Terminal patient care: advantages on the applicability of anticipated will directives in the hospital context

Objective: To know the advantages related to the applicability of the advance directives of will in the hospital context from the perspective of nurses, doctors and family members.

Method: Qualitative, descriptive and exploratory study with semi-structured interviews carried out from October to November 2014, with nurses, doctors, and family members of patients in the final stage. Afterwards, a discursive textual analysis was carried out.

Results: Four categories emerged: respect for patient’s autonomy; support in confrontation of conflicts with and from family members; reduction of conflicts in the team about treatments and conducts; disclosure and instrumentation for application of the Advance Directives of Will.

Conclusion: The respect for personal autonomy permeates the advantages when relating the conduct of treatments at the end of life with the Advance Directives of Will. Thus, disagreements involving the processes at the end of life would be supported by the patient’s desire, besides implying in the reduction of the fear of professionals in facing lawsuits and in the support of the family.

Keywords: Advance directives. Terminally ill. Ethics in nursing. Personal autonomy.
INTRODUCTION

The possibility of prolonging human life artificially, due to scientific and technological advances, sometimes imposing on people the processes of slow and painful death, requires reflection on the limitation of clinical interventions in order to respect the fulfillment of the will of the patient in terminal phase\(^1\). In view of this, the guarantee and advance of the respect for personal autonomy, as well as the opposition to therapeutic obstinacy, depriving people of a dignified death, by living in a society that still denies death\(^2\), have propelled the emergence of the Advance Directives of Will (ADW), also known in Brazil as a living will.

The ADW arose from the need to humanize the end of life\(^3\) and they deal with the patients' right to exercise their autonomy, exposing their wishes as to the treatments they would like to undergo, if they are unable to manifest their will, by being unconscious or in a terminal state\(^4\), allowing them to prepare for the inability to decide before death\(^5\). The right to choose about the refusal or not of treatments was proposed in the United States in 1969 by Luis Kutner, who coined the term “living will”\(^6\). In the 1990s, the ADW, known as Advance Directives of Will, were envisaged by the Patient Self-Determination Act, a US law approved by the Congress, constituting the first legislation in the world to address the directives\(^5\).

There are essentially two types of ADW: The first, in which the patient specifies the medical treatments that should or should not be given to him/her in certain situations, also called the living will; and the second, Durable Power of Attorney, consisting of the patient’s authorization of a legal representative to decide, on his or her behalf, when incapacitated\(^6\). In countries such as the USA, Spain, England and Mexico, where the ADW practices are supported by the legislation, although they still cause application difficulties, they are well accepted by the population, patients, family members, legal representatives and health professionals\(^6\), promoting the improvement of the physician-patient relationship and the self-esteem of this patient\(^7\).

In Brazil, differently, there is no case law. However, the Resolution of the Federal Council of Medicine (FCM) No. 1,995/12 provides for the ADW, understanding them as the set of wishes, previously and expressly expressed by the patient, about the care and treatment he or she wants, or not, to receive at the moment when he or she is incapable of freely and autonomously expressing his/her will\(^5\). Still, when a patient’s legal representative is appointed, his/her information must be considered and the ADW of the patient will prevail over the non-medical opinion, including the desires of the family members\(^8\).

The central and guiding point of the Resolution is the autonomy of the patient, subject of his/her history and life project\(^9\), based on the respect for people and loyalty\(^10\). Faced with such considerations is that the practice of the ADW has enabled patients to meet their wishes at the end of life and that those responsible for decisions that involve treatment limitations can guarantee the patient’s wishes, reducing possible conflicts arising from the indecisions of how to act in a given situation\(^11\).

On the international scenario, surveys indicated that family members and legal representatives played an indispensable role in making decisions that involved the end of life\(^9\). In a survey conducted in South Korea, 92.9% of 1289 family members approved the need for the ADW implementation\(^9\). However, the end-of-life decisions involving family members are often motivated by the perception of lack of dignity due to progressive deterioration, poorly controlled pain, chronic patient neglect, therapeutic cruelty, and unnecessary use of measures that postpone death\(^12\).

