DOI 10.18471/rbe.v31i1.16932

ADVANCE DIRECTIVES: WILLS OF HEALTH PROFESSIONALS AND FAMILY CAREGIVERS

DIRETIVAS ANTECIPADAS: DESEJOS DOS PROFISSIONAIS DA SAÚDE E CUIDADORES FAMILIARES

DIRECTIVAS ANTICIPADAS: DESEOS DE LOS PROFESIONALES DE SALUD Y CUIDADORES FAMILIARES

Silvana Bastos Cogo[1]
Valéria Lerch Lunardi[2]
Alberto Manuel Quintana[3]
Nara Marilene Oliveira Girardon-Perlini[4]
Rosemary Silva da Silveira[5]

Objetivo: conhecer o entendimento de enfermeiros, médicos e cuidadores familiares, quando remetidos à possibilidade de se tornarem doentes em fase final, sobre a aplicabilidade das diretivas antecipadas de vontade. Método: estudo qualitativo com enfermeiros, médicos e familiares de doentes em fase final de vida. A coleta dos dados ocorreu entre outubro e dezembro de 2014 mediante a entrevista semiestruturada. Foi realizada a análise textual discursiva dos dados. Resultados: enfocaram a aplicabilidade das Diretivas antecipadas de vontade e desejos de profissionais e familiares na manutenção da dignidade e autonomia pessoal; e a insegurança da aplicabilidade das diretivas. Conclusão: apesar de aceitarem e desejarem a realização das diretivas antecipadas, os participantes expressaram temores referentes à sua aplicabilidade, de que suas vontades não fossem respeitadas, ou que pudessem modificar-se ao se defrontarem com a situação de fase final, do seu abandono pelos profissionais e da sua insegurança quanto aos diagnósticos e prognósticos.

Descritores: Doente Terminal; Diretivas Antecipadas; Profissionais de Saúde; Autonomia Pessoal; Cuidadores.

Objective: learn the understanding of nurses, physicians and family caregivers, considering the possibility of becoming terminally ill, on the applicability of advance directives or living wills. Method: a qualitative study was developed with nurses, physicians and family caregivers of patients in the end stage of life. Data were collected between October and December 2014, by means of semi-structured interviews, and submitted to discourse textual analysis. Results: findings focused on the applicability of advance directives and living wills of professionals and families in maintaining the dignity and personal autonomy of patients; and on the insecurity toward applying directives. Conclusion: despite accepting and wishing the application of advance directives, the participants expressed concerns regarding their applicability, fear that their wills would not be respected, or that these could change when in face of the final stage of life, abandonment by professionals and insecurity as regards diagnoses and prognoses.

---

[1] PhD in Nursing. Assistant Professor of the Nursing Course, Federal University of Santa Maria. Santa Maria, Rio Grande do Sul, Brazil. silvanabastoscogo@gmail.com

[2] PhD in Nursing. Professor of the Graduate Program in Nursing, Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. vlunardi@terra.com.br

[3] Post-doctorate in Bioethics. Full Professor of the Graduate Program in Psychology, Federal University of Santa Maria. Professor of the Graduate Program in Nursing, Federal University of Santa Maria. Santa Maria, Rio Grande do Sul, Brazil. albertom.quintana@gmail.com

[4] PhD in Nursing. Assistant Professor of the Nursing Course and Graduate Program in Nursing, Federal University of Santa Maria. Santa Maria, Rio Grande do Sul, Brazil. nara.girardon@gmail.com

[5] PhD in Nursing. Professor of the Nursing Course and Graduate Program in Nursing, Federal University of Rio Grande. Rio Grande, Rio Grande do Sul, Brazil. anacarol@mikrus.com.br

Descriptors: Terminally Ill; Advance Directives; Health Professionals; Personal Autonomy; Caregivers.

Objetivo: conocer la compresión de enfermeros, médicos y cuidadores familiares, remitidos a la posibilidad de convertirse en enfermos terminales, sobre la aplicabilidad de las directivas anticipadas de voluntad. Método: estudio cualitativo con enfermeros, médicos y familiares de enfermos en fase terminal. Datos recolectados entre octubre y diciembre de 2014 mediante entrevista semiestructurada. Fue realizado análisis textual discursivo de los datos. Resultados: enfocaron la aplicabilidad de las Directivas Anticipadas de voluntad y deseos de profesionales y familiares en la preservación de la dignidad y autonomía personal; y la inseguridad de la aplicabilidad de las directivas. Conclusión: a pesar de aceptar y desear la realización de las directivas anticipadas, los participantes expresaron temores respecto de su aplicabilidad, de que no se respetare su voluntad, o que pudiesen modificarse al enfrentarse a la situación de terminalidad, de su abandono por parte de los profesionales y de su inseguridad respecto de diagnósticos y pronósticos.

