

# **Knowledge and Attitudes of Medical Staffin Two Health Districts Concerning Living Wills**

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**Objectives.** To explore the knowledge and attitudes of physicians towards advance directives in 2 healthcare areas. To compare the outcomes of both areas. To compare the outcomes of primary healthcare and specialised healthcare.

Design. A cross sectional, descriptive study by means of a self-administered questionnaire.

Setting. North-Málaga and North-Almería healthcare areas, Spain.

Participants. Physicians of primary and specialised healthcare.

Measurements and main results. Knowledge and attitudes towards advance directives. 194 (63.19%) questionnaires were filled out by the physicians from both healthcare districts. Mean age (standard deviation) 42.54 (80.85); 65.5% of participants were men and 33.5% were women; 51.55% from primary care and 48.45% from specialised healthcare.

Conclusions. Polled physicians revealed a positive attitude towards the usefulness of advance directives for the patient's relatives and for healthcare professionals. They also show a positive attitude towards the use and respect of advance directives. They show a high predisposition to registry their advance directive, but a low predisposition to do so in a short term.

Key words: Health care directives. Living wills. Advance directives. Advance care planning. Bioethics.

CONOCIMIENTOS Y ACTITUDES DE LOS MÉDICOS EN DOS ÁREAS SANITARIAS SOBRE LAS **VOLUNTADES VITALES** ANTICIPADAS

Objetivos. Explorar los conocimientos y actitudes de los médicos acerca de las voluntades anticipadas en dos áreas de Andalucía. Comparar los resultados de ambas áreas sanitarias. Comparar los resultados de los médicos de atención primaria y atención especializada. Diseño. Estudio descriptivo, transversal, mediante cuestionario autocumplimentado. Emplazamiento. Área Sanitaria Norte de Málaga y Área Sanitaria Norte de Almería. Participantes. Médicos de atención primara y especializada.

#### Mediciones y resultados principales.

Conocimientos y actitudes acerca de las voluntades vitales anticipadas (testamentos vitales); 194 médicos respondieron al cuestionario (tasa de respuesta del 63,19%). Media de edad ± desviación típica, 42,54 ± 80,85 años; el 65,5%, varones, y el 33,5%, mujeres. El 51,55%, médicos de atención primaria, y el 48,45%, de especializada. Conclusiones. Hay una actitud favorable hacia la utilidad de las voluntades anticipadas tanto para los familiares del paciente como para los profesionales sanitarios; también hacia su utilización y respeto. Desean manifestar su propia voluntad anticipada aunque no en un futuro cercano. El personal de atención primaria muestra una actitud más favorable hacia las voluntades anticipadas en algunos ítems que el personal de especializada.

Palabras clave: Instrucciones previas. Testamentos vitales. Voluntades anticipadas. Planificación anticipada. Bioética.

Spanish version available

A commentary follow this article (page. 67)

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\*The investigators of the project "In the end, you decide" are presented at the end of the article.

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## Introduction

ttempts are being made to improve the health care of the population with the use of advance health care directives.

Advance health care directives or previous instructions are documents which enable a person to state the health treatments that they wish to receive if the time comes to make decisions when they may be physically or psychologically unable to make them for themselves. These documents are also known as living wills. This citizen right also helps health professionals to make better decisions for the patient in clinical situations where they cannot express their wishes.

According to the data compiled in the Autonomous Community Registers up to June 2007, 36 289 people in Spain have made their advance directive since the laws<sup>1</sup> that regulate advance directives came into force in our country.

However, the making of decisions at the end of life should not be limited to the simple signing of a document. This process must be thought through, reflected upon and informed, and be part of an integrated process of participation called "advance decision planning."2-6

The creation of living wills and their corresponding registers arose so that doctors might communicate in a permanent way, making use of a general guideline or rule in which to take refuge. However, if health professionals do not have the knowledge and the attitude required to work with this tool, living wills and the advance planning process will be in danger of not being used correctly.

