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ORIGINAL RESEARCH

Do Spanish Hospital Professionals Educate Their Patients About Advance Directives?

A Descriptive Study in a University Hospital in Madrid, Spain

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Abstract It is unknown whether hospital-based medical professionals in Spain educate patients about advance directives (ADs). The objective of this research was to determine the frequency of hospital-based physicians' and nurses' engagement in AD discussions in the hospital and which patient populations merit such efforts. A short question-and-answer-based survey of physicians and nurses taking care of inpatients was conducted at a university hospital in Madrid, Spain. In total, 283 surveys were collected from medical professionals, of whom 71 per cent were female, with an average age of thirty-four years. Eighty-four per cent had never educated patients about ADs because of lack

of perceived responsibility, time, or general knowledge of ADs. Patient populations that warranted AD discussions included those with terminal illnesses (77 per cent), chronic diseases (61 per cent), and elderly patients (43 per cent). Regarding degree of AD understanding in medical professionals: 57 per cent of medical professionals claimed sufficient general knowledge of ADs, 19 per cent understood particulars regarding AD document creation, and 16 per cent were aware of AD regulatory policies. Engagement in AD discussions was considered important by 83 per cent of medical professionals, with 79 per cent interested in participating in such discussions themselves. The majority of hospital physicians and nurses do not educate their patients about ADs, despite acknowledging their importance. Patient populations of highest priority included those with terminal diseases or chronic illness or who are of advanced age.

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Introduction

The traditional doctor-patient relationship follows an authoritarian (“beneficence”) model in which a doctor’s decision-making presides over the well-being of the patient (Gracia 2001). In the late twentieth century, however, this clinical relationship changed as the importance of the individual patient’s own views was recognized. In the present day, both professionals

and patients are actively involved in shared decision-making, in which patients are able to freely express opinions and beliefs and make decisions accordingly (Emanuel and Emanuel 1999).

This emphasis on incorporating patient “autonomy” into medical decision-making is reflected in the widespread use of advance directives (ADs).¹ Advance directives are written documents in which an individual can express his or her will regarding ongoing or future medical treatments when their capacity to do so directly may be compromised (such as in cases of cognitive dysfunction and coma). In common parlance, these documents are also often termed “living wills” (Gracia and Rodríguez Sendín 2006). The content of the AD documents may vary. They can include the withdrawal of certain treatments or measures (e.g., life support), or to carry out a particular measure (e.g., palliative treatment), but always within what is considered “good practice.” Therefore, an AD document cannot include any action that may be deemed medical “bad practice.”

Bioethics requires practical tools in order for the reflections it produces to become truly useful. The elaboration of ADs makes it possible for the ethical aspects of clinical practice, such as respect for patients’ decisions, to be laid down in written documents that make it easier to put them into practice. In a certain sense, they are documents that fall somewhere between ethics and legality; two fields that, though each possesses its own characteristics, must be made to work together. On some occasions, they must be used to harmonize certain topics, as is done in this case with patient freedom through the AD.

In the fields of both bioethics and healthcare law, each country in the European Union (EU) has its own mechanisms and specifics. For example, the culture of respect for individual freedom in the tradition of English-speaking countries is not the same in Mediterranean countries, which have more of a community mindset and are less individualistic. If we add to this the fact that implementation of both bioethics and healthcare law have not been harmonized throughout EU countries, one can understand why the regulatory frameworks related to clinical

ethics, laws, and the way they are put into practice are quite unequal within the EU. In the specific case of ADs, each country in the EU governs and regulates the use of ADs through country-specific policies. In the case of Spain, country-wide AD regulatory policies have been in effect since 2002; in Madrid, the capital of Spain, since 2005. In all EU countries, it is a universal requirement that the patient himself or herself compose the AD.

While the concept and spirit of AD policies among EU countries are similar, there exist different nuances (Van Beek et al. 2013; Andorno et al. 2015; Jox et al. 2013; van der Ham et al. 2013; Peterková 2013; Pereira 2013; Sheldon 2013). Differences exist in various areas, such as the required presence of certain agents for document creation (e.g., notary, public health administration officials, witnesses, or family doctor) and the statutory duration of validity. For example, ADs in France are valid for three years and are renewable (Perceau et al. 2014), while in Spain such term limits and processes are undefined. In Spain, AD can be performed in the presence of a notary, three witnesses (two of which should not have a close relationship with the patient), or public health administration officials.

