

Challenges to implementation of advance directives of will in hospital practice

Desafios da implementação das diretivas antecipadas de vontade à prática hospitalar
Desafíos para la implementación de las directivas anticipadas de voluntad en la práctica hospitalaria

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How to cite this article:

Cogo SB, Lunardi VL, Quintana AM, Girardon-Perlini NMO, Silveira RS. Challenges to implementation of advance directives of will in hospital practice. Rev Bras Enferm [Internet]. 2016;69(6):969-76.

DOI: <http://dx.doi.org/10.1590/0034-7167-2016-0085>

Submission: 03-31-2016

Approval: 06-13-2016

ABSTRACT

Objective: to understand the difficulties and limitations in the implementation of advance directives of will in the hospital context. **Method:** qualitative, exploratory and descriptive study conducted by means of semi-structured interviews with nurses, resident physicians and family caregivers. The data were analyzed by using discursive textual analysis based on the framework of bioethics principles. **Results:** the following categories emerged: Terminality as an expression of loss and cure as an option for care; concerns about legal implications; advance directives of will demand patient autonomy and proper communication. **Conclusion:** limitations and difficulties in practice of advance directives of will from the perspective of the participants show, apart from countless conflicts and dilemmas regarding end-of life matters, that impending death experiences obstruct patients' wishes. **Descriptors:** Advance Directives; Terminally Ill; Nursing; Personal Autonomy; Caregivers.

RESUMO

Objetivo: conhecer as dificuldades e limitações relacionadas à implementação das Diretivas Antecipadas de Vontade no contexto hospitalar. **Método:** estudo qualitativo, do tipo descritivo e exploratório, mediante entrevista semiestruturada com enfermeiros, médicos residentes e cuidadores familiares. Os dados foram analisados por meio da técnica de análise textual discursiva e ancorados no referencial dos princípios da bioética. **Resultados:** emergiram as categorias: A terminalidade como expressão de derrota e a cura como opção para o cuidado? Receios das implicações legais; Diretivas Antecipadas de Vontade requerem autonomia do paciente e adequada comunicação. **Conclusão:** as limitações e dificuldades atribuídas à prática das diretivas antecipadas de vontade, na perspectiva dos participantes, indicam, além dos inúmeros conflitos e dilemas relacionados às questões de final de vida, que vivências da iminência da morte não têm possibilitado que os desejos dos pacientes sejam respeitados. **Descritores:** Diretivas Antecipadas; Doente Terminal; Enfermagem; Autonomia Pessoal; Cuidadores.

RESUMEN

Objetivo: conocer dificultades y limitaciones relacionadas a la implementación de las Directivas Anticipadas de Voluntad en el contexto hospitalario. **Método:** estudio cualitativo, de tipo descriptivo y exploratorio, mediante entrevista semiestructurada con enfermeros, médicos residentes y cuidadores familiares. Los datos fueron analizados por técnica de análisis textual discursivo, y fundamentados en referencial de principios de la bioética. **Resultados:** surgieron las categorías: ¿La terminalidad como expresión de derrota y la cura como opción para el cuidado? Temores a las implicaciones legales; Las Directivas Anticipadas de Voluntad requieren de autonomía del paciente y de adecuada comunicación. **Conclusión:** las limitaciones y dificultades atribuidas a la práctica de las directivas anticipadas de voluntad, en la perspectiva de los participantes, indicaron, además de los numerosos conflictos y dilemas relacionados al final de la vida, que las vivencias de la muerte inminente no han permitido que los deseos de los pacientes sean respetados. **Descriptor:** Directivas Anticipadas; Enfermo Terminal; Enfermería; Autonomía Personal; Cuidadores.

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INTRODUCTION

Prolonging life and postponing time of death have been some of humankind's biggest challenges. With the development of medicine and technology, it has become possible to change the natural course of illness. This has led to a new paradigm in the health field: the need to follow and care for sick patients for long periods of sickness, or not. This experience is often followed by a lot of suffering⁽¹⁾.

