%	N	%
Experience in information on LW/AD	5	3.6	134	96.4	139	100.0
Experience of decision appealing to the AD	7	5.0	132	95.0	139	100.0

The fact that 96.4% of the respondents did not have experience in situations in which the patient had been given the opportunity to decide using the AD and 95% had not experienced any situation where the patient had been informed about the right to the AD, may be explained by the fact that the Portuguese legislation is recent. These results lead us to question the introduction of legislation without public discussion and training of health professionals.

During the first two months (July and August 2014) in which the online computer platform was available in the Ministry of Health, approximately 250 people registered. The numbers fall short of the government's expectation (20 to 30 000 within one year),⁹ which may be due to the general population's lack of information.

Information on AD

For this dimension we find that 91.4% of nurses currently understand that the doctor and the nurse must observe the patient, as a competent individual, may have made choices with regards to the AD. As health professionals have a legal obligation to respect the will of the patients or their legal attorney, with regard to health care the person may or may not want provided, if due to illness or mental disability, they are not able to express it.

Approximately 80% of nurses agreed or totally agreed that the AD reflects the values and preferences of the patient in end of life therapeutic decision-making and 85% agree that in situations in which they know about it, they will respect the AD. The nurses expressed manifestly that in health care, respecting autonomy and previously expressed wishes is an ethical requirement and a dignified practice, as Nogueira mentions.¹⁰

For the assertion, "The right to conscientious objection is assured for health professionals who provide health care to the patient when asked to comply with the AD," we found that 52.5% agree and 41.7% neither agree, nor disagree. This is a significant percentage of professionals with a neutral opinion towards the possibility of exercising the right to conscientious objection. We think that nurses are not aware of the ethical implications of the AD, so that training/reflection on this matter is necessary.

Decision-making

In this dimension we find that the majority of nurses (46.8%) agree that AD is a useful tool at the time of decision-making about patients at the end of life and that the Health Care Proxy facilitates decision-making for professionals (43.2%). When facing end of life situations where the question arises regarding disproportionate treatments or interrupting care, the AD may play a role in realizing respect for the dignity of the person.¹

When the question is posed to at the personal level, 20.9% consider the possibility of appointing a Health Care Proxy and 13.7% consider the possibility of effectuating the AD without appointing a procurator.

Nurses expressed their agreement as to their availability to reflect with the patient on the creating the AD (54.7%). We note however that in the statement, "I am capable of addressing this issue with a patient without his or her family requesting it," there is a significant percentage of nurses

(37.4%) with a neutral opinion. We observe some ambiguity in decision-making before this issue and believe that this indifference is related to the fact that they do not have adequate knowledge on it.¹¹

Criticism of AD

Nurses disagree (56.1%) that AD is a legal form of euthanasia, but 37.8% answered that they neither agree, nor disagree, which can be understood as ignorance of the concept of euthanasia. These difficulties did not surprise us because it is a concept that has been discussed from various perspectives and whose etymological meaning may be elusive (good death).

As for the statement that, "The AD lacks moral authority since, if patients have lost their competence to understand their situation, their prior wishes cannot be satisfied," we find that most nurses disagree (42.5%), but over a third of the respondents (36.7%) neither agree, nor disagree. In fact, there may be unforeseen circumstances in the wishes expressed and the actual circumstances change, as real life is always richer and more diverse than what is foreseen.¹²

We found that 45.3% of the nurses agreed that, "AD may fail in practice since the personal values of a patient may change after the declaration" and because "...biomedical technology may evolve and the description of clinical situations can lead to inaccuracies of the person's actual wishes" (42.5%). Indeed, they allow what the person wants or does not want in the field of health care at the end of life to be expressed, but one should reevaluate one's state of health regularly and whenever one of the five Ds comes up.⁶ In the case of the existence of a Health Care Proxies, they play an important role, because they reflect the will of the patient which may change in the light of new possibilities of care which may represent a gain to the patient. Progress in therapy may mean the patient's wishes might not be respected in that case, if that progress enables an evolution of the situation which is favourable to the patient. It seems that these positions may reflect not only the lack of debate at the care team level, but also the lack of exposure to situations AD in Portugal. In Germany, despite a growing awareness of AD, they are still little used, the cause of which is presented as a lack of communication, fear in their

What we know about the theme

- The AD are recent in Portugal and their legalization was not accompanied by public debate and discussion.
- There are few studies about the practice with AD and a lack of comparative data on nurses'.

What we get out the study

- A scale that allows this study to be extended and contributes to nurses' reflection on AD was constructed.
- The data demonstrate that nurses have a rather inconsistent position regarding information on the topic, decision-making and criticism of AD.

application and contradictory evidence regarding the level of commitment desired.¹² In the USA, although they are mandatory, they have not been greeted with applause.¹³ In Portugal AD emerged to enable people to express their will and, when they are unable to do so, to see their autonomy respected.¹⁴ The AD, however, may not be effective, not only because the declarer has no clear notion of his wishes at that moment, merely anticipating and not experiencing it, but it also implies subjection of the physician to the will of the patient giving rise to ethical conflicts.¹³ Debate and reflection on the difficulties and experiences that have been emerging with the AD is necessary.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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