In recent years, studies in Spain have investigated patients’ opinions (Antolín 2010) and level of knowledge and satisfaction (Molina et al. 2011; Pérez et al. 2013) regarding ADs. The degree of understanding of ADs by family members (Arauzo et al. 2010) and professionals in primary care services and emergency units (Mateos, Huerta, and Benito 2007) has also been studied. However, a similar inquiry into medical professionals who work with inpatient populations in Spanish hospitals is lacking. In addition, it is not known whether such professionals inform their patients about ADs.

In this study, our main objectives were to demonstrate (Andorno et al. 2015) how hospital-based physicians and nurses working with inpatient populations educate patients about ADs and (Antolín 2010) the types of patients they believe warrant AD discussion and education. Secondary objectives of the study were to determine the presence of the following in hospital-based medical professionals: (Andorno et al. 2015) the degree of knowledge of ADs; (Antolín 2010) the extent of awareness of how to create AD documents; and (Arauzo et al. 2010) the level of interest in implementing AD measures themselves.

¹ Law 3/2005, May 23, which regulates the exercise of the right to formulate advance directives in health and creates the appropriate registry. BOCM 140, June 2005.

Methods

Design, Population, and Study Variables

We performed a cross-sectional study of doctors and nurses from the University Hospital Alcorcon Foundation of Madrid, Spain, who work directly with hospitalized inpatients. The study passed the hospital's research ethics committee. In 2012, sealed envelopes containing multiple-choice and short-answer surveys (Table 1) were distributed to individual medical professionals in the following clinical departments: allergic diseases, cardiology, general surgery, critical care, gastrointestinal diseases, endocrinology, gynaecology, haematology, laboratory and pathology service, general internal medicine, nephrology, pulmonology, neurology, medical oncology, rehabilitative service, emergency department, urology, and orthopaedic surgery.

Demographic information that was collected from eligible study participants included age, sex, occupation, medical specialty, and duration of practice in the current clinical position held. The survey questions asked professionals to specify details about various aspects of knowledge of, view towards, and approach regarding the use of ADs in routine practice. The survey questions were divided into three sections:

1. Importance of ADs in discussions between professionals and patients: Have you ever informed a patient about what ADs are and how to perform them? If not, why not? Which type of patient would you definitely choose to inform about ADs? Have you ever asked the patients if they have filled out AD documents? If answering "yes," have you entered such AD data into the patients' medical records? Who do you think should ideally inform patients about ADs?
2. General knowledge and understanding about ADs: Do you know what ADs are? If answering "yes," the respondent was requested to provide a definition of ADs that was later evaluated by a member of the research team as a separate variable we termed "real AD knowledge." Do you know the regulatory policies regarding creation of ADs in Madrid? Do you know how a patient can create an AD? Do you know how to find out whether a patient has created an AD in the past?
3. Other questions: How many patients regularly create AD documents? Do you consider it important to

create ADs? Would you create your own AD document? (choices: yes; no; not sure).

After completing the survey, respondents were instructed to seal their responses in provided envelopes that were collected one week later by the research study team. This method was chosen to minimize external influence on respondents' answers and to ensure anonymity. All demographic and question-based survey data were then analysed by the research team.

Sampling Strategy and Sample Size

Given the absence of any prior data on AD information-sharing between medical professionals and patients in Spain, our ability to optimize the power of our study based on suitable sample size was limited. Estimates were made based on the general degree of knowledge of ADs among Spanish health professionals, which has been reported to be 74 per cent based on a prior study of emergency department physicians and nurses. As our study included resident physicians who may be less well versed in AD information, we further adjusted this value downward to an overall average of 60 per cent. Assuming a precision of 5 per cent and a 95 per cent confidence interval, we therefore calculated that the required minimum sample size was 270 surveys. Considering that 30 per cent of professionals often refuse to participate, a minimum of 385 surveys was required.