Overuse of sophisticated technology has contributed to the dehumanization of health care through its disproportionate use in treatment of terminally ill patients, characterized as therapeutic obstinacy. This is a practice that is difficult to change because of the availability of new biomedical technologies⁽²⁾.

Along with the modern medical obsession with extending life by restricting the freedom of people in the last stage of life⁽³⁾, recent decades have seen clear advances toward personal autonomy, giving patients the right to be informed, to choose one of the available treatments, and to consent to or refuse a procedure or therapy. Thus, advance directives of will (ADW), commonly known in Brazil as living wills, which deal with the rights of patients to express their will while they are still able have emerged as a discussion at the forefront of global bioethics⁽⁴⁾.

Advance directives of will allow persons who have been duly informed to refuse treatment that they consider unacceptable, reinforcing exercise of their right to self-determination⁽²⁾. Due to lack of a normative jurisprudential setting in Brazil, the Federal Council of Medicine issued Resolution #1995/2012, which provides for the possibility of applying ADW⁽⁵⁾. They are defined as a set of desires expressed by patients in advance about care and treatment they want or don't want if they cannot express their wishes freely and autonomously at the time⁽⁵⁾. They are patients' advance expression of their desires, which will assist in guiding professionals and families who are responsible for making decision on behalf of patients in the event of their incapacity.

However, this resolution does not resolve a number of controversies that relate to this subject: the applicability of ADW; the expectation that final decisions will correspond to peoples' wishes; the insertion of health professionals into the ADW process; and whether the patients' decisions can be changed, among other questions⁽⁶⁾. Studies in Brazil have shown that doctors have difficulty respecting a patient's will, even when it is written, if the family opposes that will⁽⁷⁾.

However, this practice has already in place in Brazil since the adoption of the Resolution, even if permeated by uncertainty. Between 2009 and 2014, the number of living wills registered in registry offices increased by 2,000%. In 2014, that number was 314 in São Paulo, followed by 86 in Mato Grosso and 53 in Rio Grande do Sul⁽⁸⁾.

On the international scene, the reasons for not completing the ADW⁽⁹⁾ were: difficulty anticipating patients' desires; patients do not want to write down their desires; and the rapid onset of delirium or worsening health conditions. It is important to stress the difficulty of organizing an AWD, the importance of specifying preferences and/or constraints on life support treatment, and the possibility that vague or inconsistent language

can affect implementation⁽¹⁰⁾. Still, one of the main cautions against the use of these policies in decision-making at the end of life is that people may not be able to understand different treatment options without being properly informed⁽¹¹⁾.

However, despite difficulties in utilization of ADW, it appears that their use will increase, moving the focus of debate to their effective use. It is therefore important that these documents incorporate a process that fosters open dialogue between families, health professionals and patients, in order to reflect patients' real needs, beliefs, values, care goals and preferences⁽¹²⁾. The present study is based on the principlism approach⁽¹³⁾, primarily the concept of autonomy, which relates to the rights to self-government, privacy, individual choice, and freedom of will – being the engine of one's own behavior⁽¹³⁾.

The study objective was outlined bearing in mind the facts mentioned above and the possibility of understanding the perceptions of health professionals and family caregivers of terminally ill patients who are facing decisions involving end-of life situations, related to difficulties in utilizing ADW. Therefore, the objective is to understand difficulties and limitations concerning the implementation of ADW in the hospital context.

METHOD

Ethical aspects

The ethical aspects of the present study were approved under #168/2014 by the Health Research Ethics Committee of the Federal University of Rio Grande do Sul. In order to maintain the anonymity of participants, the following codes were adopted: NUR - nurse; MED – Medical residents; FAM - family caregivers) followed by numerical digits for participants' speech identification.

Study type

A descriptive study of a qualitative nature, performed with nurses, medical residents and family caregivers of terminally ill patients, intentionally chosen, associated with a university hospital in the central region of Rio Grande do Sul, Brazil.

Proceedings

Inclusion criteria were: nurses and medical residents working in a medical clinic and home care service for at least six months; and family caregivers of terminally ill patients, caregivers over 18 years old, who cared for patients considered to be terminal in homes and were designated as responsible for the patients.

