



Advance directives in the context of end-of-life palliative care

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Purpose of review

To review the definition of advanced directive, understand the implications for the patient, family and healthcare team, and address the obstacles involved in the implementation.

Recent findings

Advanced directives propose a model of healthcare based on patient preferences. Although there is sufficient evidence related to their usefulness, various factors are known to affect the use of advanced directives. Therefore, rules need to be established in order to optimize the implementation process.

Summary

An advanced directive is a legal document based on the principle of autonomy that expresses the desire of the patient in relation to different medical treatments when the patient is unable to make those decisions. The advanced directives are represented in three formats: Living Will, Appointment of a Healthcare Proxy and Legal Status of Preferences. The uses of advanced directives have an impact not only on the patients and their families, but also on the healthcare team. Despite their utility being well known, there are several general barriers that affect implementation, as well as factors related to characteristics of each study population.

Keywords

advance care planning, advance directives, end-of-life, living will

INTRODUCTION

In the USA, stories of the life and death of Karen Ann Quinlan and Nancy Cruzan showed the challenges in making decisions at the end of life when the patient is unable to do so [1].

A legal document called an advanced directive facilitates decision-making regarding medical treatments only based on the preferences expressed by the patient before an inability to do so is established. The advanced directive is rooted in the principle of respect for autonomy.

Advance care planning is an important component of attention and it plays a crucial role in palliative care. The advanced directives may be useful not only when a patient is unable to participate in decision-making, but also when he or she decides not to do so [1].

DEFINITIONS

An advance directive is a legal document in which a person can express what kind of medical assistance he or she wishes to accept or refuse in case he/she is no longer able to decide about his/her own care [1].

There are three types of advanced directives. One is the Living Will, which is expressed as a list of preferences referred to medical treatments that the patient should or should not receive in certain potential situations. This indicates, for example, if the patient accepts or refuses cardiopulmonary resuscitation, an oxygen tube, antibiotics, and so on, when he is unable to decide for him/herself.

The durable power of attorney, on the contrary, is another type of advanced directive. It is a document in which the patient names another person to make decisions when he/she is unable to do so. This agent is also called healthcare proxy (HCP) PROXY. The HCP must be a relative or a close friend who knows the desires and interests of the patient [2].

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KEY POINTS

- Advanced directives propose a model of healthcare based on patient preferences.
- An advanced directive is a legal document based on the principle of autonomy.
- Despite their utility being well known, there are several general barriers that affect implementation.
- Advanced directives are related to lower levels of distress in patients and relatives.
- The advance care planning is an important topic in today's palliative care agenda.

A third type of advanced directive is an informal statute of preferences. This may be a written or oral statement that specifies the patients' preferences as a whole, but does not address specific treatments or illnesses; for instance: whether he/she refuses to participate in decision-making, or in the delegation of decision-making, or in the identification of preferences based on his/her interests [1].

The patient has the right to make, change or revoke an advanced directive at any time and inform the physician of his/her choice, which must be placed in the medical record.

Ethically, the advanced directive represents the patient's autonomy. Initially, this reflection concentrated on protecting the patients' right to make healthcare decisions affecting them. Then, the importance was focused on the process of providing information about the nature and consequences of medical treatments. So the physician's obligation to disclose information to the patient about the nature and consequences of the proposed treatment was emphasized. Nowadays, bioethicists focus on the information deemed necessary and important to understand implications of the proposed treatments which enables the patient to give proper consent and authorization. Increased attention is given to the problems related to standards for surrogate decisions for incompetent patients. In this context, not only the standard of advance directive but also of substituted judgment and best interests are discussed [2]. Actually, the attention is focused on advance care planning.

ABOUT ADVANCE DIRECTIVES AND CARE PLANNING IN ADVANCE

In the USA, the patient self-determination act became law in 1991. Since that time, healthcare institutions that received federal funding are required to ask patients if they have an advanced

directive. In addition, institutions have a separate obligation to educate both the staff and the community about the purpose and process of advanced directive [1].

Commonly, when patients are admitted to a hospital they receive an advanced directive form in the format of a living will, like a check list in which the variables are generally expressed in a dichotomous way, for example: accept or reject the use of dialysis, accept or reject hydration. This dichotomous structure, in some situations may be inappropriate or incomplete. Moreover generally advanced directive are written in an inappropriate language, which results confusing among different readers [1].

