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Abstract:

Since 2002 legislation in Spain has allowed for the creation and documentation of end-of-life decision making. Over the intervening years the actual implementation of such documents is very low. Through extensive analysis of the literature this article explores the current status of the use of and attitudes toward advance directives (AD) in Spain, and then proposes strategies for improvement in their implementation.

Keywords: Spain, End-of-Life Decision-making, Advance directives, Advance care planning.

Introduction

In 2002, Spain passed The Patient Autonomy Act (Act 41/2002)¹ which establishes the rights and obligations of both patients and health professionals in clinical care relations. This Act specifies the ways in which patients can exercise their autonomy, including the right to draw up Advance Directives (AD) to express their intentions regarding end-of-life care.

How these Advance Directives are to be managed is a matter left to each of Spain's regions, according to the "Autonomous Communities" Act 41/2002. The Act specifies that the Autonomous Communities must regulate ADs in their territory, with the result that all have implemented their own regulations. In an attempt to ensure that all Advance Directives registered in one region are recognized and honored through out the country, in 2007, the Royal Decree 124/2007 was passed to establish a National Advance Directives Registry. Thus, the AD of a patient registered in Madrid is honored even if the person in question currently lives elsewhere within the national territory

However, despite the existence of AD legislation at both the Autonomous Community and national registry levels, their use in clinical practice is infrequent, and the number of citizens who document their intentions regarding advance care planning is very low. According to the National AD Registry², since the enactment of the laws from 2002 to 2007, the number of registered ADs rose from 36,289 in 2007 to 314,011 in 2020. This increase in numbers still representing only 0.66% of the total population.

As would be anticipated, the implementation of the national legislation in Spain has led to an increase in the number of empirical studies on ADs in the last decade^{3,4}. These studies explore the roles of (1) patients, (2) their relatives and patient representatives, and (3) health care professionals. Discussed below are the general findings from these studies, followed by our proposal to address the shortcomings revealed.

(1) Knowledge and perspective of patients

No matter what the health care setting or pathology, patients know little about ADs^{5,6,7,8,9}. Most get their information from the media, which can lead to confusion especially when it comes to topics such as euthanasia or organ donations. Chronically ill patients who are admitted to intensive care units (ICU) possess a greater degree of knowledge and understanding of their diseases, and are, therefore, more disposed to taking part in decision-making and drawing up ADs. The literature shows that once informed, people do have a positive attitude about the opportunity to draw up an AD. They believe the document should be included in medical records, will improve their relationship with healthcare professions, and give them peace of mind. They state that the key to implementation is education, for both patients and professionals; and they commonly prefer that the initiative to provide information should come from doctors, especially family physicians. Another important finding is that most believe that having an AD will not change the attitude of their doctors regarding their care, especially when they are hospitalized.^{10, 11, 12, 13, 14, 15, 16}

It is informative to look at the demographics of individuals with ADs in Spain^{17,18,19} which have proven consistent across time. Most are women between the ages of 50-60 years, with an average to high level of education, who are autonomous in daily life; and often are chronically ill. A significant number are caregivers of patients at the end of life, and others have developed an interest through involvement with some sort of private entity with a clear ideology regarding the end of life, such as Jehovah's Witnesses or advocates of the right to decide at the end of life. Their main reason for drawing up ADs is to specify interventions which they do not wish to receive, such as limiting life support, or suggesting which drugs they want to receive in order to relieve pain. In other words, their reasons for establishing an AD involve the fear of dying in poor or undesirable health care conditions. They also often hold conversations with relatives in order to discuss their preferences for treatment and care at the end of life, and who they designate as surrogates decision-makers.

(2) Knowledge and perspectives of relatives and patient representatives

Few AD studies²⁰ have been carried out on relatives or patient representatives in Spain. Those focusing on relatives or representatives of patients in intensive care and emergency care are most notable. The studies showed a positive attitude toward ADs; and although they had very little knowledge about documents and patients' wishes, they were interested in being given more information. One study found that having a relative or friend admitted to an ICU causes people to think more about ADs.²¹ Relatives of

chronically ill patients, most commonly women and younger people, showed better knowledge of illness and ADs than did the patients themselves.²²

There is only one study²³ conducted on patient representatives, which was carried out on Catalonia's AD Registry. The most common profile of representatives that emerged from the study involved women between the ages of 50-70 whose relationship with the patient was usually that of a spouse or a child. At least 66.9% of the representatives indicated that the health care team read the ADs; 82.2% believed that the patient's will was honored, and 59% stated that professionals asked for their opinions as the patient's representative. 69.2% believed the patients had a comfortable death. In general, the representatives believed that having an AD led to more respectful care when facing death. They considered ADs to be flexible and practical, and pointed out their usefulness in: helping to agree on decisions, honoring the patient's wishes, limiting and preventing unwanted treatments, avoiding and shortening unnecessary suffering, and reassuring the patient. At the same time, they believed that there should be more information given on specific problems. The difficulties they mentioned included: (i) potential disagreements between the doctor and the wishes stated in the document; and (ii) issues concerning delays in beginning palliative care.