Data collection was carried out from October to December 2014, through semi-structured interviews, digitally recorded, with an average length of 50 minutes, focusing on issues related to patient autonomy, care implications, care responsibilities and AWD application. Interviews with health professionals were carried out in the hospital, and with caregivers in their homes after at least two previous visits had been made in order for the researchers to familiarize themselves with the environment and allow the participants to get to know the researchers.

Data were submitted to discursive textual analysis⁽¹⁴⁾ after transcription, involving three steps: unitarization, where the transcripts were analyzed and fragmented into sense units⁽¹⁴⁾;

categorization, where similar meaning units were gathered, generating categories of analysis; and capture of new meanings that emerged through intense impregnation of the analyzed materials. This provided a renewed understanding of ADW⁽¹⁴⁾ applicability, from metatext production coming from the examined *corpus*. The following categories emerged from the analysis: terminality as an expression of loss and cure as an option for care; concerns about legal implications; Advance directives of will require patient autonomy and proper communication.

RESULTS

Eight nurses were interviewed: 7 were women and one was a man; the age range was 33 to 60 years old with an average of 44 years old; nursing experience ranged from 9 to 30 years with an average of 18 years; worked in the institution ranged from 1 to 14 years with an average of 7 years. The most obvious improvement levels were specialization: There were 2 master's program students, 2 people with master's degrees and one with a PhD in nursing. Seven doctors were interviewed: 3 were women and 4 were men; the age range was 25 to 42 years old with an average of 29 years old; time working in the institution ranged from 1 to 9 years.

During the data collection period, 28 to 30 patients were part of the home care service, with an average of 8 to 10 terminally ill patients. Seven family caregivers participated in data collection: 4 were women and 3 were men; the age range was 41 to 57 years old; time working as caregivers was 2 or 3 years. The family relationship were 3 husbands, 2 wives, a daughter and a niece.

Terminality as an expression of loss and cure as an option for care.

Difficulty and discomfort experienced by professionals in addressing terminality seemed to justify their choices to continue investing in treatment of terminally ill patients, rather than discussing about possibilities of end-of-life procedures.

We cannot handle the end-of-life situation. We make decisions about comfort measures and treatment restrictions in the best way at all times. The most difficult situation is acceptance of the terminal condition and being able to say that the patient will not improve, coupled with the family's lack of understanding. (MED5)

Recognition and acceptance of terminal illness by professionals and communication of the situation to patients and families are considered big challenges. If professionals do not accept death, the desire to respect patients' wishes at the end of life is not enough. Professionals' feelings of impotence, especially doctors when facing death, appear to constitute a limiting factor in implementation of ADW implementation, and also favor the therapeutic obstinacy.

We have some difficulty in dealing with terminally ill patients, because even though you know that they will not heal, the feeling of powerlessness is the biggest feeling, and I get sad. (MED1)

In this sense, even if health professionals do not feel encouraged about motivating patients to create their ADW, they should be aware of patients' situations and create opportunities for ADW implementation, informing patients of that possibility and presenting all necessary explanations for the preparation of this document. Not just patients and families may express interest in creating ADW; it also seems important that professionals understand the implementation of this document.

She wants to make the ADW, but we keep putting it off until I do not know when. Doctors do not talk about her will and her desires, they do not express opinions, they do not say what they think is best. (FAM6)

I may create a problem for the patient, because when I clearly mention the possibility of an ADW, the patient and family get scared, anxious. (MED1)

The difficulty with ADW is deciding about and facing the real death situation. (MED5)

The perennial hope for a patient's recovery and the family's search for treatment resources, especially the fear of experiencing guilt for not having invested enough in the patient's cure, seem to be limiting factors for the practice of ADW that are noticed by health professionals and confirmed by family caregivers.

I see that relatives think they did nothing and think: How can I let the patient die without doing anything? Without using treatment up to the last resort? It sometimes will only prolong the suffering. It is a cultural issue. (NUR7)

Also, hope of healing seems to support and motivate the family to take care of the patient, resulting in a limitation of ADW application.

