

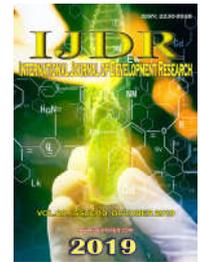


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ADVANCE DIRECTIVES: PERCEPTION OF PALLIATIVE CARE NURSES

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ABSTRACT

Introduction: A qualitative, exploratory, descriptive study carried out in two public oncology hospitals in the Brazilian northeast. Objective: to understand the perceptions of nurses working in palliative care about the advance directives of the terminal patient. Methodology: the data were obtained by open unstructured interview with 10 nurses and supported in Content Analysis. Results: two themes were constructed in which Nurses' knowledge about the anticipated directives of will and meanings for nurses about the implementation of the anticipated directives in the hospital scope. Conclusion: It will be necessary to create educational projects, especially for professionals who work directly with palliation, so that there is dissemination about this possibility of care for patients and families, making these subjects active and knowledgeable about their fundamental rights and guarantees.

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INTRODUCTION

Death, although it is a natural process, tends to be avoided by the fact that it is considered an event contrary to life, constituting itself as the finitude of life, a physiological process where cessation of vital signs occurs, besides being a cultural process, which involves difficulty in coping with it (ALMEIDA *et al.*, 2015). Over time, explanations are sought to understand human behavior in situations of death and death (LIMA, SILVA, 2014). According to Nunes and Angels (2014), each idealizes his way of dying, but when one is healthy one can not reflect on it, and the subject will arise only when death is imminent. Death must be seen in a more constructive way, as an inevitable phase. Therefore, the advance directives of will (AD) constitute a document in which it makes possible the manifestation of the terminal patient's willingness to accept or not medical treatment (DADALTO; TUPINAMBÁ; GRECO, 2013).

With this document, both health professionals and family members become aware of the patient's choices about the forms of treatment he or she wishes to undergo (ROCHA *et al.*, 2013). Finally, the advance directive of will is a possibility, not an obligation, that is, the patient does not have to do it, if he does not show interest in stipulating which treatments he wants or not, in case of incapacity. Another fundamental issue is the need for the patient to expressly inform the doctor (and even his family members so that they can also - if necessary - advise the doctor) whenever exercising their self-determination; otherwise, their preferences will be of no use, nor efficacy (PATTELA; ALVES; LOCH, 2014).

Therefore, the desires and determinations of terminal patients when discussing seek to annul with situations of absolutism of medical decision, proposing a new dialogue and discussion on therapeutic definition (GRACIA, 2010). Santana *et al.* (2013) demonstrate apprehension about the difficulty of nurses dealing with death in their work environment, emphasizing that due to this problem, it is necessary that the theme finitude

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be approached in its academic formation, contradicting the aspect that seeks only to save lives. In this sense, the research problem seeks to answer the questioning: What meanings revealed by nurses working in the palliative care sectors about the advance directives of the terminal patient's will?

MATERIALS AND METHODS

This is an exploratory-descriptive study, with a qualitative approach, carried out in two oncological hospitals in Northeast Brazil. These units were chosen because of the number of severe and / or terminally ill patients, where AD could be more habitual in the work context. The corpus of the study was defined by ten nurses that works in the palliative care department of these institutions. The inclusion criteria adopted were as follows: the nurse who is in work during the period of data collection, presents at least one year of professional work in the selected institution and that agrees to participate in the study. This decision was made due to the fact that these professionals have greater experience and understanding of end of life, and can thus enrich the research due to previous experience.