Statistical Analysis

Our descriptive analyses express qualitative variables as percentages and quantitative variables using the mean with standard deviation (SD). The association among the qualitative variables was studied by the chi-squared test, while the student's t-test was used to compare quantitative variables. The distribution of the quantitative variables was studied with a *p* value of 0.05 indicating significance in all cases.

Results

Four hundred surveys were distributed with a response rate of 70.7 per cent (*n* = 283). The distribution of surveys among the different services is shown in Table 2. Of the medical professionals who responded,

Table 1 Questionnaire on knowledge and attitude to advance directives

In order to assess the knowledge and attitude of health professionals to Advance Directives (AD), also known as living wills, we will appreciate you responding to this short questionnaire. Thank you very much for your feedback.

Gender: Male: Female: Time worked (years): _____ Age: _____

Work Category: Doctor Resident Nursing Service: _____

1. Do you know what the AD are? Yes No Not sure
If so, define briefly what AD are: _____

2. Do you know the regulatory policies regarding creation of AD in Madrid? Yes No

3. Do you know how a patient can create an AD? Yes No Not sure
If so, explain briefly how: _____

4. Do you know how to find out whether a patient has created AD in the past?
Yes No Not sure

5. Who do you think should ideally inform patients about AD?

- Physician treating in the hospital
- General practitioner
- Social worker
- Public administration official
- Other (specify) _____

6. Have you ever informed a patient about what AD are and how to perform them?
Yes No

If not, why not?

- Do not know what AD are
- Addressing AD does not seem important
- Do not consider it part of my job
- No time to do it
- Other (specify) _____

7. Which type of patient would you definitely choose to inform about AD? Point out those you consider.

- Dementia
- Terminal illness
- Disabling chronic disease
- Elderly patients
- Other (specify) _____

8. Have you ever asked the patients if they have filled out AD documents? Yes No
If so, have you entered such AD data into the patients' medical records? Yes No

9. How many patients regularly create AD documents?

- None
- Nearly none
- Some
- Many
- Nearly all

10. Do you consider it important to create AD? Yes No Not sure

11. Would you create your own AD document? Yes No Not sure

Table 2 Distribution of the surveys among services

	Service	% (n)
Medical Specialties	General internal medicine, pulmonology, cardiology, nephrology, neurology, gynaecology, and gastrointestinal diseases.	42.6 (52)
	Emergency department and critical care.	19.7 (24)
	Oncology-haematology.	17.2 (21)
Surgery Specialties	Orthopaedic surgery, general surgery and urology.	16.4 (20)
Outpatients	Allergic diseases, endocrinology, laboratory and pathology services, and rehabilitative service.	4.1 (5)

51 per cent were nursing staff, 33 per cent were senior doctors and 16 per cent were medical residents. Women represented 71 percent of respondents, and the average age was 34 (7.9) years old with an average working period of ten (7.3) years. 84 per cent of the doctor respondents had never informed their patients about the AD (Table 3). One-third of study participants did not consider AD discussions with patients to be part of their job description, while others frequently cited insufficient time to inform, or inadequate knowledge of ADs (Table 4).

Patient subgroups most thought to benefit from information about ADs included those with terminal diseases, those with chronic diseases, and elderly patients. As to who should provide the information, most professionals considered this the responsibility of the primary care physician, followed by both the public administration official and the attending physician for inpatient care of the patient (Table 4).

As regards the knowledge of AD particulars, 57 per cent of survey respondents claimed to know what ADs were. When their short-answer definitions of what constitutes ADs were reviewed, however, we found that

only 46 per cent had an accurate knowledge about ADs. Other data revealed that 19 per cent knew how to create ADs; 16 per cent were aware of regulatory policies regarding ADs; 14 per cent knew how to locate AD documents created in the past; and 13 per cent had asked patients about previous AD implementation. As shown in Table 2, the degree of knowledge among doctors varied according to medical specialty ($p = 0.007$). We found a greater extent of knowledge regarding ADs among certain specialist doctors, particularly in haematology and oncology (100 per cent were knowledgeable). The nursing staff showed no statistically significant differences between specialty groups ($p = 0.084$).

