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RESEARCH ARTICLE (ORIGINAL)

Health professionals' experiences in complying with the Advance Directive of Will in clinical practice

As experiências dos profissionais de saúde no cumprimento da Diretiva Antecipada de Vontade na prática clínica

Las experiencias de los profesionales sanitarios en el cumplimiento de la Directiva Anticipada de Voluntades en la práctica clínica

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Abstract

Background: The Advance Directive of Will allows the person to express their desire regarding their end-of-life experience. Complying with this directive requires health professionals to have the skills to deal with the complexity of these experiences.
Objective: To identify the health professionals' experiences in complying with the Advance Directive of Will in clinical practice.
Methodology: A qualitative, exploratory, and descriptive study was conducted using semi-structured interviews. Participants included health professionals from a hospital in northern Portugal. Content analysis was performed according to Bardin's framework. All ethical and legal principles were respected.
Results: Study participants consider the advance directive of will as an instrument that specifies the patient's wishes regarding end-of-life care. They emphasize that, when fulfilling these directives, they experience various emotions and feelings, like fear, impotence, and respect.
Conclusion: Complying with the advance directive of will demands the definition of criteria for supported and shared decision-making. Thus, a greater commitment to training is necessary.

Keywords: living wills; life experience; health personnel

Resumo

Enquadramento: A Diretiva Antecipada de Vontade, permite à pessoa manifestar o seu desejo relativo à sua vivencia no final da vida. Cumprir esta diretiva exige aos profissionais de saúde competências na medida em que envolve vivências de grande complexidade.
Objetivo: Identificar as experiências dos profissionais de saúde no cumprimento da Diretiva Antecipada de Vontade, na prática clínica.
Metodologia: Estudo qualitativo, exploratório descritivo com recurso a entrevista semiestruturada. Foram incluídos como participantes os profissionais de saúde de um hospital do norte de Portugal. Efetuada análise de conteúdo segundo o referencial de Bardin. Foram respeitados todos os princípios éticos e legais.
Resultados: Os participantes do estudo consideram a diretiva antecipada de vontade como um instrumento que especifica os desejos do doente quanto aos cuidados a receber em fim de vida. Enfatizam que no seu cumprimento experienciam uma variabilidade de emoções e sentimentos, medo, impotência, respeito.
Conclusão: Para cumprir a diretiva antecipada de vontade é urgente construir critérios para a tomada de decisão perfilhada e partilhada. Para isto, é necessário uma maior aposta na formação.

Palavras-chave: testamentos quanto à vida; experiência de vida; profissionais de saúde

Resumen

Marco contextual: La Directiva Anticipada de Voluntades permite a la persona expresar sus deseos en relación con su experiencia al final de la vida. Cumplir esta directiva exige competencias a los profesionales sanitarios, ya que implica experiencias de gran complejidad.
Objetivo: Identificar las experiencias de los profesionales sanitarios en el cumplimiento de la Directiva Anticipada de Voluntades en la práctica clínica.
Metodología: Estudio cualitativo, exploratorio y descriptivo mediante entrevistas semiestructuradas. Los participantes fueron profesionales sanitarios de un hospital del norte de Portugal. El análisis de contenido se realizó según el marco de Bardin. Se respetaron todos los principios éticos y legales.
Resultados: Los participantes en el estudio consideraron la directiva anticipada de voluntades como un instrumento que especifica los deseos del paciente respecto a los cuidados que debe recibir al final de la vida. Destacaron que, al cumplirla, experimentaron una serie de emociones y sentimientos, como miedo, impotencia, respeto.
Conclusión: Para cumplir la directiva anticipada de voluntades, urge construir criterios para una toma de decisiones perfeccionada y compartida. Para ello, es necesario invertir más en formación.