The interviews were guided by an exploratory open-ended question: What is the meaning of Advance Directives based on their experience as a nurse? The interview was performed considering some criteria such as: to have allowed the participant time to think before beginning the process of recording the audio; start recording when authorized by the participant; never interrupt the participant's thinking; focusing on listening and attention to what is said and how it is said to obtain material that would enable richness and quality of the data. Before data collection, it is worth mentioning that visits were made to the field in order to create a more harmonious environment and broaden the researcher's view of the routine of hospitals. From the first moment, there was a favorable and inviting reception by the nurses of the sector. In order to ensure the principle of confidentiality and anonymity, the source of the data will be presented in codified form (Nurse 1 ... 11). It was considered the principle of autonomy conferring on the participants the possibility of refusing to participate. After confirmation of interest in the research participation, the Informed Consent Form was presented, in which the objective and details of the research were presented. All the interviews were carried out in the physical space of the hospitals (Cancer Hospital of Maranhão and Aldenora Bello Cancer Hospital, in rooms intended for medical and nursing prescription). The interviews were aimed at assuring absence of noises and interruptions that could compromise the audio quality. Data collection began after the approval of the Research Ethics Committee involving Human Beings of the Federal University of Maranhão (Number 2,891,954). The development of the study respected the ethical aspects, according to Resolution 466/2012 of the National Health Council.

RESULTS

Although ADs have been regulated by the Federal Council of Medicine (CFM) since 2012, they are still poorly understood by health professionals. Among the 10 nurses participating in the study, only 02 knew their meaning. After the Content Analysis, two categories emerged: Nurses' knowledge about the anticipated directives of will and meanings for nurses about the implantation of the anticipated directives in the

hospital scope that will be presented descriptively with a cut of the speeches of the participants.

Theme 1: Nurses' knowledge about the Early Will Directives - in this theme was composed of 49 units of records in which nurses demonstrated the difficulty in understanding the directives.

It was revealed difficulty in understanding the document that guarantees the respect to the will of the terminal patients, as seen in the statements below:

At the end of the document, I still do not have much knowledge, but I think it would be important for the patient (Nurse 2).

I have never heard of this document before, it is my first experience, I came and went straight to palliative care, I had a rather restricted notion about what palliative care is, the benefits, the disadvantages of working with the terminally ill patient (Nurse 3).

A study by Cogo, Lunardi and Nietzsche (2017) emphasizes that the concept and practice of AD are unknown by nurses; however, in the interviews, the ADs revealed themselves as a possibility to fulfill the wishes expressed previously by the patient and to seek respect for their personal autonomy. They are assertive that were also expressed by the nurses participating in the research:

I think it would be very important to implement this document because first of all the patient's will must prevail. So letting him make clear his desire to want or not to be intubated, has to be respected and other aspects. So I think all this should be documented because the person when you are lucid, she is aware of your wishes, what she wants, what she does not want, so I think this should be respected. When she has little time to live, more must be his will (Nurse 7).

Studies carried out in Spain by Ameneiros, Carballada and Garrido (2012) corroborate the present study, by showing that nurses and other health professionals who work directly with patients with no possibility of therapeutic reversal do not yet have the knowledge and attitudes necessary to apply and deal with this tool, which may assume that the implementation process of AD is not widely accepted.

Another study carried out in Spain by Flores *et al.* (2013) points out that both nurses in primary care and specialized care show a favorable attitude towards the use of AD, but it contrasts with the lack of knowledge presented. In the following speech, one agrees with this finding:

Despite my little knowledge about this tool ... In fact, I have now learned what it means, I think it would be important to be deployed in Brazil. Patients in these conditions need to know about their rights and what they can do in such a situation, irreversible (Nurse 10).

I did not know the directives, but now I see that they should be talked to with patients about these news so that he can argue, ask for information, and question his therapeutic plan. I think the team needs to know more in order to better inform the patient (Nurse 8).

In this way, the importance of a greater dissemination of this tool is noticed, especially by professionals who work directly with patients in the terminal phase, so that the assistance provided is geared to meet the patient's main demands, taking into account their real wishes and desires. Another demand present in the interviews was the need to implement disciplines that covered palliative care, termination and death at the undergraduate level, since many interviewees said that such knowledge can cause frustrations and difficulties in dealing with patients in terminal phase, as perceived in the following speech:

I've been in palliative care for about 1 year and 3 months. It is my first experience, I came and went straight into the palliative care, I had a rather restricted notion of what it means, the benefits, the drawbacks of working with this type of patient. The right thing would be to have a college degree on the subject (Nurse 5).