The manifestations of autonomous decisions, which precede periods of incapacity, must be considered valid and binding after the person becomes incapable\(^5\). Thus, to the extent that one of the main motivations of patients to complete the ADW is related to the preservation of their autonomy\(^13\), this research is based on the principalist theory\(^5\), mainly in the concept of autonomy, referring to the right of self-government, privacy, individual choice, freedom of the will, to be the engine of one’s own behavior\(^13\).

Regarding the facts previously mentioned, it is considered that the ADW’s benefits are not exclusive to the patient, but they offer important support to family members and health professionals, who will have greater security to act, supported by the expressed will of the patient, besides the prolonged resolution of ethical and moral problems, before which health professionals are submitted when patients lose their autonomous capacity\(^15\).

The obligations to grant benefits, to prevent and repair damages and to weigh the possible benefits in terms of costs and damages caused by an action are central to biomedical ethics. However, many rules of compulsory charity constitute an important part of morality, which include: protect and defend the rights of others; prevent others from being harmed; eliminate conditions that will cause harm to others; help unfit people; and to rescue people in distress\(^15\). Thus, due to a growing tendency towards the respect for the person, resulting from the formation of concepts related to Bioethics, the ADW are an alternative to provide patients and families with ethical bases to avoid contradictions of conduct in the relationship between...
doctor-patient-relatives in extreme situations such as the end of life.

With the purpose of sensitizing health professionals, contributing to the reflection of studies on ADW, and the incipience of empirical research, especially the ones that indicate, under the eyes of health professionals and family; the advantages of its applicability to the practice of care, it has been outlined as a research question: what are the advantages of applying the Advance Directives of Will (ADW) for nurses, doctors and relatives of the terminally ill patients? Thus, the objective was to know the advantages related to the applicability of the ADW in the hospital context, from the perspective of nurses, physicians and relatives of the terminally ill patient.

**METHOD**

This is a descriptive and exploratory qualitative study, carried out in a public university hospital, located in the geographic center of the state of Rio Grande do Sul, with subjects selected by intentional sample.

The following inclusion criteria has been used: to be nurses and resident physicians working in the medical practice and in the home care service, for a minimum period of six months; and family members, over 18 years old, designated as responsible for the terminal patient of the hospitalization service.

Participated in the research: two nurses and one doctor from the home care service; six nurses and six resident physicians of the medical clinic unit; and seven family members, comprising a sample of 22 participants, defined by the data saturation, obtained when the introduction of new results in the analysis products no longer produces changes in the previously achieved results.

Semi-structured interviews were carried out with an average duration of 50 minutes, which were digitally recorded, from October to December of 2014. The data has been collected at the hospital, with health professionals; and at home, with the family, after at least two previous visits to an approximation with the care environment, also allowing the interviewee to meet the researcher.

Closed questions were formulated for the characterization of the participants and open questions addressing the autonomy of the patient and the ADW, focusing on their applicability in the hospital context. Due to the possibility of not knowing the term ADW, the researcher made available the CFM concept, previously expressed.

The data has been submitted to the discursive textual analysis. The unitarization, which is the first stage of the analysis, required a detailed examination of the interview transcripts, fragmenting them to reach the constituent units of the phenomenon, deconstructing the information. In the second stage of categorization, the units of meaning were grouped and progressively organized and named with greater precision, giving rise to the final categories. Finally, the capture of the new emergent occurred through the intense impregnation of the analyzed materials, allowing the emergence of a renewed understanding about the applicability of the ADW, from the production of meta-texts, coming from the answers of the study participants.

The process of discursive textual analysis of the lines allowed the construction of the emergent categories: respect for the patient’s autonomy, support in coping with conflicts with family members, reduction of team conflicts in decisions about the treatment and behaviors, and the dissemination and instrumentation for the application of the ADW.