Palabras clave: directiva anticipada de voluntad; experiencia de vida; personal de salud

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Introduction

Today, society seems to be increasingly concerned about the end of life. In fact, with scientific and medical advancements, it is possible to counteract death by prolonging life thanks to the numerous treatments and healthcare available to man seeking immortality. However, this quest does not always mean quality of life and causes suffering in many situations. Thus, health professionals face new challenges, particularly nurses who provide care that meets the actual needs of the person's transition throughout life. Respecting the patient's autonomy and fulfilling their will is one of the major objectives of care. Thus, greater attention and reflection have been put on the call for recognizing the right to die with dignity since those who accompany end-of-life patients easily understand that dying in hospitals is often frightening, surrounded by much technological pageantry but also much loneliness. We try to give the patient more time to live, but to what extent do all these interventions that keep death at bay respect the person's will? And how can we intervene when the person cannot make a decision? Thus, the social awareness that more humanized and person-centered health care is necessary at any stage of the life cycle has led health professionals in their clinical practice to reflect on the exercise of the person's autonomy as a fundamental pillar of health care, which can be translated through informed consent and an advance directive of will (ADW).

Thus, the ADW arises as a need to strengthen the understanding of the principle of autonomy in the face of the great medical-scientific evolution, mainly in life-sustaining medicine, when the patient has lost their cognitive capacities. This constitutes the first legal tool for individuals to communicate their will regarding end-of-life health care formally. Nunes (2016, p.106) reinforces the importance of ADW in respecting the principle of autonomy, stating that "... the ADW is the expressed protection of a person's, an informed person's, freedom and autonomy, requested within the limits of the ethical and deontological action of professionals ...", thus allowing the person to participate in health care planning.

In Portugal, Law no. 48/1990 of 24 August (Lei n.º 48/90 da Assembleia da República, 1990), in Base XIV, defines that people, besides the right to be informed about their situation, also have the right to decide to receive or refuse the care proposed to them. We should also highlight the collaboration of the Portuguese Code of Medical Deontology, published in 2008, by establishing in its article 46 that medical conduct should obey the patient's self-determination, especially if there is a written document in which the patient's wishes are recorded (Regulamento n. º14/2009).

The growing need to adapt jurisprudence to the social scenario experienced resulted in the 2012 approval of Law No. 25/2012 of 16 July (Lei n.º 25/2012 da Assembleia da República, 2012), constituting the first Portuguese Law on the Living Will. It is a written document anticipating a person's will to receive or not receive health care.

The National Ethics Council for Life Sciences (2010) states in point 9 of opinion 59/CNECV/2010 that health teams should inform people when preparing the ADW. Based on all these assumptions, this study aims to identify health professionals' experiences in implementing the ADW in clinical practice to contribute to its recognition by health professionals as an essential document for a dignified death.

Background

Talking about death is complex, meaning that finitude is undoubtedly the greatest battle a person faces. We are born with a body to live and die.

From a biological point of view, death is considered the interruption of all vital functions of the person. It is just one more stage to be completed in the life cycle. We have been witnessing an institutionalized death, which no longer takes place at home, in an intimate and familiar space, assisted by the last religious rites, instead occurring in a hospital. For Serrão e Nunes (1998, p. 86), "death ceased to have a family and social expression." This hospitalization of death for health professionals became a symbol of failure and inefficiency, the health sciences became obsessed with avoiding and preventing death at any cost (Vicensi, 2016).

The desire for immortality often leads to the person being cared for only in their physical dimension, neglecting their multi-dimensionality. When death occurs in health care units more focused on cure and technicality, such as intensive care units (ICUs), the monitoring and respect for the patient's autonomy are sometimes affected. These ICUs are an expression of medical and scientific evolution that serves the human effort to delay and stop death almost indefinitely. These units are endowed with technical and human resources specialized in assisting critically ill patients and integrating and expanding the therapeutic possibilities of many patients who, due to the severity of their condition, would not survive without this resource. However, despite this specialized care, death is quite common in this care setting, either due to the irreversible recovery of failing organs or the complexity of the disease. Vicensi (2016, p. 66) refers that ICUs are ". . one of the most aggressive and tense hospital sites, they are often ... the last resort to try to prevent death". The health professionals in these units work in an unstable environment where the forces of life and death are in a permanent struggle. Nunes (2016) states:

> What matters most is not the mere extension of life but its quality in expressing the person's decisions about themselves. In other words, the dignity of each person at the end of their life. (p. 115)

It should be noted that the patient's autonomy has gained importance when deciding what to do, so the paternalistic attitude of physicians and nurses, once readily accepted, is now difficult to accept in society. Thus, the ADW is the first legal instrument for the person to communicate their will regarding end-of-life care formally. Saioron et al. (2017) define AWD as the patient's previously expressed wishes about the care and treatment that they want to receive when they are unable to freely and autonomously express their will.