It is recommended that all United States citizens have an advanced directive, especially those over 65 years old, as the aged population represents 70% of deaths in that country. However several studies showed that, many patients still do not have advanced directive [3[■],5,6].

Discrepancy exists in the literature regarding the use of advanced directives. On one hand, some studies have shown that only about 20% of the United States population have advanced directives [3[■],4,5]. But on the other hand, one study has shown that up to 70% of community-dwelling older adults have completed advanced directives. The popularity of advanced directives has grown tremendously, despite debate about their effectiveness [7,8].

Niebró *et al.* [2] stated that, in the USA, advance directive programs have failed because people were not competent in decision making at the end of life. This study defined competence as the ability to declare a preference and understand the information on which the decision is based. It is not only necessary to have adequate information about the nature of the disease and treatment procedures, it is also important to know about the circumstances which may influence possible future treatments and patient's preferences. The strong argument against these programs is the lack of necessary information about possible uncertain future situations, making it impossible, in most cases, to consider an advance directive as an expression of competent consent [2].

Silveira *et al.* used data from survey proxies in the Health and Retirement Study involving adults aged 60 and older who had died between 2000 and 2006 to determine the prevalence of the need for decision making and loss of decision-making capacity, and to test the association between preferences documented in advance directives and outcomes of surrogate decision making. Of 3746 patients, 42.5% required decision making, of whom 70.3% lacked decision-making capacity and 67.6% of those, in turn, had advance directives. From the

999 decedents who both needed decisions and lacked capacity, 6.8% had a living will only, 21.4% had a durable power of attorney for health-care only, and 39.4% had both. This study confirms the high concordance between patient's preferences for care and the care actually received before death [7].

The goals of an advance directive (designation of a surrogate and identification of preferences) can be accomplished by asking two questions:

- (1) 'If you cannot, or choose not to participate in healthcare decisions, with whom should we speak?, and
- (2) 'If you cannot, or choose not to participate in decision making, what should we consider when making decisions about your care?'

These questions can be easily asked and, if necessary, repeated over time as the patient's condition changes. Information gathered in a conversation can often be far more pertinent to a patient's circumstances. This information can unburden surrogates who might otherwise be bereft of specifics to guide decision making [2].

IMPACT OF ADVANCE DIRECTIVES

Several researchers have found that patients who want to talk with their doctors about advance directives had lower levels of stress, depression and anxiety, than those who did not want it [1,7].

Pautex *et al.* [9], found that patients in three palliative care units participating in an advance directive study were less depressed 1 week after inclusion, had a lower anxiety score on the second week and there was a trend towards a higher level of satisfaction. They advise that the result is not only explained by the use of advance directives, but also by the discussions and exchange among patients, proxies and professionals about fear of pain, humiliation, abandonment, and death. So, probably, an open communication process relieves fears and improves communication.

Mack *et al.* concluded that patients who had earlier discussions about end-of-life care were less likely to receive aggressive measures before death. Use of aggressive care was much less frequent when end of life discussions took place at any time before the last 30 days of life, and the odds of hospice use were nearly twice as high [10]. Azoulay *et al.* [11,12] showed that when patients died in ICUs after end-of-life decisions had been made, 60% of relatives developed marked posttraumatic symptoms, and among those relatives who shared in end-of-life decisions, 82% developed these

symptoms. Increasing the interval between the initiation of an advance care planning discussion and the patient's death might be one concentered way to diminish the surrogate's potential suffering from his or her decision-making responsibilities [11,13].

When a dying patient's family members have more time to prepare for the loss, they are less likely to suffer complicated grief during the bereavement process. Advance directives, as well as the presence of a proxy, are factors that contribute to reducing stress in these scenarios [11,14].

Other researchers have found that those patients who agreed to complete an advanced directive did not die earlier than those who did not complete them, and furthermore significant economic costs were saved in medical care [1,15].

Despite this evidence, barriers persist with regard to their use. It is essential to try to understand which factors can block the use of advance directives in order to adapt care measures in advance care planning [1].