I had never had any previous experience. I graduated in 2006, I still did not have any related courses, so it was a new experience for me. It has several hospitals that work with cancer and does not have clinics that work with palliative care, so it is still undergoing improvement (Nurse 4).

Studies by Cogo, Lunardi and Nietsche (2017) reinforce the concern expressed by nurses, who suggest that expanding knowledge about terminality should be inserted in the spaces of society, especially in the training spaces of health professionals, so that, effectively, the right to personal autonomy is guaranteed. A study conducted by Cassol, Quinta and Velho (2015) corroborates this study, stating that by the recent theme, the anticipated directive of will is little known by the participants of this study, which demonstrates the importance of a greater approach both in the academy and in practical assistances, seeking to value the right of choice of therapy by the sick person and also in the sense of the assistance being in compliance with the Brazilian legislation and the Resolution N° 1,995 / 2012. A contributing factor for this scenario according to Cogo and Lunardi (2015) is the fact that the scientific production on AD in Brazil is still incipient, lacking empirical studies on the subject in terms of evaluation and practice, in order to contribute with necessary for the implementation of ADs at the national level. Contrary to the international scenario, where there are researches pertinent to the effectiveness of the application of AD, in the national scenario, they lack research focusing on its applicability (COGO, LUNARDI, 2015). Although insufficient, in 2013 a significant increase in studies and publications was observed, possibly associated with the approval of the CFM Resolution on ADs in 2012 (CFM, 2012).

Research has shown that there is a trend in the applicability and implementation of AD, although there are still doubts about its practice, also denoting that the lack of knowledge of professionals, as well as lack of legislation, negatively impact this process (CAMPOS *et al.*, 2012). In view of the findings, it is important to note the importance and need for the expansion of educational projects, especially for professionals who work directly with palliation, so that they have knowledge about the directives, and can disseminate about this possibility of care for patients and their families, these active subjects in their health-sickness process.

Theme 2: Meanings for nurses about the implementation of advance directives in the hospital setting.

This theme was composed of 33 units of records, revealing the understanding of the AD by the nurses in the scope of their implantation in the hospital context. According to Cassol, Quintana and Velho (2015), the freedom of the patient's choices regarding their treatment is fundamental, since there are no conflicts with technical knowledge. Although there is still difficulty in dissociating care from institutionalized routines, it is imperative to recognize the patient being as autonomous in the practice of care. It is observed below the testimonies that elucidated this thought and they revealed the guarantee and respect the autonomy of the patient as one of the meanings understood by the nurses interviewed:

It has to prevail the will of the patient, so he making clear his will to want or not to be intubated, has to be respected and other aspects that the family does not respect the will of the patient. Sometimes he wants to know about his diagnosis and the family does not want him to know, so I think all this should be documented, because the person when he is lucid, is aware of his wishes, what he wants, what he does not want, so I think this should be respected (Nurse 2).

In my opinion I think this tool would not bring so much improvement, but we are treating the patient and he has the free will to make the choice of what he wants for himself. And there is much to the family issue, which sometimes they comment: Ah if the patient is no longer conscious, he is not responsible for himself. With this, the family ends up responding to it and most of the time, the opinion of the family is not the same opinion of the patient (Nurse 1).

As a nurse, I see it would be a document that would help a lot in our clinical practice, because we deal with many situations that family members do not want the patient to know of some truths, so we deal with some ethical dilemmas here. And having the DAVs, having a legal value both to support the team and to support the family and the patient himself, both to defend the patient's will, would help a lot, to really know what he wanted (Nurse 5).