The ADW thus reinforces the patient's autonomy in the face of medical and scientific developments, especially when the patient is no longer cognitively capable of deciding or expressing their will.

We can also state that creating a document such as the ADW, in which the person writes down the treatment they want or do not want, in case their decision-making capacity is reduced or non-existent, brings medicine closer to today's society.

For an ADW to be understood clearly and objectively, its written communication must be based on precise concepts and permeated with strict guidelines. The first legal document that used the term Living Will appeared in California in 1976 and in the health care proxy statute in 1983, followed by others until culminating with the Patient Self Determination Act, a federal law enacted in 1991 (Nunes, 2016).

In Europe, this issue became more relevant in the 1990s, after the North American Patient Self Determination Act, and constitutes a current practice in many countries. Countries such as Finland, the Netherlands, and Hungary, with a more liberal tradition regarding autonomy, legislated on this topic in the 1990s.

In other countries, the recognition of the ADW as a patient's right was only feasible after the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, also known as the Convention on Human Rights and Biomedicine or the Oviedo Convention, whose signatories are the Member States of the European Council, drawn up on 4 April 1997. In Portugal, the Convention was approved for ratification by the Resolution of the Assembly of the Republic no. 1/2001, of 3 January (Decreto n.º1/2001 do Presidente da República, 2001), which determines, in article 9, that "the previously expressed will regarding a medical intervention by a patient who at the time of the intervention is not capable of expressing their will shall be taken into account" (Decreto n.º1/2001 do Presidente da República, 2011, p. 15).

After the Oviedo Convention, Belgium was the first country to legislate on the subject in August 2002, followed by Spain in November of the same year.

England and Wales legislated the ADW in 2005, as did France. Austria in 2006, and Germany in 2009 (Dadalto, 2015). Despite being a signatory to the Oviedo Convention, Italy only legalized the Living Will on 14 December 2017.

In Portugal, the first draft law on the Living Will was presented by the Portuguese Bioethics Association in 2006 (Nunes & Melo, 2012) to the Portuguese Parliament, in which the need to create a document with a national registry, where each person can exercise the right to formulate an ADW within the scope of health care provision, is mentioned. The growing need to adapt jurisprudence to the social scenario experienced resulted in 2012 in Law No. 25/2012, of 16 July (Lei n.º 25/2012 da Assembleia da República, 2012) being the first Portuguese Law on the Living Will. Portugal presented specific legislation on the subject only a decade after this recognition. The diploma also regulates the appointment of a Health Care Proxy and creates the National Register of Living Wills (RENTEV), whose purpose is to "receive, register, organize, and update, as to national citizens, foreigners and stateless persons residing in Portugal, the information and documentation relating to the ADW document and the health care proxy" (Lei n.º 25/2012 da Assembleia da República, 2012, p. 3730).

Capelas (2016), in his opinion article, mentions a study conducted by the Institute of Health Sciences of the Portuguese Catholic University and the Portuguese Association of Palliative Care, where 78% of Portuguese people do not know what the Living Will consists of. Of those who do know what it consists of, more than 90% obtained this information from the media when it should have been from health professionals and health institutions.

It would be important to encourage the involvement and participation of health professionals in informing and capacitating patients about the preparation of the ADW. In an opinion article, Capelas (2016) refers to this participation of health professionals as a way to respond to the principles inherent to informed consent (in this case, prospective). To be considered valid, the citizen must have the skills to make the decision. For the same author, the ADW could never be perceived as a unilateral document but rather as an opportunity for a shared, accompanied, informed decision that meets the real needs and wishes of the person being cared for at each moment of their life. Thus, for the health professional, caring for a patient with an ADW is a doubled opportunity for shared decision-making because it requires them to validate it. For this, clarification and continuous information will be necessary.

The purpose of an ADW will never be to advocate active euthanasia but to allow the patient to decide when certain efforts should be suspended. In this context, an ADW that has explicit refusal to certain medical treatments may eventually lead to an accelerated death of its author since the primary objective of the ADW is the self-determination of the person that allows them to choose to die with dignity, without suffering and recourse to futile or disproportionate means of treatment.