CHALLENGES AND OBSTACLES

Just wondering, 'do you have an advance directive?' is an appropriate way to address this issue. However, there are obstacles that may interfere with this question [1]. The barriers to the use of advance directives have been well studied and apply to health staff, patients and Proxies, as well as to ethnic, cultural factors and beliefs.

One of the reasons why healthcare staff omit this question is based on the belief that advance directives will confront the patient directly with his finitude and physicians do not feel comfortable with these conversations as the lack of communication skills in medical training is well known [1,24].

In the study of Pautex *et al.* [9], 25% of the total number of patients refused to anticipate what might happen in the future, but agreed to be included in the study protocol. They did not want to be involved in making medical decisions or talk to professionals about their preferences for care at end of life.

In a study conducted in Korea [16] of 247 patients with advanced cancer and a life expectancy of less than 6 months admitted in palliative care unit, 68% had their advance directives written in the medical record but the 95.2% of advance directives were written by patients' relatives. The author stated that due to cultural aspects of Korean society, many families do not want to discuss about end-of-life issues with their loved ones.

Finland has a long tradition of discussing and accepting various forms of end-of-life decisions. It was the first country, in 1971, where a diagnosis of brain death could be used to determine the official

death of the patient. However a survey that included physicians respondents ($n = 800$), showed that their experience with advance directives was limited. Less than half had been in a situation in which the living will had been active during the decision-making process, and in most of the cases that situation occurred less than five times [17].

On the opposite scenario, Albania has a history of a totalitarian regime for 25 years, and a paternalistic position about advance directives, which made its application extremely atypical. Medical teams are not allowed to withdrawal support, even when there is an explicit request of the patient [18].

Considering ethnic and cultural patient barriers, it was found that African-Americans and Hispanics participated less well in the advance directives form compared with Whites [1].

Numerous studies have explored the factors that come into play when making advance directives. A study performed with patients more than 50 years old who were provided with advance directives forms showed that about 90% did not complete them [19]. Those who did said that they needed additional information and more time to do it [1,19]. Another example is revealed by the SUPPORT study, which reported that 127 (39.5%) patients from a sample of 339 preferred not to receive Cardio Pulmonary Resuscitation, however less than half left expressed orders of not resuscitation [11,20].

Other barrier mentioned by Abbo *et al.* [21] is that advance directives are traditionally written to apply to terminal illness, and thus, do not easily capture patient preferences for medical assistance during acute and chronic illness. Therefore they developed a specific advance directive modified form and compared it with traditional ones. The 86% of patients preferred the modified advance directives as reflected their wishes more clearly. A future challenge will be to validate and develop advance directive that includes more specific preferences and options.

ADVANCE DIRECTIVES IN DIFFERENT MEDICAL SCENARIOS

The withdrawal of dialysis is the third most common cause of death within dialysis patients, and more than half of the times they are mentally incompetent to make that decision. Singer *et al.* [22] found that 25% of the 532 surveyed patients on dialysis, would hold the treatment in three scenarios: severe stroke, severe dementia and permanent coma. Knowledge about life support preferences of patients can be helpful to replace surrogate decisions to continue or not on dialysis.

A recent review in the field of intensive care showed that there is little evidence of the effects that an advance directive has in critically ill patients and recognizes the benefits in the reduction of economic costs. This review also suggests that the advance directive does not change medical behavior according to the patients' wishes, and therefore cannot be assumed to always respect the patient's autonomy [23].

A study about the perspectives of clinicians on advance directives in patients with dementia found that advance directives had greater acceptance among young doctors, although they expressed lack of training in patient communication. Other findings showed practical difficulties in its implementation, time lag between formulation and implementation, difficulties in predicting the evolution of patients, lack of legislation and specific institutional policies [24**].

CONCLUSION

The advance care planning is an important topic in today's palliative care agenda. Advance directives' effectiveness is worldwide known recently, though its implementation, benefits and obstacles have been extensively studied among different cultures and medical scenarios. Advance directives are considered an important tool for providing care consistent with patients wishes, which also guarantee better quality of life and respect of their autonomy but, unfortunately, their use is limited and yet poorly valued due to the interaction of the different factors mentioned above.

In the current context, the bio-psycho-socio-spiritual model has begun to arise as the latest healthcare paradigm and the advance directives may be regarded as a faithful representation of this change.

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Conflicts of interest

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- of special interest
- of outstanding interest

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