Descriptores: Enfermo Terminal; Directivas Anticipadas; Personal de Salud; Autonomía Personal; Cuidadores.

Introduction

Despite the medical advances, it is impossible to rule out death. Considering its invincibility, accepting it as a limit imposed by life, helps to walk, alongside health professionals, patients, and family, the path of dignity and prevent prolonged suffering(1). Thus, dealing with the limits of life has imposed new instruments that delimit the decision-making process for terminally ill patients, requiring a different look at the end-of-life experience(2).

In this perspective, the Federal Medical Council (CFM) of Brazil has approved the Resolution 1.995/2012 on the Advance Directives (ADs), which refers to the wishes previously expressed by the patient about the care and treatment they want to receive when incapable of freely and autonomously express their will(3). It may indicate if they wish to undergo mechanical ventilation, drug treatment, surgery, cardiorespiratory resuscitation, among other resources(1).

Nevertheless, there are many controversies concerning this resolution, provoking a great debate about its applicability, since the limits of human life are not strictly defined, considering a context of advances that modify and extend these limits(2). The resolution portrays the quick development of biomedical technology, which, by bringing benefits to human longevity, stimulates reflection on the non-mechanization of death and the naturalness of dying(2).

Given the above, and seeking to respect the expressed wills, Advance Directives emerge, considering the personal autonomy and human dignity. Approaching the ADs declaration requires further actions addressing the fundamental proposal of the declaration itself: to ensure that the patient's final wishes will be respected(4). In this context, this research is based on the principles theory(5), mainly in the autonomy concept, referring to the right of self-governance, privacy, individual choice, and freedom of the subject's will to guide their own behavior.

Since very few people know the possibility of preparing their ADs, physicians often ask family members to decide on behalf of their terminally ill loved ones, hoping they will know the patient's preferences(6), although they usually do not know what the patient wants(7). Additionally, even when death follows a prolonged illness, the family in often unprepared, and doctors do not always have end-of-life discussions with their patients while they are still able to decide(6).

It is worth highlighting the difficult of health professionals and family members to take care of patients in the final stages of life. For professionals who deal with suffering and pain situations in their daily lives, with death as a constant element, the feeling caused by these situations commonly translates into impotence, frustration, and anger(8). As for family caregivers, taking care of end-of-life patients demands time, dedication, abdication, and constant suffering, as there is nothing they can do to reverse the situation presented, and they are often delegated responsibility to decide for the treatments, which causes them anguish for not knowing how to act(7).

Discussing the removal of an invasive mechanical ventilation, for example, requires a lot of ethics and preparation. In Brazil, however, most family members, physicians, and nurses are open to this discussion, and family members wish, more than doctors, that this matter be introduced into their practices and addressed early. Furthermore, the majority prefer a joint decision, which international consensus recognizes as ethically ideal(9).

In the international scenario, in which the practice of ADs has been occurring for decades, it is observed that, though the issue still raises certain difficulties of application, it is well accepted by the population, the patients, and health professionals(10-11). Nonetheless, there are still certain reservations about generalizing the results of countries that authorize the practice of ADs, because different legislations and health care systems, as well as cultures, can have a great impact on decision-making processes(12).

In Brazil, few researches approach ADs and the perceptions of health professionals on this topic. Studies carried out focus on the professional issues related to the application of ADs, such as the knowledge and understanding of nursing(13-14), psychology, nutrition, physiotherapy(14), and medical(14-16) professionals, as well as the right to ADs(16); physicians' respect for the patients' anticipated wishes, at a time when they are unable to communicate, and if this manifestation was a valid instrument to avoid dysthanasia(17); and the possibility of proposing an ADs model for the country(18).

It is important noting that studies on how the families of end-of-life patients treat the issues related to ADs are incipient in Brazil. An exception was the investigation that evaluated, through quantitative methods, the perception of oncology patients and companions about the knowledge and acceptance of ADs. This study indicated that the family/companion knowledge was of 0.41 points (in a scale from 0 to 10). After explaining the meanings, the purpose of preparing ADs, companions obtained an average of 9.39 points(19). Moreover, in relation to implementing ADs in Brazil, the mean of acceptance was 9.75 among the companions. Family members also indicated that they thought more appropriate for the doctors (8.92), or the doctors together with the patients (8.87), to make the decisions, excluding their participation(19).

Family plays a key role in decision-making processes. In this sense, a survey conducted in South Korea, with 1,289 family caregivers, verified that 92.9% approved the need for implementing ADs(10). End-of-life decisions involving family members are usually motivated by perceived lack of dignity due to progressive deterioration, poorly controlled pain, chronic patient abandonment, therapeutic cruelty, and unnecessary use of measures to postpone death(12).