The approval was obtained from the Research Ethics Committee in the Health Area of the Universidade Federal de Rio Grande, 168/2014. All the participants have signed the Free and Informed Consent Form and, in order to guarantee the anonymity of the participants, codes have been used to identify them: nurses (ENF), physicians (MED) and family members (FAM), followed by numerical figures. It is important to emphasize that the ethical commitments have been respected regarding: the balance between risks and benefits; the provision of procedures that ensure the confidentiality, the privacy and protection of the participant; the respect for cultural, social, moral, religious and ethical values; the respect for the habits and customs of the participants; the guarantee of the return of the data and benefits obtained with the research for the people involved.

**RESULTS**

Among the eight nurses interviewed, seven were female and one male, ranging in age from 33 to 60 years old, with an average age of 44 years old. They presented an average time of 18 years of graduation in nursing. Their professional time in the institution ranged from 1 to 14 years, with an average of seven years.

Of the seven physicians interviewed, three were female and four were male. They were characterized by ages between 25 and 42 years old, with an average of 29 years old; with professional time in the institution from 1 to 9 years. Of the physicians interviewed, six worked in the residency in internal medicine and one of the professionals in the home care service.

The family members interviewed had an average of 50 years old; and the period as caregivers of the terminally ill
patient, ranged from 2 to 3 years. The kinship of the relatives was three husbands and two wives, plus a daughter and a niece. It should be emphasized that the family members did not have an employment relationship, exercising their full-time patient care activities, except for one of the spouses who, from time to time, performed professionally.

**Respect for the patient’s autonomy**

The respect for autonomy, guiding all the actions related to the ADW, was the main advantage of its applicability, especially in the context of the termination of the disease, for nurses, doctors and family members. The ADW seem to be the guarantor for compliance with the patient’s wishes.

> For patients who are unconscious or unable to express their will, the decision is left to family members and staff. With the ADW, we will do the will of the patient who was conscious when he/she had decided. (ENF.5)

> The ADW make explicit the autonomy of the patient, because at some point it is lost and thus it will be respected until the end of life, in fact, the will of the patient. (MED.3)

> If he had left, I think I would do what he said, because we always respected each other’s wishes, we used to get along. (FAM.3)

**Support in coping with conflicts with/from family members**

From the perspective of resident nurses and physicians, the ADW would minimize discomforts and professional conflicts arising from family disagreements in decisions about treatment behavior in end-of-life situations.

> When the family does not have a harmonious relationship, they appear with such remorse and they want to do everything. So it is good for the patient to decide on themselves. (ENF.5)

> It would assist us when the patient is unconscious and the relatives are giving opinions contrary to the opinion of the patient, and it would help us in the case if it is a terminal patient. (MED.2)

Nurses and physicians stated that they would choose to restrict treatments for the recognition of incurability, and the ADW would assist the team, especially not to deceive patients and others involved in a supposed intervention.

> The professionals would be calmer and safer in relation to the conduits, because it is distressing. [...] You will reanimate just because the family is there, and the familiar does not understand and you end up doing it. (ENF.7)

> You are not going to be afraid, of course, that it is not only the patient asking, but you are in agreement with the situation, and you will not have to pretend, for example, that you have revived him/her. (MED.5)

> Furthermore, the ADW would reduce problems related to the fears of nurses and physicians regarding the legal implications for actions that, if not performed, could lead to punishments, such as failure to perform intubation or cardiorespiratory resuscitation (CPR).