Studies by Dadalto, Tupinambás and Greco (2013) corroborate these assertions, emphasizing that it is not enough for the individual to have the right to make his choices through the anticipated directive of the will. Collective efforts are necessary to respect the autonomy of the sick person, and it is necessary to rethink the cultural forces of health professionals and family members, which is represented by the maintenance of life at any cost, thus characterizing therapeutic obstinacy. The challenge is to ensure that in the practice of care the real will of the patient is fulfilled. A meaning unveiled in our study shows that the decision of the family can impact the implantation of the directives in the hospital scope, since these tend to influence in some way the patient's decision. Studies conducted in the United States by Schenker *et al.* (2012) with 30 relatives, showed that despite the difficulty, there are efforts in the attempt to reconcile the needs of the family with that of the patient in the terminal phase. The interviews below prove this thought:

There is a case of a patient who has no indication of invasive measures, and the relative is against it or does not want us to talk to the patient about it or that he or she knows that he is in palliative care (Nurse 5).

Regarding what the family might think of this, I think it would be difficult for them, mainly because they are the ones that most interfere in the conduct of the patient's treatment. Then, realizing that the patient's autonomy really would prevail, it would be a shock to them, but over time, they would realize that this is right, respect the will of the other. And for the patient, it would surely be an important gain, because he would not be submissive in this process, being able to decide on what he wanted or not in this death process (Nurse 10).

We are faced with cases of patients who do not know their clinical condition, the family knows and does not want to tell them. There are attempts to talk, to try to convince the family to understand the reasons they can not be hiding from the patient. And in other situations, the family feeds a hope that is not good for the end-of-life patient (Nurse 7).

Often we realize that the patient has no more indications for therapeutic treatment for reversal of the condition, he is willing to give up the invasive procedures, but the family does not want us to talk to the patient about this or that he knows about it (Nurse 2).

Therefore, it is understood that the applicability of AD may be associated with the degree of understanding of the professionals and of patient and family instruction, and it is important to emphasize the last two social actors in this end-of-life process. Research carried out in Santa Catarina by Campos et al. (2012) regarding the degree of knowledge about the terms "living will", "biological will" or "advance directives", showed that 94.5% of the patients and 88.7% of the companions indicated that they were totally unaware of the terms. Another Spanish study by Antolín et al. (2012) who analyzed the knowledge about the living will among 382 patients found that only 13.1% (51) knew the meaning of the terms. This result, despite having been carried out in a country with a living will included in the law since 2001, is similar to that found in the research carried out in the south of Brazil by Campos et al. (2012). Studies by Cogo, Quintana and Silveira (2017) corroborate this view, pointing out that the advantages listed by the nurses in their study, show that the applicability of ADs has a significant and coherent importance to patient care; however, it requires previous instrumentalization to support its introduction in the hospital environment, and it is fundamental in this process that professional nurses provide information to their families about AD, in order to dialogue and contribute to all involved in the process of termination of life. The statements below confirm this assertion:

I think it really is missing out on spreading the meaning of these directives to people in general, starting with those in this palliative care sector and then taking them to other sectors as well (Nurse 1).

In my opinion, more speeches, more outreach, even social networking could help in that. I found this topic very interesting, because it is something new and if it is

actually used in hospitals it will be something revolutionary (Nurse 8).

The possibility of reducing situations of therapeutic obstinacy was one of the meanings unveiled by the nurses in our research. Studies by Silva, Quintana and Nietzsche (2015) corroborate our study, pointing out that reflecting the behaviors related to patient care in the terminal phase contributes to alleviate the difficulties in acting in the face of the termination of life process, seeking to reduce situations of therapeutic obstinacy, providing humanized care.

The statements below demonstrate this assertion:

Most patients and family members will try all possibilities. We have the vision of nursing and medicine, we can understand that it will not bring improvements, it will not improve the clinical picture of the patient and that often can further weaken the patient, as has happened here (Nurse 9).