I believe in the possibility of his recovery, we have to believe, if this hope is taken from me it will be difficult to have the strength to fight. If there's no way I will end up losing the will to care. (FAM2)

In this sense, for health professionals, the existence of ADW with patients' previous expression of their desire not to invest in continued care for them could demotivate teams in assistance and care provided to patients.

I got worried when he asked us not to do anything, We will not change our position, because he asked not to be resuscitated, intubated, or to go to ICU. We already realize about that in the care. There is disregard for professional care and it can be seen with a different look. (NUR4)

Concerns about legal implications

Concerns about legal implications appear to be a determinant and limiting factor in ADW practice by nurses, doctors and family caregivers in the hospital context. Since there is still no specific legislation, the back-up for ADW is the CFM resolution, which, in the respondents' opinion, still raises doubts about applicability.

I would do all that is within the legal scope, I would not expose myself and respond to a court process. Often, I understand that people do something, not by conviction, but to not be bothered. (NUR8)

The AWD Resolution is very vague, it leaves room for different interpretations. I would be afraid and, in fact, all doctors are afraid of a court process. (MED3)

There is not a law. I am afraid to come with the manifestation, and professionals do not want to comply, because no legislation exists. (FAM7)

By contrast, professionals' compliance with ADW may occur as an administrative decision, exempting possible responsibilities.

I do not see it as appropriate if it is treated administratively as a document that nobody knows the reason for and without having a discussion supporting it. If it was signed, if the patient understood what it meant, it doesn't matter; but if something happens, I have my support. (MED4)

Despite legal concerns regarding compliance with the ADW, it is emphasized that, from point of view of doctors, advance statements cannot be followed closely and with strict priority, especially in cases where there is doubt.

The patient wrote that he or she does not want resuscitation, but it will help because he or she is not terminal, and this can limit us. The document, it should stay in the background. (MED2)

Advance directives of will require patient autonomy and proper communication

Advance directives of will are based on respect for patients' autonomy and family caregivers, requiring proper communication among health professionals, patients and families. Another difficulty identified by family caregivers was that doctors may conceal the terminal diagnosis from patients. The concern is that this may be harmful and not beneficial, and could prevent the adherence to AWD implementation.

She does not know about her condition and we think that talking about it may worsen the situation. She has high hopes of healing and getting her life back, she has to live without knowing it, because if she happens to find out, her hope will disappear, she will lose faith, courage, she will lose everything. (FAM5)

Still, for nurses and doctors, limited understanding by patients and their families is another limiting factor for ADW. Possible limitations due to education or cultural beliefs or differences, among others, make it necessary to allocate additional time for detailed explanation of ADW. Of particular concern is the risk of distortions due to insufficient or inadequate understanding when the possibility of ADW is mentioned.

The people are very ignorant, the family is not aware of what is happening, and they distort much of what we say. (NUR2)

It is complicated to explain and understand, you come from a poor family and you are confused about the term euthanasia; it's a matter of education, culture and beliefs. (MED2)

Health professionals' fear of inadequate communication about ADW and their implementation, and the resultant failure to respect the possibility of exercising patient autonomy, appears to lead to investment in treatments that cause therapeutic obstinacy and impose suffering on patients and their families.

When the family disagrees with the patient's decisions on an ADW, it is complicated if the patient cannot speak; the professional will end up doing everything. (NUR7)

I see professionals protecting themselves for not adequately understanding the care situation and I believe this leads to therapeutic obstinacy. (MED4)

For nurses and doctors, ADW implementation in hospitals requires that professionals be available more, due to the demand for healthcare services and staff turnover, rather than full investment in patients.