> The risks of lawsuits against nursing would be reduced, because often, due to deficiencies in records and communication, we became legally fragile. (ENF.2)

> The ADW would give us support, they would avoid headaches, and help with medical procedures, giving us legal ground. We would be respecting the patient’s will. (MED.2)

> I find it a practical and objective question for the family, it is a rest, that the family relieves themselves of having to make a painful and difficult decision. (ENF.6)

> It is important to have a relative who has this document and who will defend their will, it is a support for this family member. [...] If it is verbally placed, it may not be respected, but if there is a document, he/she becomes responsible and it is possible that the will is actually going to be respected. (MED.4)

> I do not know what to do, I did not talk to her about what she would like in such a situation. If she had spoken or written, I would have calmed down, because it is too painful to decide whether someone lives or dies. (FAM.3)

> Still, with the support of family members, the professionals mention that the consent of the family member favors the assistance of the professionals in favor of the patient.
I feel calmer to talk about treatment restrictions when the familiar understands and abides by the decisions, because he/she knows what is happening and the chance of impending death. I think the service flows in a more natural and sincere way. (MED.7)

Reducing team conflicts in treatment and behavior decisions

The ADW would also help reduce the conflicts of health professionals related to indecisions regarding different treatments and behaviors, often associated to the high turnover of professionals.

I would feel supported by the ADW [...] we work with large teams and this would help lessen the professional conflict and therefore help the institution. (ENF.8)

When one decides for the end of life and the other decides to invest, we must group a decision. [...] while someone is willing to invest, I do not take it as a posture to give up the patient. (MED.2)

The ADW are seen by professionals as a strategy to provide patients with peace of mind, under the point of guaranteeing personal autonomy, considering that their wishes will be fulfilled, freeing professionals from acting stubbornly in the prolongation of their lives, when they are admittedly terminal. In this sense, the conflicts and dilemmas that health professionals can experience when they care for the terminally ill patients, originated from the decisions that involve the limitations of therapeutic effort, demand situations that are difficult to solve easily.

The directives would benefit the patients and it would be tranquility at that time that generates a lot of stress. They would not spend the last moments of life in the emergency doing futile procedures. (ENF.7)

It would certainly improve a lot, reducing dysthanasia. (MED.5)

For nursing, the professional support instilled in the practice of the ADW constitutes the possibility of greater tranquility and it may guarantee that its possible behaviors related to limitations of treatments will not be questioned, especially in the face of inadequate communication of medical decisions to nursing, which hampers their decision making, especially in emergency care.

The ADW would facilitate the decision-making, because sometimes we run after the doctor to know what it was or not to do and we are reviving and maybe this was not the will of the patient. (ENF.1)

It is something to back up and reassure the staff to feel safer when treating the patient. (ENF.3)

The ADW would facilitate our team functioning. (MED.5)

Disclosure and instrumentation for the application of the ADW

The advantages mentioned by nurses and resident physicians demonstrate that the applicability of the ADW is important and consistent with patient care; however, it requires prior instrumentalization to support its introduction into the hospital environment.

It demands instrumentalization and training on what it really means. (ENF.4)

We need to learn how to use and make the document; it could be implemented, from a training with professionals. Not today, because many universities do not have the proper preparation. (MED.2)

Although the participants of this research, almost all of them, had no previous knowledge about the ADW, it was possible to perceive their interest in adhering to the practice in the hospital context, obviously with the need for training in order to make them capable.

The ADW are on the way to increasing the possibility of working on these issues. I do not see that they are always necessary, but the existence of a legislation will increase the discussion forum. It’s a long walk but it has to be tackled. (MED.4)

Thus, health professionals should provide information to the families about the ADW, in order to dialogue and contribute to all those involved in the termination of life process.

We need more clarification on how it can be done and I believe that the professionals can help us, because we need specific clarifications regarding the area that we do not dominate. (FAM.7)

For the family members, this research alerted to the need of talking with patients about their desires so that,
even if they did not perform their ADW, they could express their wishes and, if possible, have them respected.