These considerations reveal that the concern to know how those involved in the end-of-life care of patients, specifically nurses, physicians, and family caregivers, would act in the possibility of becoming terminal patients implies the probability of reflecting on their performance as professionals and caregivers, confronted with the care provided. Health professionals should be the most prepared for end-of-life care, besides working with the hypothesis that they may someday experience similar incapacity situations like their terminally ill patients(20).

Given the above, and considering the hypothesis that experiencing such situations could change the way of looking at the end-of-life care and that health professionals, as well as the family caregivers of patients in the final stages, may not provide care that meets the patients' and their loved ones' preferences, this study aimed to know the understanding of nurses, physicians, and family caregivers, when faced with the possibility of becoming end-of-life patients, on the applicability of ADs.

Method

This is a descriptive and exploratory qualitative research conducted at a university hospital of a city in the State of Rio Grande do Sul, Brazil. It is a secondary and tertiary reference hospital for the Central-West Region of the State, covering 46 municipalities and exclusively serving the Unified Health System (SUS). Participants inclusion criteria were: nurses and resident physicians working in the medical clinic unit and in the home care service for at least half a year. As for the caregivers, the criteria were: family members aged 18 years and older, assigned as caregivers, and who provided home care for patients considered in the final phase.

In the medical clinic, there are 24 beds for different specialties, namely: neurology, pneumology, gastroenterology, cardiology, gerontology, infectology, among others. On the other hand, the home care service assists patients with chronic diseases, who are clinically stable after hospitalization, and patients who have a family caregiver responsible for the home care. The service is limited to 30 patients and aims to maintain the continuity of treatment in the family environment; reduce the average length of hospital stay, helping to optimize the occupation of hospital beds; and reduce the risk of complications, such as hospital infections, in addition to the emotional exhaustion of the family and the patient.

The abovementioned units were chosen due to their characteristics of treating and assisting end-of-life patients, thus constituting environments full of experiences of conflicting situations and ethical dilemmas originated by the termination process, concerning issues of suspending or not the treatments, as well as situations related to fulfilling the patients' wishes and that involve maintaining their autonomy.

The study comprised eight nurses, seven resident doctors, and seven family caregivers, totaling 22 participants defined by data saturation(21). Data collection took place from October to December 2014, through semi-structured interviews, focusing, both to health professionals and family members, on questions related to personal desires regarding the applicability of ADs through the following questions: How would I like to be taken care of in a disability/terminal situation (communication preferences); Desire to prepare ADs (reasons for the interest or disinterest and obstacles); And respect for autonomy in the face of disability.

There was an initial approximation with the professionals to meet them and inquire about their interest in taking part of the research. Later, date and hour for the interview were scheduled. Regarding the family caregivers, previous visits took place, aimed at establishing an approximation with the family. Interviews, with an average duration of 50 minutes, were performed with the professionals in a single meeting in the hospital environment, in private rooms, and at the homes of family caregivers.

Participants were clarified about the study objectives and data collection strategy. After reading and signing the Free and Informed Consent Term (FICT), the interviews were recorded digitally. The speeches were transcribed and then underwent grammatical corrections. Data were examined according to the discursive textual analysis(21), unitarization, by disassembling collected information to reach constituent units referring to the phenomenon(21); and categorization, by organizing and grouping the sets of units of analysis(21). Capturing an emerging novelty, through the impregnation of the analyzed materials, enabled the emergence of a renewed understanding about the applicability of ADs(21), based on the production of metatexts from the corpus.

Research Ethics Committee in the Health Area of the Federal University of Rio Grande do Sul approved the study under protocol No. 168/2014. The anonymity of the research participants was preserved and the transcribed speeches were identified by code (NUR: nurse, PHY: physician, FAM: family caregivers) followed by an ordinal number.

Results

Among the 8 nurses interviewed, there were 7 females and 1 male, with a mean age of 44 years, presenting a training time in nursing ranging from 9 to 30 years, and average professional practice of 7 years. Of the 7 physicians interviewed, 3 were female and 4 males, with a mean age of 29 years, professional practice of approximately 1 year, and there was only 1 professional with 9 years of service.

The 7 family caregivers were aged 41-57 years, and regarding the kinship: there were 3 husbands, 2 wives, 1 daughter, and 1 niece. The time of care provided to the terminally ill patients ranged from 2 to 3 years. Additionally, the family members interviewed did not work, exercising their full-time patient care activities, except for one of the spouses, who seldom acted professionally.

Two categories emerged from data analysis: Advance directives and the desires of health professionals and relatives, and Advance directives and the fears of health professionals and relatives.