In some situations where there is no acceptance of the diagnosis, we deal with ethical dilemmas, because we know that there will be no reversion of that clinical picture, but the familiar or sometimes the patient himself, wants to insist on the maintenance of life at any cost, thus making one more situation of dysthanasia (Nurse 3).

I think that all the professionals who work in the palliative care sector are faced with situations of therapeutic obstinacy, because there is no clarification of the real meaning of these terms. Euthanasia, dysthanasia, orthotonasia, few professionals know how to differentiate these terms, which ends up impacting the care of the terminal patient (Nurse 1).

It is fundamental that the care provided to the nurse respects the ethical and legal principles foreseen as evidenced in the Code of Ethics of Nursing (CFM, 2012) in Article 5 that establishes to exercise the profession with justice, commitment, equity, resolve, dignity, competence, responsibility, honesty and loyalty and Article 6, in which nurses must base their relations on law, prudence, respect, solidarity and diversity of opinion and ideological position. Thus, the terminal patient's will directives are an instrument that ensures the right, in addition to avoiding the patient's embarrassment to be subjected to futile medical treatments, which accelerate the risk of death and cause suffering (DADALTO, 2013). The nurse must also improve the technical, scientific, ethical and cultural knowledge, for the benefit of the person, family and community and the development of the profession, according to Article 14 of the Code of Ethics of Nursing. Thus, the social responsibility that this professional has in making the knowledge of the public and present directives in his / her hospital routine, disseminating to other professionals, patients and relatives, is noticed. The lack of national legislation on AD in Brazil was revealed as a barrier in the implementation of the document in the hospital scope according to the interviewees. This finding is described in the statements below:

I think that the directives, having a legal value both to support the team and to support the family and the patient itself, would facilitate the implantation process in the

hospital, as it would be a tool to defend the patient's will and would help a lot (Nurse 4).

For us professionals would be even better, because then we would have a legal backing to be able to actually meet the terminal patient's desire (Nurse 7).

As a nurse, I see that it would be a document that would help a lot in our clinical practice, because we deal with many situations that relatives do not want the patient to know of some truths, so we deal with some ethical dilemmas (Nurse 6).

Research by Cogo et al. (2016) in a university hospital in the central region of Rio Grande do Sul, Brazil corroborates our study, since it affirms that there are fears related to the ethical and legal implications that determine the limitation of the practice of AD by nurses, physicians and caregivers in the hospital context. As there is still no specific legislation support, the support to the DAV rests with the CFM Resolution. In Brazil, the Resolution of the Federal Council of Medicine nº 1.995 / 12 provides for the anticipated directives of will, conceptualizing as an optional document that can be done when there is a moment of life when there is a will, and can also be revoked when requested. The DAV according to the resolution are defined as the set of wishes, previously and expressly expressed by the patient, about the care and treatments he or she wishes to receive or not, once the patient is unable to freely and autonomously express their will. Despite the progress, there is still no specific national legislation on the subject. According to Dadalto (2013), although there is no rule about ADs at the national level, however, it can not be disseminated the understanding that this document is invalid in the country, because according to the author:

The constitutional principles of the Dignity of the Human Person (Article 1, III) and Autonomy (principle implicit in Article 5), as well as the prohibition of inhuman treatment (Article 5, III) are sufficient frameworks to validate this document in the scope of Brazilian law, since the purpose of this is to enable the individual to dispose of the acceptance or refusal of extraordinary treatment in case of termination of life. Therefore, it is essential that the fundamental right to freedom be exercised in the most genuine way possible, without paternalistic attitudes, be it family, government, doctors or any other intermediate entity. And for this to happen, it is necessary to investigate the existence of an exclusive space for personal decisions, protected by the Federal Constitution, immune to external political interference or normatizable. Advance directives of will assure the exercise of the right to freedom that is fundamental, since this document is seen as a possibility, a space that the individual decides on the possibility of being immune to external interventions, whether medical, family or any individual and / or institution that intends to impose its own will (DADALTO, 2013). The Federal Constitution of 1988 ensures the dignity of the human person (article 1, III) and predisposes that no one shall be subjected to torture or inhuman or degrading treatment (Article 5, III), such guarantees are fundamental and sufficient to certify respect and autonomy of the terminal patient.