*I have never thought of talking about any subject related to death with her; maybe if I had talked about death with her, I might be thinking and living this time in another way. (FAM.1)*

You warned me to suddenly, in a conversation, ask her about what she thinks. It’s something that you never think to ask and that is super important. (FAM.5)

### DISCUSSION

The introduction of THE ADW in the hospital context for nurses, physicians and family members interviewed made it possible to face terminal situations, supported by the respect for the patients’ expressed wishes. Thus, the ADW establish themselves as the exercise of the right to freedom, since it is a space for making personal decisions, immune to external interference, be they doctors, family or any person and/or institution that wants to impose their own will(4).

The rights of autonomy have become so influential that it is difficult to find clear defenses of the traditional models of beneficence, that is, if the content of the health professional’s obligation to be beneficent is defined by the preferences of the patient, then instead of beneficence triumphs the respect to his/her autonomy. Beneficence provides the primary goal and foundation of medicine and healthcare, while it respects the autonomy and establishes the moral limits of the actions of professionals in pursuing this goal(5).

Thus, the data presented have indicated that the application of the ADW could provide peace of mind and ensure respect for the patients’ autonomy, exempting health professionals and family members from the responsibility of decisions at the end of life. It is a possibility to avoid or even reduce ethical and bioethical problems among health professionals, patients and families, from the biotech conquests that provoke discussions about the processes of dying and end-of-life decisions. There are those who favor unfavorable practices, justifying them with the application of the right to freedom of self-determination, and on the other hand, there are those who argue against it, maintaining their position by the principle that the right to life as unavailable, in extreme situations such as the end of life(17).

In the international panorama, studies with physicians(6-8), nurses(18) and university health professionals(6,9) showed acceptability and effectiveness in the application of the ADW in the care of terminally ill patients. In South Korea, a survey of 303 oncologists found that 96.7% agreed on the need to complete the ADW(6). Another study carried out in hospitals in Murcia, Spain, with 607 physicians, nurses and undergraduate students, showed that 63.3% of the subjects emphasized the importance of patient preferences regarding treatment and life support procedures in terminal situations(6).

Research results with 30 family members in the United States have shown that there seems to be an effort to reconcile individual and family emotional needs with their beloved ones, which has made the negative experience of family members responsible for patients lead to increased requests to improve the support for families by professionals(14). In Brazil, relatives of the terminally ill patients consider that the decisions were made first by the doctors or by the doctors together with the patients; that is, excluding their participation(18).

Likewise, based on data from this research, the professionals highlight the ADW as the possibility of exempting relatives from their responsibility, as well as minimizing conflicts between health professionals and family members in decision-making processes that involve the end of life. Thus, the ADW, in addition to protecting autonomy interests, may reduce the stress of families and health professionals who fear making a wrong decision(10), avoiding difficulties of the health team in the conflict between the family and the patient’s wishes(20).

Providing the individual with the possibility of making clear in the ADW what values and desires should guide decision making is important in order to avoid/help resolve those conflicts(20). In addition, they indicate a way of opposing dysthanasia, guaranteeing the dignity of the patient, treating him/her as a person and not as an instrument of useless therapy and causing more pain and suffering(10). The absence of directives can lead to aggressive and unwanted care, which has been associated with reduced quality of life and care(20).

The ADW would provide support to physicians, since in practice, actions must be carried out, and it requires them to register certain actions restricting treatment to the terminal patient, in the medical record, with the consent and signature of the family members. Thus, it would be a way of supporting them and would serve as a skillful means to protect them from possible responsibility when making or not making use of the treatments and care dispensed by the previous choice of the patient(20).

In addition, the nurses would also be supported, because, inserted in the discussions and connoisseurs of the
ADW, they would act in order to inform, respect, accompany and care for the patient, not being able to avoid the process of planning, designing and complying with the ADW\(^\text{(1)}\). The relevance of nursing in relation to ADW issues is due to the decision not to do a certain procedure, not to provide care or intervention. Another issue concerns the necessary articulation with other health professionals, namely, with physicians. Sometimes there is a conflict over the care decision; however, end-of-life decisions must constitute a team decision. However, even if the decision is not built as a team, its implementation necessarily requires the intervention of the doctor and the nurse, and it may happen that one decides in one direction and the other in the opposite direction\(^\text{(18)}\).