Out of all respondents, 7.4 per cent believed that no patient had ever created AD documents; 64 per cent believed that almost none had; 24 per cent felt that some patients had; and 2 per cent thought that many had done so. Eighty-three per cent of professionals considered implementing ADs to be important.

The healthcare personnel indicated interest in creating AD documents themselves in 79 per cent of cases, with nursing staff exceeding doctors by 10 per cent.

Table 3 Answers according to professional category

	Doctors % (n)	Nursing % (n)	p
Inform about AD and how to perform them	15.21 (21)	5.67 (8)	0.015
Ask whether patients filled out AD	22.30 (31)	4.22 (6)	<0.0001
Know the AD documents	60.40 (84)	33.10 (47)	<0.0001
Know the regulation	23.02 (32)	9.30 (13)	0.002
Know how a patient can create an AD	25.89 (36)	11.97 (17)	0.,0001
Register in medical record	20.14 (28)	4.22 (6)	0.0001
Know how to find out them	22.3 (31)	5.63 (8)	<0.0001
They would like to create their own AD	68.60 (94)	78.40 (109)	0.087

Table 4 Professionals' opinions regarding the information on ADs

		%(n)
Which type of patient would you inform?	Dementia	19.1 (25)
	Terminal illness	77.1 (101)
	Chronic disease	61.1 (80)
	Elderly patients	43.5 (57)
	Other (specify)	
	All persons	18.3 (24)
	All patients	9.9 (13)
	Nobody	0.7 (1)
	The patient who requests it	1.5 (2)
	In an irreversible situation	0.7 (1)
Who should inform?	Physician treating in the hospital	48.9 (64)
	General practitioner	62.6 (82)
	Social worker	21.4 (28)
	Public administration official	54.2 (71)
	Other (specify)	
	Any sanitary professional	2.3 (3)
	Nursing staff	4.5 (6)
	Social organizations	0.7 (1)
Why do they not inform patients?	Do not know what ADs are	18.3 (20)
	Do not think it is important	12.8 (14)
	It is not part of my job	33.9 (37)
	Do not have time	21.1 (23)
	Other (specify)	
	Have not had the occasion	13.8 (15)
	Do not know how to perform the AD	9.2 (10)
	Others	13.8 (15)

Among medical professionals, surgery specialties were less willing to perform the AD than other specialties. Among professionals who would like to create ADs, 98 per cent consider AD implementation by the patients themselves to be vital, but only 12.8 per cent of them have actually informed the patients about how this may be achieved. The differences between various professions are shown in Table 3.

Discussion

In our study, we found a number of revealing observations about the knowledge, perspective, and approach of healthcare professionals in AD discussions with patients

in Madrid, Spain. Most notably, a large majority of professionals (83 per cent) consider AD creation and implementation important, but only 16 per cent have informed their patients about them. Interestingly, the main reasons cited for this discrepancy are a lack of feeling of responsibility for doing so (as many do not consider it part of his or her job description), an absence of time to do so, and inadequate knowledge of ADs. In order for this situation to improve, advances need to be made in these areas: enhanced general education and training on the form and function of ADs and increased opportunities during clinical practice workflow to engage in AD discussions with patients.

Proper identification and recognition of suitable agents for AD discussions and document creation and

implementation need to be clarified. Is it the hospital-based physician's, the primary care physician's, or the medical specialist's role to educate patients about ADs? Undoubtedly, primary care physician involvement is essential, given that patients often have a more prolonged follow-up and greater trust in these doctors. This conclusion has been seen in past studies and was echoed in our study as well, as more than half of the respondents identified the primary care physician as the most suited individual for this role. Nevertheless, one should not forget the importance of hospital professionals in these discussions (Herrerros et al. 2012), since inpatient admissions due to acute illness often influence patients to become more receptive to conversations about ADs. The growing importance of multidisciplinary team-based care and care coordination in improving overall health outcomes is applicable to ADs as well. As such, we feel that AD information-sharing and decision-making should be multidisciplinary and coordinated, not just involving primary and specialized care professionals but also public administration officials and social workers.