The National Ethics Council for Life Sciences (2017) points out that:

> . . . the legal framework for ADWs aims to promote, above all, the prospective autonomy of each one of us so that the preparation of an ADW is seen as a reflective process, capable of achieving the desideratum of issuing reflected and conscious, unique directives that may be binding on health care providers. (p. 4)

We cannot limit ourselves to the patient's will alone when implementing an ADW, but it is also important to take into account their personality, beliefs, culture, and interpersonal relationships. It is indeed important to take into account the whole person and their circumstances. Respecting the person means promoting and defending the person's dignity. Dignity comprises the protection of the integrity and identity of the human race. Deodato

(2014, p. 91) considers that it is "respect for life and its unequivocal valorization, for the promotion of ways of life that are fulfilled with others, that defends the person's autonomy and individual power to direct their will." He also adds that it is "respect that gives importance to individual projects while supporting their construction in the sense of the humanity of life" (Deodato, 2014, p. 91). According to Kant, dignity is unique and irreplaceable, it has no equivalent, and human beings are free to use their understanding and assume their destiny through their own will. Thus, we can conclude that autonomy is central to Kant's philosophy. Therefore, health professionals faced with end-of-life situations must make complex decisions, as they involve respect for individual autonomy and the acceptance that each person is autonomous to self-determine. It is important to stress that health professionals involved in ethical decision-making should, above all, possess communication and relational skills to implement shared decision-making and respect, above all, the patient's dignity and allows them to make choices freely and consciously. In this context, Law No. 25/2012 of 16 July (Lei n.º 25/2012 da Assembleia da República, 2012), which approved the Living Will, created a legal instrument that binds the person's will in advance, with regard to the treatments that they intend to receive or not in a given health condition, thus ensuring the right to self-determination at a time when the individual capacity for its enjoyment is limited. It should be noted that the preparation of a Living Will allows the person to express their will about the final moments of their life, but nursing professionals cannot remain on the sidelines of the process of planning, designing, and fulfilling ADWs.

Research question

What are the health professionals' experiences in complying with the ADW in clinical practice?

Methodology

A qualitative, exploratory-descriptive study was conducted to identify the health professionals' experiences in complying with the ADW in clinical practice.

The study participants were selected to obtain a wealth of information and, therefore, the study sample included health professionals who met the following inclusion criteria: physicians and nurses working in an ICU and members of the in-hospital palliative care support team (EIHSCP) in the northern region of Portugal; and physicians and nurses with more than one year of professional experience. According to the inclusion criteria and the principle of data saturation, 15 health professionals (11 health professionals from an ICU and four health professionals from an IEHSCP) participated in the study.

The participants are eight females and seven males, aged between 30 and 61 years. Four categories were defined: [30-40[; [40-50[; [50-60[; >60. The length of service varies between seven and 33 years, and the length of service in the ICU/EIHSCP varies between 1 and 20 years.

As for academic qualifications, nine are nurses, of whom three have only a bachelor's degree in nursing, three are nurse specialists in rehabilitation nursing, one is a nurse specialist in medical-surgical nursing, and two have a master's degree in palliative care. As regards the medical professional group: six are physicians, two have an integrated master's degree and a specialty in general and family medicine, and four have an integrated master's degree and a specialty in internal medicine.

For data collection, a semi-structured interview was applied to understand and interpret the phenomenon under study, gathering information about ICU and EIHSCP health professionals' experiences in complying with an ADW. A script was designed based on the study objective, with the following semi-open-ended question, "Report your experiences in the implementation of the advance directive of consent", which allowed the interviewee to explain concepts, ideas, opinions, and experiences. The script was subjected to validation, which served as training for the actual interviews and allowed validating the appropriateness of the questions. No changes were made, and the original version was kept. It should be noted that all ethical and legal procedures were followed. Before starting data collection, we contacted the clinical director and the nurse manager of the respective services to explain the research proposal, negotiate the period and place to approach the participants and our commitment to disseminate the results to the professionals of those services. At the beginning of each interview, the objectives of the study were explained and presented, ensuring confidentiality and anonymity.