In general, there is not very much in the literature on the subject of living wills in Spain, 8-11 and what there is, is mainly theoretical. 12-16 There have been few studies carried out in our country on the knowledge and attitudes of the population<sup>17</sup> or health professionals on living wills and advance planning in general.

The objective of the present study is to examine the knowledge and attitudes of the medical staff of the North Malaga and North Almeria Health Areas.

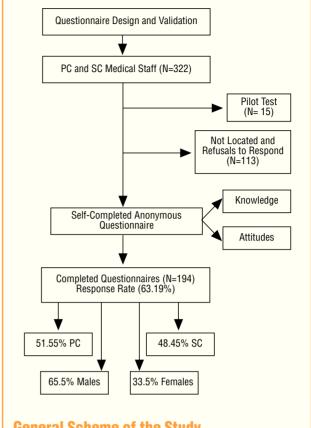
## Methods

#### Design

A descriptive, cross-sectional study was performed in primary and specialized care by means of a questionnaire, in the North Malaga and North Almeria Health Areas.

#### **Study Population**

The total population was made up of 322 primary and specialized care doctors from both areas. To comply with the inclusion criteria, the professionals surveyed had to be family doctors in primary care or specialized care physicians in internal medicine,



### **General Scheme of the Study**

A cross-sectional, descriptive study on the knowledge and attitudes of primary care (PC) and specialized care medical staff on advance directives.

traumatology, mental health, rehabilitation and preventive medicine. Of these 322 professionals, 15 participated in the questionnaire pilot study. It was not considered appropriate to carry out sampling due to the population size, so the final study population was made up of a total of 307 doctors.

#### Questionnaire

A self-administered anonymous questionnaire was used, designed and validated by the research team to achieve the objectives of this study. This questionnaire examines the sociodemographic variables (age, sex, and care level), as well as the knowledge and attitudes of the doctors on living wills. The first 3 items of the questionnaire examine the knowledge of the doctors on living wills, while the following 9 items examine the attitudes of these professionals towards these documents.

The questionnaire is composed of dichotomic variables and a Likert type scale (0-10).

The design and validation of the questionnaires guarantees its validity and reliability, since it was submitted to an expert panel, a judges test and a test-retest reliability test. Finally, a pilot test was carried out with 15 participants.

The complete questionnaire, available on the Internet, is shown in Appendix 1.

#### Methods

This study was carried out within the framework of a wider project called "In the end, you decide," approved and authorised by the Andalusia School of Public Health Research Committee of Granada.

In primary care, a member of the link nursing staff was responsible for the distribution and collection of the questionnaires, whilst in specialized care it was the social worker of each hospital who was responsible for carrying out this task.

The verbal consent of the participants was sought before handing out the questionnaire. The origin of the study was explained and confidentiality and anonymity of the data were guaranteed. This information was also given in writing as an attachment to the questionnaire.

The survey was carried out between December 2005 and January 2006.

#### Data Analysis

The data obtained were analysed with the program SPSS for Windows version 14.0. The descriptive results of the 2 health areas are shown and the responses of the medical staff of both areas are compared using the  $\chi^2$  test or the Student t test.

## Results

The total number of doctors who responded to the questionnaire was 194 (63.19%), with a mean age of 42.54±80.85 and a range of 25-63. Of those surveyed, 65.5% were males and 33.5% female. There were 51.55% primary care doctors and 48.45% from specialized care.