It will be difficult for the staff to understand ADW, there will be resistance and it will be difficult because there is no time to examine patients completely, the demand is too high. (MED6)

It is less work for you to intubate the patient than to explain why it is inappropriate, in that context, to follow the procedure. Depending on the support you have, it is difficult to choose one or another procedure in an emergency, and it is difficult to check your own behavior. (MED4)

If you do not intubate, that patient will require more work. If you intubate, he or she stays there and you solve your problem. If you do not, the patient will be in greater respiratory distress and the professional will have to find ways of providing more comfort. You end up working harder, and some people are not ready and others just do not want it. (NUR7)

Meanwhile, there is an urgent need to prioritize time to talk about ADW and focus on ways to facilitate understanding by patients and family members, clarifying doubts and uncertainties regarding treatment indications and limitations, and contributing to ADW applicability.

I believe lack of understanding comes from lack of explanation capability and not lack of a person's ability to understand. There's no way the person does not understand, you have to know how to explain and I think the professionals end up underestimating the family and patient's capacity to understanding. Communicating requires work, and you have to make an effort. (MED4)

DISCUSSION

Facing death as a situation of medical failure has led to the practice of therapeutic obstinacy. It is necessary to invert this paradigm, regarding death as a natural process during which

a human being needs support. The present study found evidence of the intention of prolonging the lives of terminally ill patients from the perspective of nurses, doctors and family caregivers, reflecting limitations in ADW application. From this point of view, this research confirms the argument that the culture of medicalization of life forces us to continue to postpone its final moment⁽¹⁵⁾.

With that in mind, and emphasizing the research findings, doctors seem to be more afraid of investing too little rather than doing too much for patients, and patients seem to feel the same way and are likely to be grateful that additional tests and exams are carried out. Still, doctors are in position of power in relation to patients and family caregivers, who tend to follow their recommendations⁽³⁾. Given the ethical dilemmas present in the treatment of terminally ill patients, there is a pressing need to reflect on the limits in the life prolongation, who is responsible for this decision, and the option of advance directives of will⁽¹⁾.

Studies have shown that, in practice, it is difficult to define the criteria for the determination of futility. There is often disagreement in the medical community, and there may be conflicts because of family beliefs in miracles and the insistence of religious traditions that everything possible be done⁽¹³⁾. Nevertheless, patients often want family, friends and doctors to be honest among themselves in all aspects; i.e., they want the truth, and effective discussion of the disease process and treatment options⁽¹⁶⁾.

In addition, medical paternalism sometimes sets a limit on autonomous choices by interference or refusal to accept a person's preferences concerning what is good for them. This usually involves coercion, on the one hand; or lies, manipulation or concealment of information, on the other, to prevent harm to patients or benefit them. Therefore, disclosing certain types of information and telling the truth could harm patients under their care; however, medical ethics requires them not to cause this damage. So, for the good of the patient, some information should be omitted or disclosed only to the family, because it may compromise clinical judgment and be a threat to the patient's health⁽¹³⁾. Thus, the present study identified the issue of diagnosis concealment as a common practice among those involved, considering that the truth will not benefit patients because of their disease conditions. However, in these situations, sincerity would help patients to express not only their will, but also their doubts, fears and desires, helping family caregivers and health professionals.

Communication difficulties seem to limit ADW application from the perspective of respondents. In addition to limited time, overwork and high turnover, professionals seem to be afraid to talk about issues related to death, to address ADW, and consequently bring to the fore the possibility of terminal illness. Therefore, there is need to pay attention to the way information is presented, which can manipulate patients' perceptions and reactions, providing an unsatisfactory basis for making decisions⁽¹³⁾.

When patients do not have ADW, substitute decision-makers often make inaccurate forecasts of the patients' desires or make decisions that are not condoned by doctors, because they are not in accordance with patients' best interests⁽¹⁷⁾. Still, decisions to be made about life situations show that, despite the previous planning of desired treatment, chronically ill patients often change

their minds about their medical treatment over time and the evolution of their health. This instability adds to the challenge of respecting the patient's autonomy for substitute relatives⁽¹⁷⁾.

A survey was conducted in the Netherlands of patients in good, moderate and poor health who had all previously completed ADW. The results showed that their perceptions about dignity and their desires remained stable over the course of their disease, suggesting that the understanding of dignity did not change substantially with changes in health status⁽¹⁸⁾.