Data were collected in December 2018 and January 2019. A total of 15 interviews were carried out in a room of the service that allowed for a trusting and private environment. After the end of each interview, they were completed with notes and reflections that emerged throughout the interview.

Content analysis was performed according to Bardin's framework (2016). In the first stage, the interviews were transcribed, which supported further analysis and allowed becoming familiar with the information obtained. An identification code was given to each interview. Then, the information was organized and ordered so that we could start reducing the data. Subsequently, after reading, we established the units of analysis allocated to the respective thematic areas, which led to the emergence of themes for each of the domains considered. We always considered the study objectives and thematic areas, so we identified categories and subcategories. Thus, we initially coded the units into categories and subsequently compared them with each other to be grouped into themes and possible similarities between them. The study received a favorable opinion (no. 50/2018 - CES) from the hospital's ethics committee.

Results

In order to address the multiple dimensions and aspects of end-of-life care, new ideologies are necessary that consider the complexity and integrality of care in a holistic way. We should consider the determinant role of health professionals in ensuring respect for the patient's autonomy and the adequate preparation and implementation of the ADW. Thus, it became pertinent to identify health professionals' experiences when complying with the ADW in clinical practice.

Next, we present the data collected in an interview applied to the health professionals who participated in the study in 2018 and 2019. For a clearer perception of the categories presented, we presented and analyzed the units of analysis inherent to the theme of the health professionals' experiences in complying with the ADW in clinical practice (Table 1).

Table 1

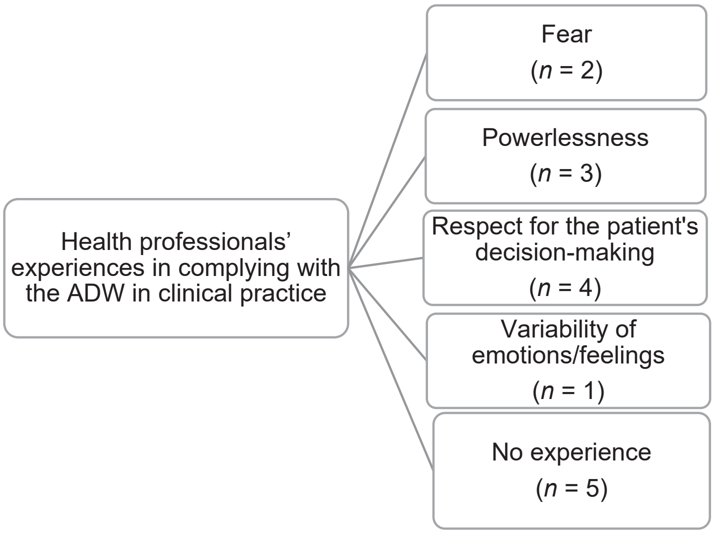
Health professionals' experiences in complying with the advance directive of will in clinical practice

Categories	Units of Analysis
Fear	. . . when the person's will is unknown, we are always afraid to decide because we do not have sufficient knowledge and information to respect the ADW, especially when it involves resuscitation maneuvers. . . EI4. When we are overworked, our fear increases because we find it difficult to discuss the ADW as a team, but we try to know the patient and respect their wishes. . . EP4. . . . There was a situation that made me quite fearful because a family member requested his sick relative not to be intubated. Still, due to the team's insecurity, the patients ended up being intubated. . . EI8.
Powerlessness	. . . we often feel powerless, like in this situation: I had a patient who had very clear ideas, and he knew very well what he wanted, but we did not accept the refusal of further treatment because we thought that there could still be a positive response to the treatment, we felt that we should not stop. However, the family also understood that the patient's wishes should be respected, and it was done so. . . . MP1.
Respect for the patient's decision-making	I've had two patients with a living will, one lady was a Jehovah's Witness, very basic things, like the issue of blood. The other one wasn't, he was a Dutchman, if I'm not mistaken, he had a very well-defined living will that said: when I get here, I don't want invasive treatments, I don't want them to do . . . I want to die in peace! It was all very clear. . . MP1. . . . in this team, I have only had two situations (that I remember), two living wills of all the many patients that we care for. Both were foreigners and knew exactly, they had outlined what they wanted and what they didn't want, and it was relatively easy because it was the fulfillment of the patients' wishes. Both of them mentioned non-resuscitation, among other things, such as not wanting invasive treatments. The patients' and their loved ones' wishes were fulfilled, and there were more friends than relatives, they knew that it was written and well-defined, and everyone was aware of it, so it was peaceful because it was foreseen. . . MP2.
Variability of emotions/ feelings	. . . yes, I have already had an experience related to Advance Directives of Will, but here in this unit we didn't (...), we didn't talk much about the living will. I don't even know if it could be related to Advance Directive of Will because it was the opposite, it was a patient who didn't want their situation to be abandoned at all, while the medical team wanted to stop investing because they no longer had anything to offer them, and it was very complicated to live with that. EI1
No experience	. . . we have never had any cases. . . EI2; EI3; EI6; EI10. . . . I've never had one, and as far as I know, I don't remember anyone signing a Living Will. I think most people are not aware of it. . . MI7.