Advance directives and the desires of health professionals and relatives

Personal desires of nurses and physicians, when faced with the possibility of a terminal illness, are predominantly based on the respect for their autonomy, along with the intention of preparing ADs, despite their fear and doubts about its applicability.

> *I would like my wishes to be respected, to be treated with respect, privacy, and if I say I am in pain, it is because I am. I would fight a lot to have my autonomy respected.* (NUR4).

> *Respect the pains, beliefs, and culture.* (PHY3).

Besides wanting respect for their expressed wishes, professionals stated that they would like to be permanently aware of their diagnosis and prognosis. If they were sick, sincerity should permeate their communication with the professionals assisting them, so they could understand the situation, as well as their effective action in the decision-making processes for their treatment.

> *I would want them to explain me the situation. I would not want them to exclude me from conversations; this is very bad, and we do it. We call the relative aside and talk to them.* (PHY5).

> *Clearly, I would like to prepare ADs, defining my diagnosis and prognosis. I want to express what is to be done or not. It would be interesting and good.* (PHY6).

Family caregivers who admit, in various moments, omitting the diagnoses of terminal illnesses to the patients under their care, declare the desire to be aware of their own diagnosis to participate in decisions.

> *I think it is wrong not to tell the truth, but I'd like to know everything about what is going on, to be able to say what to do or not with me. Because somethings are pointless, they just end up hurting.* (FAM6).

Relatives are frequently called to decide for the patients. The professionals interviewed, however, have demonstrated difficulties in allowing their relatives to decide on the conduct of their care, either by the usual unpreparedness of the family or by the suffering this decision-making process brings.

> *I consider important to decide what I want to be done. I would tell the family, but depending on the situation, the family is not ready.* (NUR7).

> *For the family, this is great! They are not responsible for the difficult decision; it is an embarrassing situation.* (NUR6).

In this context, preparing ADs would help to take away the responsibility of family members for decisions considered difficult in the face of incapacity and end-of-life situations.

> *We cannot talk to our relatives about it, but this would avoid suffering in deciding what treatments should or not be done or removed.* (PHY7).

The intention of nurses and doctors, of preparing ADs, is related to ensuring their quality of life and dignity. Nevertheless, their interest lies in depending mainly on using the available resources while there is still chance of recovery.

> *I would do the document, but if there was some hope, I would want them to do everything.* (NUR5).

> *I would like to prepare ADs. The limit would be the possibility of living with quality of life, which I relate to dignity.* (NUR8).

> *I would leave it* [ADs], *considering the issue of prognosis and quality of life. In an extreme situation of palliative care, terminal state, I would not want them to prolong the suffering.* (PHY1).

Nurses and physicians, given the possibility of preparing ADs, exposed their treatment and care preferences in the face of a supposed terminal disability situation.

> *I would put in the ADs what they will respect, which would be: do not intubate, do not reanimate, and no hemodialysis.* (NUR6).

> *I would not like to undergo dialysis, tracheostomy, gastrostomy, nasogastric tube, and being on a respirator.* (NUR8).

> *I would not want intubation; it is something very invasive.* (PHY1).

Health professionals emphasized the importance of maintaining comfort measures to guarantee dignity.

> *Not feeling pain, in an airy environment, being able to distinguish between day and night, and being treated with respect and dignity.* (NUR7).

> *I would like everything regarding comfort, and receive care from a relative.* (PHY1).

> *Maintain oxygenation, rest in bed, absence of pain and noise, and hygiene.* (PHY2).

Family caregivers have expressed the possibility of manifesting, through ADs, their desires in the face of a supposed condition of incapacity, like the care they provide to their relatives.

> *If I had a chance to register my wishes, I would not want anything, because I have already enjoyed life, and put an object there. Other people have more time to live than I do and need more things.* (FAM4).

> *If I were in a situation like his, I would like to be taken care of the way he has been, but I do not know if they would take care of me. I find it very difficult, because it is not easy.* (FAM3).

> *I take care of him the way I want to be taken care of. Hopefully, I'll have the chance to be taken care of as I take care of him, because it is difficult for people to devote themselves completely.* (FAM7).

The interest of family caregivers in communicating their wishes through ADs is strongly associated with not transferring to their family members the decision-making for their treatment, either because of the anguish they feel when deciding about treatments for their sick relatives, or to relieve their relatives from future suffering, or for fearing they will make decisions different from their will. They also wish for themselves that all the available resources that would influence the length of their life, without quality and prospects of cure, should not take place, like the care provided to their relatives.

> *I would like to express my will so as not to let others decide and avoid any embarrassments and suffering for other people. And that they do not decide for something I would not like.* (FAM6).

> *If I were in a situation like hers, I would not want to be intubated or that they kept doing things that would not solve anything.* (FAM1).