<b>TABLE</b>	Knowledge and Attitudes of Medical Staff
1	of the 2 Health Areas*

Quantitative Variables  Question		Tota	ls			Malaga NHA					Almeria NHA			
		SD Minimum Maximum		Mean	SD Minimum		Maximum	Mean	SD	Minimum	Maximum	P		
1. Knowledge of AD														
Very poor 0 1 2 3 4 5 6 7 8 9 10 Excellent	5.29	2.526	0	10	5.01	2.415	0	10	5.53	2.608	0	10	.151	
4. Good idea to plan and write health wishes														
Not a good idea 0 1 2 3 4 5 6 7 8 9 10 Very good idea		2.093	0	10	8.22	2.059	0	10	8.29	2.131	2	10	.813	
5. Useful tool for professionals														
Not useful 0 1 2 3 4 5 6 7 8 9 10 Very useful		2.259	0	10	7.87	2.247	0	10	8.33	2.257	0	10	.154	
6. Useful tool for families														
Not useful 0 1 2 3 4 5 6 7 8 9 10 Very useful	8.23	2.074	0	10	8.0	2.107	0	10	8.37	2.044	3	10	.307	
7. The representative helps professionals to make decisions														
Not at all 0 1 2 3 4 5 6 7 8 9 10 A lot		2.516	0	10	7.63	2.519	0	10	7.70	2.524	0	10	.848	
8. You would recommend your patients to make an AD														
Never 0 1 2 3 4 5 6 7 8 9 10 Always	7.88	2.394	0	10	7.45	2.531	0	10	8.26	2.207	0	10	.018	
9. You would like their families to make an AD														
Would not like that at all 0 1 2 3 4 5 6 7 8 9 10 Would like that a lot	7.95	2.294	0	10	7.86	2.293	0	10	8.04	2.303	0	10	.583	
10. You would comply with their AD														
Unlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely	7.99	2.769	0	10	7.81	2.724	0	10	8.15	2.812	. 0	10	.404	
11. You would respect the AD of a patient														
Never 0 1 2 3 4 5 6 7 8 9 10 Always	9.04	1.512	4	10	8.90	1.430	5	10	9.16	1.578	4	10	.242	
12. You would make an AD next year														
Unlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely	5.30	3.542	0	10	5.00	3.396	0	10	5.56	3.663	0	10	.275	
Quantitative Variables		Totals			Malaga	a NHA			P (χ² Test)					
Question														
2. ADs are regulated by the law in Andalusia														
Yes		135 (69.	6%)			60 (65	5.9%)			75	(72.8%)		.101	
No		7 (3.6%)				6 (6.6%)				1 (1.0%)				
DK/NR		52 (26.8%)				25 (27	7.5%)		27 (26.2%)					
3. Have read the Andalusia AD document														
Yes		73 (37.6	6%)			29 (31	.9%)			44	(42.7%)		.120	
No		121 (62.	4%)			62 (68	3.1%)			59	(57.3%)			

<sup>\*</sup>SD indicates standard deviation; DK/NR, don't know or no response; AD, advance directives; NHA, North Health Area.

The reasons why some doctors did not complete the questionnaire were either due to their refusal to respond or because it was not possible due to their situation (sick, holidays...).

The data which describe and compare the knowledge and attitudes of the doctors of both health areas are shown in Table 1.

No significant statistical differences were found between the 2 areas, except in item number 8.

Table 2 shows the data obtained for primary care and specialized staff. Differences were found in items 7 and 11 where the attitude of primary care medical staff is significantly more positive towards living wills than specialized care is. Differences were found in the significance limits in item 10.

## **Discussion**

Firstly some considerations have to be made on the nature of the methodology which, to a greater or lesser extent, could affect the validity of the data. The difficulty in extending the results obtained to a general medical population needs to be pointed out. Similarly possible selection biases produced during the data collection process or to the limitations that could be derived from the validation of the questionnaire, should also be considered.

In general, we can deduce from the results obtained that knowledge of advance directives by medical staff could be much better. These professionals self-scored their knowledge with 5.29. That they are regulated by law was known by 69.6% and only 37.6% say that they have read the Andalusian Advance Directive document.