For the effectiveness of the implementation of the ADW, this research evidenced the need for the interaction of a multiprofessional team, especially among the nurses and physicians who worked directly with the patients, and with their relatives. Some studies have shown that the practice of early directives happens effectively when there is adequate communication between health professionals, family members and the patient\(^\text{(19)}\).

Therefore, the ADW must be inserted in the relationship between professionals and the patient as a means for the patient’s autonomy, his/her desires for treatment and care, before a possible state of incapacity can be exercised, ensuring his/her dignity and self-determination\(^\text{(2)}\). Thus, the ADW propose a challenge to recognize the autonomy of patients in the decision-making processes of treatments that directly affect the relationships between physician and patient, physician and patient’s family and physician and the care team\(^\text{(19)}\). The ADW helps health professionals understand patients’ values and desires, acting as vehicles for in-depth and ongoing discussions among health professionals, patients and family members\(^\text{(16)}\), and it can assist the medical staff when the family stands against the will that has been manifested by the patient\(^\text{(20)}\).

According to the principle of beneficence, morality requires that, in addition to respecting the autonomy of the patient, it contributes to providing him/her with well-being; potentially, it requires more than the principle of non-maleficence, as it requires the implementation of positive attitudes to help others, not merely refraining from performing harmful acts\(^\text{(3)}\).

Thus, the ADW are not an easy task to implement, as they raise bioethical doubts. In this research, the interviewees focused on the need for training in order to obtain instrumentation and, in the future, the practical applicability of the ADW. In this sense, a campaign to raise the awareness of Brazilian citizens about the importance of respecting the will of their families, in order to avoid conflict between their expressed will in the ADW and the will of the family\(^\text{(20)}\), is the main challenge to help the application of the ADW.

Finally, the use of the ADW in Brazil can be effectively respected if there is a collective effort to guarantee the right of the individual to express his/her will, in addition to the wishes previously expressed, so they can be effectively fulfilled\(^\text{(20)}\).

**CONCLUSION**

It is evident that the recognition of the possibility of respect for the personal autonomy of the terminally ill patient permeated the advantages of nurses, resident physicians and family members when dealing with end-of-life treatments. However, it is necessary to emphasize that the ADW, because they are an issue with multifaceted characteristics, and because Brazil is still incipient in its application, require research regarding its effectiveness in the practical context and studies are necessary in this direction, since its use has been increasing.

The recognition of the feasibility of the ADW was highlighted by health professionals, in order to intermediate the patient, family and professional support. In this process, it is important to recognize that the benefits conferred can contribute to the quality of care provided in end-of-life situations and these are actually used in the service of personal autonomy in the process of death.

The desire to respect the wishes of the terminally ill patient guarantees, besides tranquility to the patient, by virtue of the fulfillment of their desires, the reduction of ethical and moral conflicts between professionals, family and patient, the support of the actions of the health professionals and the support to family members who are not responsible for interfering with treatment decisions that do not correspond to the patients’ wishes.

It should be highlighted that, with the implementation of the ADW in the hospital context, disagreements involving the end-of-life processes would be supported by the patient’s desire, as well as reducing the fears of the professionals in suffering legal suits. The relationship and interaction of health professionals, family members and patients would be established in a more relaxed way.

Although the acceptance of the ADW in the hospital context has been verified, this study has as limitation the restriction of analysis to the nurses and medical residents of a hospital institution, as well as the patient’s relatives. Thus, it is suggested to expand studies to other health pro-
professionals, family members, as well as patients, in order to know the perceptions of different publics, aiming at the applicability of the ADW.

The theme is relevant because it addresses the issue of care for the terminally ill patient, with the prospect of scientific developments to improve knowledge for the implementation and applicability of the ADW in the context of assistance to the population.

REFERENCES


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