(3) Knowledge and perspective of health care professionals

The reports of studies carried out on health care professionals, primarily doctors and nurses in different fields of medicine, showed a positive attitude towards the potential usefulness of ADs to both professionals and the patients' family and representatives.^{24, 25, 26, 27} Although very supportive of AD dissemination and development; they were nonetheless, there was a widespread lack of basic knowledge about ADs in terms of their design, binding nature and implementation procedure.^{28, 29} Interestingly, although professionals expressed a willingness to draw up their own ADs, very few had done so.

A common feature apparent throughout the reported studies was the need for more training for healthcare professionals^{30, 31, 32}, regarding: the decision-making process at the end of life, delivering bad news, mourning, approaching palliative care, coping with suffering, and the planning of shared patient care. All issues typically included in ADs. As a result, most Spanish professionals have never informed their patients about ADs^{33, 34} and do not know whether patients admitted to their care have filed ADs. Furthermore, they seldom know how to consult the proper AD registry. This lack of knowledge is common to all hospital units^{35, 36, 37}, including those (the ICU³⁸, internal medicine wards¹¹) in which patients are often incapacitated, with the resulting risk that their advance wishes may be violated.

The ease with which ADs can be accessed varies across Autonomous Communities. For example, in Catalonia, the inclusion of ADs in the patient's medical record improves end-of-life care and compliance with patients' wishes. In contrast, in other Autonomous Communities, such as Madrid, ADs cannot be found in medical records, and can only be accessed by checking an online platform. Such registries require a password, periodic renewal of which usually expires, because ADs are rarely consulted. It is a cumbersome and logistically difficult procedure for professionals.

In addition to poor training and the cumbersome bureaucracy of the implementation procedure, the research assessments pointed out the following common problems: (i) insufficient time to complete ADs; (ii) failing to consider ADs a part of their job, (iii) disagreements between patient instructions and the opinions of relatives or doctors, (iv) instructions not in accordance with good clinical practice guidelines, (v) fear of legal action, (vi) patient prejudice about ADs and (vii) difficulty discussing death with patients themselves. It is worth noting that in contrast to the view of patients professionals thought patients should take the initiative to initiate the discussion about ADs, not the professionals themselves.

Summary of the current situation and proposal for future improvement

Studies on ADs in Spain carried out on health professionals, patients and their relatives showed that despite major legislative development, there is still a great lack of knowledge regarding the document and its implementation. The process is excessively cumbersome, and it tends to have little relevance in decision-making. This can lead to situations in which patients' ADs may not be adhered to. This remains true although among professionals and citizens there is an increasing interest in ADs and, in general, they have a positive attitude towards both ADs and ACP. In order to increase the utility and improve the availability of advance directives and advance care planning, the authors suggest several strategies. After analyzing the available bibliography on ADs in Spain, and after detecting both deficiencies and problems, the following strategies are suggested for improvement in implementing the advance decisions reached by patients. Common to all is the importance of increasing the amount of information available, in the society at large as well as to particular populations for whom it might be most relevant.

(1) Improvements in education and public awareness

It makes no sense to regulate documentation of end of life planning if no one knows anything about them or how to have one drawn up and registered. Having the population at large initiating the discussion with their health care providers or institutions is as useful as having those discussions initiated by healthcare providers and indicating to a provider a willingness to consider an AD or ACP may also

contribute to wider social acceptance. Primary care is the ideal place to start talking about the care they might wish to receive in the future, but this dialogue may also take place in other settings such as nursing homes, palliative care, or special services. And although it is useful to identify groups of patients like the chronically or terminally ill and the elderly who have a potential interest in ADs, young healthy individuals may also find themselves in extreme situations in which they may no longer be able to make their own decisions.

(2) Document improvement

Inconsistencies in requirements of and access to ADs among the various Autonomous Communities can make general information hard to provide. Fast, adequate procedures should be established in the Spanish health system to facilitate AD use, with appropriate ways for users to draw them up in a simple way, specific procedures for primary and specialist care, and user-friendly instructions and tools. When ADs are included in the medical record, as in Catalonia, they are more easily integrated into regular clinical relationships. A state-wide expectation of a specific period of validity or reviews after a certain time period would allow the ongoing adaptation of the documents to the individual's values, needs and preferences as their health situation changes. And it is important to name a patient representative (or several) who knows the individual's preferences when the document is drawn up. This representative may be able to clear up doubts and act as a person of reference in confusing situations or in circumstances not specified in the document. Creating an AD must be performed with the advice of health professionals, and professionals must record the document in the medical record and assure they are considered in decision making.

(3) From AD to ACP

Finally, despite any potential improvements which may be implemented, there are problems with advance directives that cannot be solved. They are static documents which are sometimes difficult to interpret, and they can be difficult to find and to consult. An Advance Care Plan (ACP) is a more effective and comprehensive way to respect patient wishes, and the authors recommend this more expansive discussion, which may include the drafting of an AD, to health care professionals and the community at large.

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