

# Perceptions, Attitudes, and Knowledge toward Advance Directives

Subjects: Ethics

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Advance directives are an expression of a person's autonomy regarding end-of-life care. An advance directive (AD) is a tool that enables the exercise of prospective autonomy. It serves as instructions for the care a person wishes to receive or refuses in the event they become incapable of expressing their preferences at the end of life.

Keywords: :advance directives ; advance care planning ; living will

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## 1. Introduction

In recent years, with special emphasis since the beginning of the century, we have seen that the ethical principle of autonomy in decision making regarding health has been strengthened <sup>[1][2]</sup>. In other words, the right of the individual to exercise self-determination has been affirmed as a guarantee of respect for their dignity. In addition, this is so much so that it is no longer enough to exercise self-determination in the present, and we have reached the consensus—at least in some countries with mature democracies—that prospective autonomy must also be respected. We enter the realm of the wills that a person can leave written and that must be respected in the future. It is no longer a matter of obtaining the person's consent for an act that will be conducted in the present but rather the formalisation of consent, an expressed will that will have its eventual manifestation of respect in the future in the case that the person is incapable of communicating. In short, scholars are discussing the advance directives (ADs), which are considered a milestone in civilisation for all the above reasons <sup>[3]</sup>. This document, which was born in the 1960s in the USA at the hands of a lawyer <sup>[4][5]</sup>, is now an instrument that has spread throughout the world, with signifying the inalienable respect for the self-determination of the person that wrote this document <sup>[3][6]</sup>.

This document was gradually disseminated around the world, with a greater impact in the 1990s in several US states, and in the following decades in European countries <sup>[1][6]</sup>. It was becoming admissible to respect the wishes of people who, for reasons of illness, were now incapable of expressing themselves, but who had written down their wishes regarding the healthcare they wished to refuse and/or receive in end-of-life situations. This form of respect for prospective autonomy, known as ADs, can take two distinct forms, which are not mutually exclusive <sup>[3][7][8]</sup>:

(a) Living will: a document in which the person expresses the healthcare they refuse or wish to receive if they are unable to express their wishes autonomously.

(b) Durable power of attorney for healthcare: a document which allows an individual to appoint a proxy to make healthcare decisions on their behalf when they lose the capacity to do so.

## 2. Perceptions, Attitudes, and Knowledge toward Advance Directives

The population's knowledge about ADs is extremely low. Despite some cultural and clinical specificities of some study samples, the empirical data reveal a population with an important level of illiteracy about ADs. This fact has been maintained over time, as already noted in a systematic literature review conducted between 1994 and 2016 on the population's knowledge about ADs <sup>[9]</sup>, as well as other studies <sup>[10][11][12][13]</sup>. This is perhaps one of the most important data points to highlight because of its practical consequence, i.e., despite the existence of this instrument for the exercise of prospective autonomy, a citizen's right, its residual knowledge contributes to the low rates in the implementation of ADs <sup>[9][14][15]</sup>. As mentioned before, these data have also been maintained over time, with the USA showing higher rates, and reporting that one-third of the population will have ADs <sup>[16][17]</sup>. Moreover, the rates are lower in Europe, and are between 0.66% and 19% <sup>[10][11][12][14][18][19]</sup>. There may be several reasons for this discrepancy, despite the cultural differences between populations, but it is necessary to note that in the USA, the discussion and legalisation of ADs began in the

1970s, while in most countries, especially European, discussion on this issue began only at the beginning of the 21st century [20][21]. Regardless of this time lag, which may justify some progress in the numbers in the USA, it seems to us that the knowledge deficit is a barrier to not starting the process of the elaboration of ADs [9][14].

The lack of knowledge about ADs is high, and as people were able to see from the studies in countries without a legal framework for ADs that the samples exhibited a lack of knowledge about ADs, with values exceeding 80%. Even so, in countries with a legal framework, the rates of lack of knowledge were 56.8% [22] and 47% [18], demonstrating that even with the implementation of a law, measures must be taken to increase the literacy of the population in this context. It seems that there is a need to involve political decision makers in the area of health and, simultaneously, involve health professionals so that projects can be developed in the community to provide citizens with more information and training to prepare ADs [9][23][24].

Even so, the attitudes and perceptions about ADs are very favourable, which indicates that, despite the populations' low levels of knowledge in this area, when they are informed about what an AD entails, they provide a very positive assessment and display a growing interest in the subject. In some studies, participants have the following perceptions about the added value of ADs: respect for the person's autonomy, avoiding therapeutic futility, ensuring comfort at the end of life, and relieving the family and physicians from ethical decision making in end-of-life care. These are in the same line of evidence pointed out by other studies [9][17][24].

An important fact about communication in end-of-life care planning and the role of health professionals should be highlighted. Other studies confirm the importance of individuals discussing the care they receive or decline at the end of life. For the participants in the research studies, this conversation would be important and more effective for elaborating ADs if they had the support of a healthcare professional [25][26][27][28][29][30]. It seems evident to us that a citizen, when faced with doubts which are admittedly technical, should want to obtain advice. Incidentally, this idea is already in practice in the USA under the Federal Patient Self-Determination Act of 1990, and health institutions are obliged to inform citizens of their right to prepare their AD and to provide advice to this effect [31][32].

### 3. Conclusions

An advance directive (AD) is a tool that enables the exercise of prospective autonomy. It serves as instructions for the care a person wishes to receive or refuses in the event they become incapable of expressing their preferences at the end of life. This is what we could call a reinvention of the practice of prospective informed consent [33]. This instrument is currently widespread in several countries; however, the level of completion of the population to prepare informed consent is low. Understanding how the population perceives, knows, and what attitudes it has toward ADs will allow us to identify the needs in this area, and to direct more appropriate and stimulating measures.

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