Another major finding in our study is the fact that patients of advanced age or suffering from chronic or terminal illness were considered more deserving of AD information. In keeping with the multidisciplinary approaches to healthcare mentioned earlier, we suggest that the hospital-based medical professionals should especially focus their efforts on AD engagement in these patient populations. Furthermore, both primary care and specialist physicians play a key role in AD education in these patients. It is concerning that only 19 per cent of respondents feel responsible for AD education to patients with dementia. This observation further highlights the perceived lack of knowledge about ADs, since patients need to be of legal age and sound mental capacity in order to properly complete AD documents.² Medical professionals should better understand ADs as a useful tool in the protection of patient autonomy in medical decision-making, which takes on special importance once the individual's ability to articulate his or her wishes is lost.³

Regarding knowledge about ADs, our study extends the findings of prior studies of inadequate understanding of ADs in primary care (Simón-Lorda et al. 2008), intensive care (Solsona et al. 2003), and emergency department settings (Wiese 2011) by demonstrating that marked lack of knowledge of ADs is even higher among hospital-based professionals. This may have been influenced by the age of the participants in our study, who had an average age of thirty-four years and an average working period of ten years. Older age, female gender, and occupation in medical (as opposed to surgical) clinical services were associated with greater knowledge about ADs, a finding seen in other studies as well (Mateos, Huerta, and Benito 2007). In our study, we observed that older professionals asked patients more often about ADs and were most likely to engage them in education regarding AD document creation and implementation.

The majority of medical professionals in our study did not know the method of creating and registering AD documents, a finding that reveals the lack of sufficient education regarding AD policies. Efforts should be made to enhance understanding of how AD documents are created, implemented, and enforced to improve health system efforts for better use of ADs in clinical care (Herrerros et al. 2012).

None of the aspects cited in this discussion as requiring improvement is reflected in the law, neither in Spanish law nor in that of other EU countries. Laws and regulations establish a minimum so that the people may exercise a right, which in this case means honouring the decisions of the sick about the way in which their own body is to be handled. However, beyond that minimum, there are many finer details that are not regulated but are necessary in order for the contents of laws and regulations to be truly put into practice. No matter how many laws and regulations are enacted regarding ADs, if their implementation after enactment is lacking, people will be unable to properly exercise their right to decide when they are no longer able to do so. And it will be impossible to put all of the work on reflection and debate carried out in the field of bioethics into practice properly. Bioethics practices that have no effect on real life are not truly useful, and regulations that are poorly designed or not appropriately put into practice are not either. In bioethics and healthcare law, work must be carried out at the same time on the practical aspects that make it possible for all the reflection and guidelines to have an effect on real life.

² Law 41/2002, November 14, regulating patient autonomy and rights and obligations of information and clinical documentation. BOE. 274, November 2002.

³ Law 3/2005, May 23, which regulates the exercise of the right to formulate advance directives in health and creates the appropriate registry. BOCM 140, June 2005.

Otherwise, the work that is performed in both of these areas will be fruitless. In this sense, we must highlight that healthcare professionals hold responsibility in terms of the laws and rules governing their area of work. This responsibility includes making the means for enforcing the rules and regulations available, so that they become more than just a legal document. Healthcare professionals must not wait for lawmakers to solve problems. They themselves must work to make sure that the rules and laws are applied.

Therefore, in the specific case of ADs, in addition to reflecting about their meaning and the values involved, and as well as enacting regulations, it is important to consider the following factors: Who should be putting them into practice? In what way? Which patients should be given priority? In what way should training be given to professionals? How should the population be educated and information disseminated amongst the people? What resources are needed to do so? Who should be coordinating all of these programs? At the same time as considering all of these questions, we must attempt to provide a response to them. Our study only allows us to affirm what has already been highlighted above, and therefore it is of great importance to carry out further studies to find answers to these questions, both inside the EU and in other countries in which ADs are currently a reality. In all of these countries, it must be evaluated whether they are actually being put into practice and, if so, in what way. By doing this, it will become possible to detect potential aspects that require improvement.

In conclusion, our study demonstrates that the vast majority (84 per cent) of hospital-based physicians and nurses do not inform or adequately engage their patients in AD education or discussions, despite acknowledgement of the importance of ADs. Those patient populations who particularly merit such discussions are those with terminal or chronic illness or are of advanced age.

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