Family caregivers, despite taking care of their relatives with dedication and self-denial, changing their family routine, do not wish that in a situation of similar dependence they also need to receive care from others.

> *I would not want someone to dedicate their whole time to me, because they end up having no life; it is all about disease and nobody takes care of it. I would not want something just to increase my suffering.* (FAM6).

Nurses and physicians reported difficulties in dealing with issues concerning end-of-life situations, which often prevents that conversations on this matter take place in the family environment.

> *For the sake of positive thinking, we do not talk about diseases, which in a way is good and bad. It is good for avoiding negative thoughts, and bad because it would need to be discussed with people still conscious.* (NUR5).

> *I have already tried to talk to my family about my wishes in a situation of incapacity, but my mother did not want to think about it and became angry. It is hard to deal with this.* (PHY5).

Advance directives and the fears of health professionals and relatives

Nurses and physicians mentioned their fears about preparing ADs, regarding the uncertainties of the diagnosis, given that sometimes patients are completely unaware of their true condition and prognosis of the disease.

> *I would fear the terminal diagnosis because I have seen patients on which we should not take actions and they recovered. If they proved me there was no way back, I might prepare ADs, otherwise no.* (NUR3).

> *I would not decide it* [about ADs] *unless I could investigate the disease. I would want to use all the available resources. If it was a well-informed situation, I would have more interest. But as it is a situation with limited information, which I do not know, I do not have interest in it.* (NUR4).

Clarifying the diagnosis allows patients to decide on treatment situations, but despite their wishes of knowing their diagnoses and prognoses, they recognize that the possibility of using or not all the resources available will depend on the situation presented.

> *I want them to take all the actions, until the very last, do not give up on me, despite knowing the situation, unless I spend a few months suffering without return, that changes the ADs, if I am able to respond.* (NUR1).

> *In terms of deciding to use the available resources, it depends on the situation. Maybe I wanted them to take actions, maybe not. Surely, I would only know that if they explained me.* (PHY5).

> *I would not want them to take all the actions in terminal cases and without quality of life.* (PHY1).

Patients should prepare ADs while they are still lucid and capable. Nevertheless, professionals have expressed their interest in doing it only when aware of the irreversibility of their disease condition, even though this is a moment when they might be unable to decide on the care and treatment options.

> *I will be interested in preparing ADs once I know there would be no return. I want everything to be done, after spending a few days in the ICU, my ADs must be very specific.* (NUR4).

> *Right now, it would not be necessary, because I am healthy, but if I developed a cancer without perspective of cure, surely, I would do it.* (PHY3).

On the other hand, there are still doubts concerning the fulfillment of the wishes manifested in an end-of-life situation by the relatives assigned to fulfill the desires.

> *When I said that I would leave it* [ADs]*, there is the matter of belief, philosophy, spirituality, that I do not know if I have the right to ask and if it is going to be respected.* (NUR6).

Nurses and physicians, as well as family caregivers, regarding the applicability of their ADs, reported the fear of possibly changing their mind about the situation experienced and the impossibility of reversing their choices, whether to take actions or not, given the disability.

> *I get scared and afraid; supposing I prepare ADs and need to use them, and what is written is what is going to be considered; if that happens, it may be a different situation and I want to change my mind but cannot do it.* (NUR1).

> *My will is written. Today, I have an opinion, but in the hospital, I might change it.* (PHY7).

> *Today, I may be saying something, but tomorrow I might change my mind.* (FAM5).

> *The fear of changing my mind when the situation happens. I do not want to suffer like her, but I am afraid to leave something written and they stop taking care of me, because I asked them to.* (FAM7).

The suffering experienced by relatives in the care provided to the end-of-life patients seems to guarantee that, faced with the supposed incapacity situation, they would not change their previously expressed preferences.

> *I do not think I'd ever change my mind, knowing the situation I was going to experience. They* [doctors] *tried all the resources available to save a life, but when it comes to such a point, when life can no longer be saved, it will not be reestablished, in my opinion, I do not think I would change the ADs.* (FAM6).

Nonetheless, there was also the fear that care and treatment would be abandoned due to the desires expressed in the ADs of not taking actions.

> *If I had a record to not resuscitate me, I do not know if, in a situation in which I should be resuscitated, people would imperatively not do it just for something that is written.* (PHY2).

Discussion

Obviously, thinking about death raises fear, anguish, and doubt, especially regarding oneself. In this sense, impressions of death are contextual, being impossible to see them as an imminent event, once manifestations concern something abstract. Therefore, it is difficult to predict desires for when they are dying, if they have the time and conscience for such discernment(20).