TABLE 2	Knowledge and Attitudes of Doctors as Regards Their Specialty*													
Quantitative Variables			itals		Primary Care				Specialised Care					
Question		Mean	SD Mi	nimum	Maximum	Mean	SD Mi	nimum	Maximum	Mean	SD	Minimur	m Maximum	P
1. Knowled	dge of AD													
Very po	oor 0 1 2 3 4 5 6 7 8 9 10 Excellent	5.29	2.526	0	10	5.33	2.374	0	10	5.24	2.69	1 0	10	.815
4. Good ide	ea to plan and write health wishes													
Not a good idea 0 1 2 3 4 5 6 7 8 9 10 Very good idea		8.26	2.093	0	10	8.35	1.982	2	10	8.16	2.21	1 0	10	.528
5. Useful to	ool for professionals													
Not us	eful 0 1 2 3 4 5 6 7 8 9 10 Very useful	8.11	2.259	0	10	8.31	2.029	2	10	7.90	2.47	6 0	10	.212
6. Useful to	ool for families													
Not us	eful 0 1 2 3 4 5 6 7 8 9 10 Very useful	8.23	2.074	0	10	8.44	1.805	3	10	8.00	2.31	7 0	10	.145
7. The repr decisior	resentative helps professionals to make ns													
Not at a	all 0 1 2 3 4 5 6 7 8 9 10 A lot	7.66	2.516	0	10	8.03	2.120	2	10	7.27	2.84	0 0	10	.037
8. You wou	uld recommend your patients to make an AD													
Never		7.88	2.394	0	10	8.06	2.238	0	10	7.69	2.54	9 0	10	.282
9. You wou	ıld like their families to make an AD													
Would not like that at all 0 1 2 3 4 5 6 7 8 9 10 Would like that a lot		7.95	2.294	0	10	8.08	2.159	0	10	7.82	2.43	6 0	10	.428
10. You wo	ould comply with their AD													
Unlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely		7.99	2.769	0	10	8.36	2.385	0	10	7.59	3.09	4 0	10	.056
11. You wo	ould respect the AD of a patient													
Never (	0 1 2 3 4 5 6 7 8 9 10 Always	9.04	1.512	4	10	9.27	1.221	5	10	8.78	1.74	4 4	10	.028
12. You wo	ould make an AD Next year													
Unlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely		5.30	3.542	0	10	5.38	3.461	0	10	5.20	3.64	3 0	10	.732
Quantitative	Variables		Tota	ls			Primary	/ Care			Speci	alised Ca	re	P (χ² Test)
Question														
2. ADs are	regulated by the law in Andalusia													
Yes		135 (69.6%)				66 (66%)			69 (73.4%)				.394	
No		7 (3.6%)				5 (5%)			2 (2.1%)					
DK/NR			52 (26		29 (29%)				23 (24.5%)					
3. Have rea	ad the Andalusia AD document						······································							
Yes			73 (37	.6%)			33 (3	3%)			40	(42.6%)		.170
No			121 (62	2.4%)			67 (6	7%)			54	(57.4%)		

<sup>\*</sup>SD indicates standard deviation; DK/NR, don't know or no response; AD, advance directives.

As regards the attitudes of the doctors about advance directives, in general, they revealed a positive attitude towards these documents.

It is worth mentioning the great contradiction found between the theoretical readiness and the real possibilities of complying with an advanced directive.

In our country, there are few studies that have examined the knowledge and attitudes of doctors towards advance directives and towards advance planning in general.

The study by Bachiller et al<sup>18</sup> showed that only 10.8% of doctors surveyed knew the legislation on advance directives in detail, 9.8% had detailed knowledge of the existence of advance directives in other autonomous communities. That all patients must be informed on the existence of this document was expressed by 98.2% and 31.5% had no reservation in applying the will of the patient. Santos de Unamuno et al<sup>19</sup> polled 169 family doctors and found that 82.5% of those surveyed considered their knowledge on advance directives to be limited or zero. Only 11.8% had read the current legislation, and 97% were in agreement that advance directives could help in decision mak-

In Canada, Hughes et al<sup>20</sup> found that family doctors were supporters of advance directives, but they used them very infrequently. The majority of these professionals were of the opinion that education programs about these were needed.