Although the need for legislation is pertinent and guarantor of its use in Brazil, it has been noticed in some statements that

only the implementation of the law by itself may not facilitate its use, as seen in the following statements:

Only that I think that only having the document legislated would not be enough, because the majority of the population does not know what it is, does not know. It is no use having the document and not being used. That's the difference from here to the United States, there they know, apply, and actually use (Nurse 6).

Unfortunately, there is still no law to guarantee its use here in our country, but I think it is really lacking to spread the meaning of these directives to people in general, beginning with those in this palliative care sector and then to other sectors as well (Nurse 9).

Having a document with a legal basis for the team would be important. Only that I think that only the legislated document would not be enough, because the majority of the population does not even know what it means, does not know. It would not be good to have the document if you do not use it (Nurse 7).

It is something that I know the patient can do, but it has no legal value, even if he has done it, but if at some point he is unable to answer for himself and the companion wants a decision different from the one in the document, of the companion (Nurse 8)

Studies carried out with patients and relatives in Southern Brazil developed by Cassol, Quintana and Velho (2015) corroborate our findings, evidencing that repercussions related to AD occur due to the lack of consideration of its use, to the intense impact that would cause in the culture of the institution its implantation. Allied to this the understanding that, for the interviewed professionals, the family still remains with decision power overlapping in relation to the anticipated directive of will manifested by the patient. A study conducted by Neto (2015) showed that only 21.8% of health professionals dealing with end-of-life situations know the ADs through the CFM Resolution and that 58.6% of those interviewed do not feel comfortable following the VC- over there. This finding may corroborate the hypothesis that the lack of knowledge about the document causes difficulties in accepting and using the document. This fact, it is inferred that the directives are understood by the nurses as a guarantor of the autonomy of the patient, being able to corroborate to reduce situations of therapeutic obstinacy present in the hospital context of patient with life-threatening diseases. It is also understood that the decision of the family impacts the conduction and planning of the therapeutic plan of the patient in the terminal phase, being relevant that the nurse seeks means to guarantee the understanding of what the directives are, their importance and benefits for the patient in end-of-life process. Although there is no national legislation on ensuring its use, the knowledge of health professionals about AD empowers the multiprofessional team and can be a timely tool for future implementation in the national context.

Conclusion

The anticipated directives of will are perceived by nurses as an innovative tool, whose central objective is the search for the guarantee and respect to the autonomy of the patient in terminal phase. Because it is still a document considered recent

in the Brazilian context, there is a deficit in the knowledge of nurses who work in sectors that deal directly with patients with life-threatening diseases. However, it was perceived acceptance and search for more clarifications on the part of the nurses about the subject during the period of the research. The nurse understands that the applicability of the anticipated directives of will may positively impact on the reduction of cases of therapeutic obstinacy or futile medicine, since the patient can freely decide on which treatments he or she wishes to submit, respecting his right of choice, change what was previously decided. It was possible to realize that the lack of a specific law that guarantees and guarantees the use of advance directives of will is something that worries professionals about its use, although there are other legal mechanisms, without force of law, that can guarantee its use. In addition, as important as its implementation in the Brazilian legal framework, it is fundamental that there be education about the document, both for the professionals who work in the palliative care sectors, as well as for the terminal patient and family, because in this way, their importance can be perceived by society in general, which may have an impact on the process of drafting legislation on the subject. Given the results obtained, it is necessary a process of awareness of the society on the theme and creation of educational projects since graduation, extending to fields of action of professionals, aiming to provide assistance based on the knowledge of this document and rights assured to the terminal patient. It was perceived as limitations of the study the approach of only two hospital contexts that work with Palição, thus suggesting the need for other studies, which would contribute to broadening the discussion about the document in the various sectors of society.

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