Despite being a difficult proposal to explore, it was possible to verify what health professionals and family caregivers think about the care and treatment they would like to undergo in a situation like that found in the care of their terminally ill patients, besides considering preparing ADs.

Guaranteeing that their desires and autonomy are respected in case of disability, while maintaining their dignity, as well as comfort measures, are imperative for the health professionals and family caregivers interviewed, when faced with the possibility of experiencing a terminal illness. Therefore, autonomy, essential in all phases of life, must be considered valid and obligatory for an incapable patient(8). Respecting the autonomous patient means to recognize their right to have opinions, make choices, and act based on personal values and beliefs(5).

Although the study participants express interest in ADs, they demonstrated concern about the fulfillment of the written wishes, as well as fearing following treatment and care restrictions without their contextualization with the disease presented. Health professionals, for working in this area, seem to be more fearful when thinking of registering ADs, because they are aware of the usual care given at the end of life. In this regard, they wished that all resources available were used on themselves until certain there is no chance of recovery, but rejected the prolongation of life without dignity and autonomy. In this perspective, the physicians interviewed were very calm about the treatments, when faced with the possibility of their death, because they know what can happen to them. Moreover, they usually want to be sure of their situations, and that heroic measures to artificially prolong it do not take place, when the time comes for their death(22).

It is noteworthy that the research participants reported fears regarding the possibility of having their lives unduly prolonged, causing greater suffering without reversibility of the disease. In this regard, the fear that there is a so called super treatment, accompanied by pain and suffering, is also present in the general population(8), considering that the wide availability of new technologies and the use of clinical interventions are undesirable adverse events that can lead to unnecessary suffering in a progressive and irreversible situation(23).

Study conducted in four hospitals in the State of São Paulo, Brazil, with physicians and nurses, on the possibility of applying ADs to themselves, in case of a terminal illness, verified that, among the 81 participants, 88.9% would like to have their will respected, without artificial prolongation of life(1). None of the respondents indicated they would prefer to undergo all therapeutic options to prolong their existence. Nonetheless, 9% said they did not feel prepared to decide how they would like to die in the event of a disease in the final stage, and 72% preferred to have their wishes respected based on the conditions they stablished for themselves without artificially prolongating their lives(1).

Furthermore, for the family caregivers of patients in the final stage who face the possibility of confirmation and certainty of their own terminality, of their death(24), thinking about their preferences represents a difficult task, because this possibility seems far from happening with them. Thus, the research demonstrated that the end-stage coping seems to be faced in order not to wish to experience all the suffering experienced by the terminally ill relatives under their care. Under this approach, the prospect and desire to avoid prolonged life seem more evident in family caregivers than in health professionals, who often presented fears related to the possibility of reversing the disease, given the knowledge for acting in the health area.

It should also be noted that the interviewees' statements, regarding the desire to know about their diagnoses and prognoses, considering the possibility of experiencing a terminal illness, are fundamental in the intention to prepare ADs, unlike the omission and denial they commonly adopt with their patients. From this perspective, being aware of the diagnosis, treatment options, and prognosis is essential to preserve the dignity, appropriating the right to a joint decision with the family and the health team, both in terms of treatments and in relation to the place of residence until the end of life(8).

Survey conducted in Brazil with 202 physicians, 150 outpatients, and 150 family members, found that about 92% of patients believed they should know about their terminal condition, compared to 79.2% of physicians and

74.7% of relatives. Patients were more likely to support being informed about the diagnosis and terminality. Additionally, they felt that this knowledge would improve their quality of life, and its open discussion was not perceived as stressful. Terminal patients preferred to know the truth about their bad prognosis more than expected by their physicians and families(25). In this way, besides differing from the data found in the research, it is worth highlighting that patients, family members, and caregivers become aware of diagnoses and prognoses to assist in the decisions and the possibility of preparing ADs.

Moreover, for the family caregivers of this research, the supposed irreversibility of the disease should be known. They believed that faith could act positively in coping with the disease to seek its reversal, even if aware of this impossibility. In this sense, there is an ambivalence between hope, believing that a miracle can happen, hence curing the illness, and the disbelief that nothing else can be done except for comfort measures, providing a better quality of life in death(24).

It was also possible to verify that the interviewees did not wish to delegate the decision-making responsibilities to their relatives, probably because of the difficulties they experienced when having to decide, often without knowing for sure the wishes of their patients. In this perspective, patients' preferences for the care they wished to receive at the end of life were generally unknown to the care team, as well as to family members, who are frequently still designated to make the decisions regarding end-of-life treatment and care(23). In addition, relatives sometimes made decisions that conflicted with the patient's wishes, which they previously expressed through ADs(5).