For a more objective perception, we present below the health professionals' experiences when complying with the ADW in clinical practice (Figure 1).

Figure 1

Health professionals' experiences in complying with the advance directive of will in clinical practice.



Discussion

Fear was experienced by some participants as an unpleasant feeling when implementing the ADW. In relation to this experience, we found that other studies also mention fear as something felt by some health professionals when complying with the ADW, such as the study of Cogo et al. (2017), in which they mention that some health professionals feel afraid to follow the instructions included in the guidelines, especially when the family disagrees with what the patient has previously defined. Also, the study of Cogo et al. (2017) emphasizes fear as something experienced by health professionals in the applicability of the ADW. In another study, this feeling is also evidenced: "Added to this is the fear of fulfilling something that was previously expressed, but which may not correspond to the current wishes . . ." (Cogo et al., 2017, p. 28).

Powerlessness is also experienced by some study participants when implementing the ADW, meaning that they report not knowing how to deal with the duality of opinions (patient, family, health team). Saioron et al. (2017) share this feeling of powerlessness by mentioning that it is not always easy to accept a patient's request to stop investing. Health professionals understand that sometimes, with technological and therapeutic advances, they may delay the evolution of the disease process and ensure quality, generating helplessness and, at the same time, an ethical dilemma for the health professionals involved.

Often, health professionals are not trained to stop or to define limits in their interventions in patients without therapeutic possibilities of cure.

Respect for the patient's decision-making has been verbalized as an experience related to the ADW. Indeed, most studies related to ADW highlight this feeling. Cogo et al. (2017), Lunardi, and Nietsche (2017) also share this opinion, concluding that the ADW is a self-determination instrument and facilitates the patient's decision-making. The authors also conclude that personal decision-making should be immune to external influences from family members or health professionals. Many health professionals do not specify their experiences but claim to have experienced multiple feelings and emotions when implementing the ADW. However, it should be noted that a considerable number of interviewees (five nurses) revealed they had no experience with the ADW. Other studies also point to the same. Rodrigues (2017), in her Master's dissertation, found that very few professionals had ever had any experience with the ADW.

Conclusion

When health professionals implement the ADW in their clinical practice, they experience various emotions and feelings arising from the conflict between what they think is best for the patient and what the patient understands to be best for them. Therefore, investing in training, information, and greater awareness of health professionals in ADW management is essential.

This study also highlights the need for health professionals to invest in patient-centered care models.

Thus, more objective and precise criteria should be defined to guide health professionals in implementing the ADW and mitigate their feelings of fear and helplessness. Patient-centered care should be adopted to respect the patient's autonomy and, consequently, the patient's wishes.

This study has some limitations, namely the non-generalization of results due to the choice of a qualitative study and its sample size.

We believe that this study has implications for care practice, training, and research to the extent that it demonstrates the need to invest in a change of care, promoting a comprehensive view of the person and, thus, the dignification of the end-of-life process, taking into account the patient's wishes.

Author Contributions

Conceptualização: Santos, L.
Investigação: Santos, L.
Metodologia: Santos, L.
Administração do projeto: Santos, L.
Validação: Cerqueira, M. M.
Redação - rascunho original: Santos, L., Cerqueira, M. M.
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