## **What Is Known About the Subject**

- Advance directives did not have legal value in Spain until the year 2000.
- From that time there has been a proliferation of laws on this subject.
- However due to the newness of these documents, there are few studies on advance directives in general, and studies on the knowledge and attitudes to these of medical staff are very limited.

#### **What This Study Contributes**

- The doctors surveyed showed a very positive attitude towards the usefulness, use and respect of advance directives.
- Doctors expressed great willingness to comply with their advance directive although not in the near future.
- This study demonstrates the need to extend training on advance directives for the doctors of both districts studied.

Other surveys carried out on family doctors in Finland<sup>21</sup> and Australia<sup>22</sup> are also in agreement with our study on the positive attitude of these professionals towards advance directives and in the need to improve their knowledge on the legislation and its use.

The previously mentioned facts demonstrate the need to establish training programs on advance directives and advance planning in general, which would enable doctors to use a tool which, if used correctly, could benefit both the users and the professionals of our health system.

It also must be pointed out that to establish suitable and effective programs, it would be of great importance to develop new lines of research aimed at determining which programs would be most suitable for training and educating our professionals. In the international scene, studies have been carried out<sup>23-25</sup> with the aim of identifying the effectiveness of different education programs to improve the knowledge, attitudes and skills of doctors as regards advance directives. To develop projects of this nature in Spain would involve a great leap forward for research into advance planning and the end of life, enabling the health system to provide suitable programs to suit the needs of doctors.

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Investigators of the "In the end, you decide" project

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#### COMMENTARY

# Advance Directives: The Challenge for Developing a Role From Primary Care

#### Fernando Flordelís Marco

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The basis of advance health care directives (AHCD) is the respect and promotion of personal freedom. The content of this law, due to its sensitivity and importance, should beg a question to organisations and doctors: Do we have the challenge to develop an active role from the field of primary care? I believe we have.

Let's look at some of the evidence.

The concept of advance directives is more than just legal considerations and is, in the health environment, an advanced expression of the freedom of choice of people which determines the freedom to accept or reject certain medical treatments according to the life circumstances and personal values.

Social progress seen as favourable by the population within the framework of well-being fosters the freedom of choice in doctor-patient shared decisions, overcoming the paternalistic attitudes of doctors, as well as the perceptions of the state as supreme guardian of the interests of individuals. As mentioned in the study, 36 289 people in Spain have filled in their AD document. Without a doubt it is an interesting path, but experts like the late David Thomasma stated that "The living will is only effective within a close clinical relationship" (DM, May 25, 2001). All an integral process of participation within the framework of advance decision planning, which the authors of the study point out.

Therefore, to examine the knowledge and attitudes doctors and health professionals to establish the improvements necessary to guarantee the use of this right of the people, should be a prime objective as a first step to planning concrete strategies in our health centres.

For the people, to be faced with death is an important maturing process which helps to make doctor-patient communication more effective.

When? At any time, everyone chooses their own.

Paraphrasing Jean de la Bruyère: "Death comes but only once but it is felt all throughout life."

#### Relevance of the Study

It could not be more useful to consider the media and social impact of the voluntary deaths of Sampedro, Jorge León,

Madelein Z, and the case of Inmaculada Echevarría. A digital search introducing these names finds sufficient titles, opinions, and expert analyses, by professional bodies, associations for the chronically ill, citizens associations, ethics committees, legal advisory councils, ministries and ministers, which on the whole could be considered as the best evidence available so that the doctors may become acquainted with it in their practices, where the right of the patient to limit the therapeutic effort is legal and ethically correct.

The communication media have saturated society with public, real, practical, and useful knowledge, of the laws that enable the principle of autonomy to be developed in health care practice.

The social debate that arose from the case of Inmaculada Echevarría on the right to a dignified death goes towards "normalising" the effective palliative solutions that limit the therapeutic effort respecting the will of the people.