Family caregivers declared they preferred not to need care due to their incapacity, but, if necessary, they would want to be taken care of just as they did for their sick relatives. Furthermore, research data enabled to notice the concern of the interviewees about receiving care with their dignity and autonomy respected. Patients at an advanced stage of the disease seek relief and control of pain and other symptoms, wanting to take control over their own lives, without prolonged suffering, not being a burden for the family, able to strengthen ties with significant people, and have dignity at the end of life. They also hope that their physicians do not abandon them(8).

The fact that the interviewees mention the fear of preparing ADs, due to possible changes of will that may occur over time, in the case of experiencing a terminal illness, makes it essential a constant review of the ADs to avoid misunderstandings or that the wishes do not correspond to the current yearnings. Patients can modify their preferences without changing their instructions(5). Thus, in a study that interviewed physicians about their thoughts concerning their own death, a geriatrician explained that, by registering her ADs, she constantly reviewed the document, since something could always be modified due to her professional experience, besides the apparently immutable change of opinions over time(20).

Article approaching end-of-life preferences clarifies that nurses and physicians have shown resistance in addressing end-of-life situations with their families, despite working in the health area and being familiar with these experiences. In this context, early dialogue with loved ones during the period without incapacitating diseases can help prepare everyone for the possibility of experiencing terminal situations, as well as include a person responsible for attending their wishes(6).

Conclusion

Reflecting on the possibility of being in an end-of-life situation is not an easily conceivable task for health professionals and family caregivers, as well as the general population. Even if it involves the possibility of finding themselves in such a situation, it does not fully guarantee which decisions would occur when experiencing it. This is probably why there are great difficulties in applying the ADs.

The interest in preparing ADs is permeated by the fear that their wills are not really respected, worried that they might change their mind when faced with the terminal situation, fearing the abandonment of professionals, and insecurity about diagnoses and prognostics. These situations impose limitations and possibly resistance on the applicability of ADs. Nevertheless, though it is difficult to respect or consider the patients' preferences, their absence creates even more difficulties, because the incapacitated patients would receive care without really knowing what they wanted for themselves.

Ideally, all patients with a serious and disabling illness should talk to their family, friends, and health professionals about their values and how they would like to be considered for care and treatment in the face of a disability. Additionally, the family, which plays a key role in decision-making, would be backed, thus reducing their suffering, as well as enabling prior planning of care and consequently improving the quality of death.

Collaborations:

1. conception, design, and data analysis and interpretation: Silvana Bastos Cogo and Valéria Lerch Lunardi;
2. drafting of the article and critical review of intellectual content: Silvana Bastos Cogo, Valéria Lerch Lunardi, Alberto Manuel Quintana, Nara Marilene Oliveira Girardon Perlini, and Rosemary Silva da Silveira;
3. Final approval of the version to be published: Silvana Bastos Cogo, Valéria Lerch Lunardi, Alberto Manuel Quintana, Nara Marilene Oliveira Girardon Perlini, and Rosemary Silva da Silveira.

References

1. Rossini RCCC, Oliveira VI, Fumis RRL. Testamento vital: sua importância é desconhecida entre os profissionais da saúde. RBM. 2013;70(2):4-8.
2. Alves CA. Diretivas antecipadas de vontade e testamento vital: uma interface nacional e internacional. In: Pessini L, Bertachini L, Barchifontaine CP, organizadores. Bioética, cuidado e humanização: sobre o cuidado respeitoso. São Paulo: Loyola; 2014. p. 189-96.
3. Resolução n. 1995, de 9 de agosto de 2012. Dispõe sobre as diretivas antecipadas de vontade dos pacientes. Brasília: Conselho Federal de Medicina; 2012 [Internet]. [cited 2013 Sept 5]. Available from: http://www.portalmedico.org.br/resolucoes/CFM/2012/1995_2012.pdf
4. Rocha AR, Buonicore GP, Silva AC, Pithan LH, Feijó AGS. Declaração prévia de vontade do paciente terminal: reflexão bioética. Rev Bioét. 2013;21(1):84-95.
5. Beauchamp TL, Childress JF. Princípios da ética biomédica. 4a. ed. São Paulo: Loyola; 2002.
6. Handy C. End-of-life wishes: what everyone needs to talk about but no one wants to. US News Healt [Internet]. 2015 Jun 8. [cited 2015 Apr 12]. Available from: http://health.usnews.com/health-news/patient-advice/articles/2015/06/08/end-of-life-wishes-what-everyone-needs-to-talk-about-but-no-one-wants-to
7. Schenker Y, Crowley-Matoka M, Dohan D, Tiver GA, Arnold RM, White DB. I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. J Gen Intern Med [Internet]. 2012 [cited 2014 Nov 3];27(12):1657-65. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3509291/
8. Kovács MJ. Cuidando do cuidador profissional: o sofrimento da equipe de saúde no contexto hospitalar. In: Pessini L, Bertachini L, Barchifontaine CP, organizadores. Bioética, cuidado e humanização. São Paulo: Loyola; 2014. p. 82-97. V. II - Sobre o cuidado respeitoso.
9. Fumis RR, Deheinzelin D. Supressão do suporte respiratório em unidades de terapia intensiva: famílias, médicos e enfermeiros opiniões sobre dois cenários clínicos hipotéticos. Critical Care, 2010;14(6):R235.
10. Keam B, Yun YH, Heo DS, Park BW, Cho CH, Kim S, et al. The attitudes of Korean cancer patients, family caregivers, oncologists, and members of the general public toward advance directives. Support Care Cancer [internet]. 2013 [cited 2014 Nov 4];21(5):1437-44. Available from: http://link.springer.com/article/10.1007/s00520-012-1689-z#page-1