The above indicates that, in the ADW context, peoples' beliefs, choices and consent may change over time, which may lead to moral and interpretive problems. It would be inconsistent to impose will on other action determined by an advanced directive. Thus, it is necessary to consider judgment about patients' capabilities, distinguishing autonomous decisions that must be respected from those that need to be checked and perhaps supplanted by substitute relatives⁽¹³⁾.

In decisions involving families and terminally ill patients, it has been maintained that the decisions made by substitute relatives must be based on prior knowledge of patients' desires or on patients' best interests⁽¹⁷⁾. Making decisions considering what is best for patients when they cannot communicate their wishes is a daily and difficult occurrence for physicians. The importance of making informed and shared decisions by the health professionals who assists patients is essential for quality care and outcomes. Patient participation in treatment leads to better outcomes, which meets the traditional belief that the maintenance of health depends on care based on good and comfortable relationships between doctors and the patients⁽¹²⁾.

Few people write a document or leave explicit instructions; in addition, designated persons in charge may not be available when needed or may be unable to make good decisions for patients, or may still have conflicts of interest, for example, from the perspective of receiving an inheritance or being promoted in a family business. Still, patients can modify their preferences about treatments without modifying in time their instructions, and some, when they become legally disabled, protest against designated relatives' decisions⁽¹³⁾.

A study conducted in the United States with 30 substitute decision makers showed that family members actively involved in supporting treatment decisions for terminally ill patients experienced significant emotional conflict between the desire to act according to the values of their loved ones, the wish not to feel responsible for their loved ones' death, the desire to pursue any chance of recovery, and the need to preserve family welfare. Also, the study found that substitute relatives often did not know patients' preferences⁽¹⁹⁾.

Some of the coping strategies of family caregivers were: to recall previous discussions on the likely desires when facing terminality; to delay or postpone making the decision; and consult spiritual and religious practices, i.e., the hope of recovery according to religious beliefs⁽¹⁹⁾. Physicians and health professionals need to identify strategies to improve decision-making, including compliance with family members' emotions, facilitating their decision-making, and paying attention to their emotional and spiritual needs and potential conflicts⁽¹⁹⁾.

Legal guardians can make decisions with which doctors radically disagree and, in some cases, ask doctors to act against their conscience. Some patients do not have adequate understanding of the decisions that health professionals or guardians may have to make, and even with proper understanding, it is often difficult to predict clinical situations and possible future experiments⁽¹³⁾.

A study focusing on decision-making by substitute relatives found that, in addition to strongly depending on patients' desires and best interests, the substitute relatives considered other factors such as their own desires, interests, emotions, religious beliefs and past experiences with health care. Decision-making by substitute relatives is more complex than patients' decision about themselves; substitute relatives need to obtain more information about patients' preferences for care planning⁽¹⁷⁾.

Family consensus in decision-making is important because it distributes the responsibility for decisions among several individuals, resulting in a decrease in the guilt felt by relatives and helping to maintain family cohesion through suffering. It also makes substitute relatives feel more comfortable in their roles and to feel that they are able to align with patients' wishes when making decision⁽¹⁷⁾. When patients' preferences are not known, the responsible people may use their own desires as a decision-making guide, but may also consider their own beliefs and interests⁽¹⁷⁾.

The emotional needs of family caregivers, especially, the possibility of avoiding guilt, influence their decisions. Substitute relatives direct their decisions regarding patients toward every possible chance of recovery, in an effort to avoid feelings of guilt for not trying everything possible and to meet their obligations toward patients. This highlights the need for ADW so that decisions to refuse life-sustaining therapy do not mean that substitute relatives have given up or that they are personally responsible for negative results or patients' death⁽¹⁷⁾.

Regarding concerns about legal liability due to the absence of specific legislation in Brazil, ADW must be constantly discussed to suggest that patients express what they really want on the alleged failure conditions. Besides ethical conflicts that may weaken effects of the Resolution, professionals may face conflicts of opinion that increase their uncertainty about decision-making. At such times, physicians who face possible threats and risks of suffering lawsuits may ignore patients' ADW, preferring to follow family guidance⁽¹⁵⁾. Distribution of patients prior preference can be an important element of this argument⁽²⁰⁾.