11. Cucalón-Arenal JM, Marín-Ibáñez A, Cía-Gómez P, Blay-Cortés MG. Opinión de los universitarios sobre los cuidados al final de la vida. FEM [internet]. 2013 [cited 2014 Nov 3];16(3):181-6. Available from: http://scielo.isciii.es/pdf/fem/v16n3/original7.pdf

12. Sarmiento-Medina MI, Vargas-Cruz SL, Velásquez-Jiménez CM, Jaramillo MS. Terminally-ill patients' end of life problems and related decisions. Rev Salud Publica [internet]. 2012 Jan-Feb [cited 2014 Nov 5];14(1):116-28. Available from: http://www.scielosp.org/scielo.php?script=sci_arttext&pid=S0124-00642012000100010

13. Cassol PB, Quintana AM, Velho MTAC. Diretiva antecipada de vontade: percepção de uma equipe de enfermagem da hemato-oncologia. J Nurs Health. 2015;5(1):4-13.

14. Chehuen Neto JA, Ferreira RE, Silva NCS, Delgado AHA, Tabet CG, Almeida GG, et al. Living will: what do healthcare professionals think about it? Rev Bioét [Internet]. 2015 Sept/Dec [cited 2017 Feb 20];23(3):572-82. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300572&lng=en. http://dx.doi.org/10.1590/1983-80422015233094.

15. Silva JAC, Souza LEA, Costa JLF, Miranda HC. Conhecimento de estudantes de medicina sobre o testamento vital. Rev Bioét [Internet]. 2015 Dec [cited 2017 Feb 20];23(3):563-71. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-80422015000300563&lng=en. http://dx.doi.org/10.1590/1983-80422015233093.

16. Piccini CF, Steffani JA, Bonamigo EL, Bortoluzzi MC, Schlemper Jr BR. Testamento Vital na perspectiva de médicos, advogados e estudantes. Bioethikos. 2011;5(4):384-91

17. Stolz C, Gehlen G, Bonamigo EL, Bortoluzzi MC. Manifestação das vontades antecipadas do paciente como fator inibidor da distanásia. Rev Bioét. 2011;19(3):833-45.

18. Dadalto L, Tupinambás U, Greco DB. Diretivas antecipadas de vontade: um modelo brasileiro. Rev Bioét. 2013;21(3):463-76.

19. Campos MO, Bonamigo EL, Steffani JA, Piccini CF, Caron R. Testamento vital: percepção de pacientes oncológicos e acompanhantes. Bioethikos. 2012;6(3):253-9.

20. Consultório da mente. O que os médicos pensam sobre a sua própria morte? Albert Einstein [Internet]. 2012 [cited 2015 July 12]. Available from: http://www.consultoriodamente.com/index.php?option=com_content&view=article&id=10:how-do-i-localise-joomla-to-my-language&catid=32:languages&Itemid=54

21. Moraes R, Galiazzi MC. Análise textual discursiva. 2a ed. Ijuí: Unijuí; 2013.

22. Murray K. How doctors dieit's not like the rest of us, but it should be zocalo public square. [Internet]. 2011. [cited 2015 July 12]. Available from: http://www.zocalopublicsquare.org

23. Franco TB, Gama ZAS, Hernández PJS. Advanced knowledge of patient preferences for end-of-life care in national health service hospitals of the Murcia Region. Rev Calid Asist. 2011;26(3):152-60.

24. Valduga EQ, Hoch VA. Um olhar sobre os familiares cuidadores de pacientes terminais. Unoesc & Ciência. 2012;3(1):5-32.

25. Fumis RR, Camargo B, Del Giglio A. Physician, patient and family attitudes regarding information on prognosis: a Brazilian survey. Ann Oncol. 2012;23(1):205-11.

Received: June 22, 2016

Approved: February 21, 2016