However, it is not easy to face this problem. While ethical debate continues within the medical community, especially in the Federal Council of Medicine, the issue of the legal limits of professional resolutions seems to create among doctors concerns about the legality of the Resolution and the inherent risks and possible legal questions concerning non-intervention⁽¹⁵⁾. As a result, a recent survey in Brazil revealed that legal implications are what most interfere in medical actions when facing end-of-life issues, resulting in failure to perform what they believe to be the best for their patients⁽²¹⁾.

Thus, difficulties regarding ADW can be circumvented by carefully worded documents, along with appropriate counseling and specialized explanations of medical possibilities and treatment options. However, some interpretation problems

will remain in spite of the increased involvement of health professionals, especially doctors and nurses, and the educational tools used. Certainly, ADW are a promising way for people to be able to exercise their autonomy. The problems are mainly practical, and some can be overcome by the use of appropriate implementation methods⁽¹³⁾.

Interpretation of the results of the present study should take into consideration several limitations. This study was performed in only two units of a hospital in the central region of Rio Grande do Sul; experiences of nurses, doctors and family caregivers may be different in that area from other places and hospitals. However, these results provide depth to the understanding that ADW are an alternative for providing autonomy to patients by fulfilling their wishes, despite the barriers that hinder ADW effectiveness in hospitals. In addition, the guidelines for ADW use can contribute to improved performance by health professionals, especially doctors and nurses, in the actions endorsed, reducing ethical conflicts related to treatment limitations, when conducted in order to comply with expressed desires of patients, giving medical professionals peace of mind in their professional practice.

FINAL CONSIDERATIONS

Issues related to the end of life justify and require reflection and discussion on the part of health professionals and society. The main purpose of the introduction of ADW is respect for the dignity and autonomy of human beings, not only in life but also at the time of death, and recognition the need to value the needs and suffering of each person and their end-of-life issues.

The limitations and difficulties attributed to the practice of ADW in hospitals, from the perspective of nurses, doctors and family caregivers of terminally ill patients, indicate and reinforce the need to work on this issue to correct erroneous knowledge. Also, they indicate and reinforce the need to effectively and voluntarily carry out a policy, free from outside interference of patients, that reflects their desire for respect for their autonomy in disability and end-of-life situations.

The possibility of inserting ADW into the patient care context, considering the numerous conflicts and dilemmas related to end-of-life issues, may change the way death is perceived and contribute to the removal of stubborn healing practices when healing is no longer possible. Also, ADW may be seen as an alternative for fostering compliance with the wishes expressed by individuals when they are capable. However, inside the Brazilian reality, sometimes, the experience of impending death has not enabled respect for patients' desires, prolonging medical paternalism.

It is worth highlighting that a new look is needed at death and its relationship to life. Patients being examined by excellent health professionals is not enough. The professionals must meet the patients' expectations, as the ones most interested in this process. Clearly, when patients are found to be incapacitated, it is important to give voices to family members, who often act as caregivers and are recognized as responsible relatives. This segment of the population must be assisted,

because they sometimes feel neglected and that they have the grave responsibility of deciding, literally, on life and death.

When professionals, family members and patients are included in issues related to terminal illness, the time is taken to ensure patients' dignity and compliance with the desires they have previously expressed. In addition, families in stressful situations feel reassured. For health professionals, it raises the possibility that the actions involving end-of-life care are not stressful to the point of continuing obstinate behavior as a way to avoid heartfelt conversations.

It is essential that the difficulties and limitations in AWD application mentioned by nurses, medical residents and family caregivers of terminally ill patients be shared and understood. Then efforts could be directed toward remedying them and decreasing their occurrence, in order to respect the autonomy of patients and provide good-quality end-of-life care. In the light of these considerations, further Brazilian studies are needed that encourage this practice, in order to effectively comply with patients' desires and respect their autonomy, which are at the heart of advance directives of will.

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