Thus it would be easier to make decisions that respect the previous instructions and that doctors and the population "are felt to be" within the current laws and good clinical practice.

#### The People

People are not reluctant to talk about death and, in my experience—"community forum" (70 people) and focal group activity—, demonstrated, naturally, that they would like to express their advanced directives to the doctors, and their main concern is to receive effective palliative care.<sup>2</sup> The ethical and legal dilemmas are also a daily reality in primary care, care in the terminal stages and care in the dying process, when the patient and family have decided that it happens at home, increasingly places the doctors in difficult situations. To collect, at the appropriate time, someone's AD as one more page in the clinical history in our daily routine would make subsequent clinical decisions much easier, both for professionals and families.

### The Professionals

The qualitative results of an investigation with 209 health professionals from 16 health centres<sup>3</sup> were able to con-

## **Key Points**

- The social evolution felt by the citizens is overcoming the paternalistic attitudes of health care professionals, as well as the conceptions of the state as supreme guardian of the interests of the individual.
- The bases of advance directives are the respect and promotion of the freedom of the person. Do we accept the challenge to play an active role from primary care?
- "That every citizen who wishes it, and at a time they consider appropriate, may express their feelings, their concerns, their will, on the medical care they would like to receive, or not receive, at the end of their life."

clude that the rejection attitudes were very uncommon, and a clear majority of professionals were in favour of using a living will in the clinical history as one work tool more.

However, difficulties are often pointed out when personally confronted with patients to talk about the subject of death and, therefore, to obtain an AD.

This could explain the contradiction found in the study between the theoretical willingness and the real possibilities of complying with an advance directive document by the professionals.

The expression of an AD must be based on a prospective and confident doctor patient relationship, it would be an implicit agreement, contained in conversations, effective communication, with periodic follow-up and recorded in the clinical history, more than a document, which could also be effective, when it is thus decided the patient is well informed.

The professionals, besides having knowledge on AD, should inform the patients, perhaps prioritising by risk, on their favourable attitude to personalise certain aspects, according to clinical situations, in the contents of the advance directive document.

#### The Response to the Initial Tentative Question

Primary care should actively participate in spreading awareness of these rights, fostering in the clinics, "that every citizen who wishes it, and at a time they consider appropriate, may express their feelings, their concerns, their will, on the medical care they would like to receive, or not receive, at the end of their life."

Just like a record in the clinical history and/or an advance directive document, each citizen decides, no more no less.

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- 1. Villar Abad G. La regulación de las instrucciones previas en Autonomía del Paciente, Información e Historia clínica. In: González Salinas P, Lizarraga Bonelli E, editors. Estudios sobre la Ley 41/2002, de 14 de noviembre. Madrid: Thomson/Civitas; 2004.p. 321-64.
- 2. Flordelís Marco F. Testamento vital en las historias clínicas. Trabajo Social y Salud. 2000;37:85-104.
- 3. Flordelís Marco F. Testamento vital en las historias clínicas. 2nd. part. Trabajo Social y Salud. 2002;42:151-76.

## Material para internet



KNOWLEDGE AND ATTITUDES ON ADVANCE HEALTH CARE DIRECTIVES (AHCD) OR LIVING WILLS LEASE FILL IN THE FOLLOWING DETAILS
LEASE FILL IN THE FOLLOWING DETAILS
MALE   FEMALE
AGE
DOCTOR NURSE
Ve present 12 questions below. You only have to mark your response with a cross.
. What score would you give for your knowledge of advance directives (AD) (living wills)?
ery oor 0 1 2 3 4 5 6 7 8 9 10 Excellent
. Are ADs regulated by the law in Andalusia?
YES NO DON'T KNOW
. Have you read the Andalusia AD document?  YES NO
. Do you agree that patients should plan their health care wishes by writing them in an AD declaration?
on't Strongly gree 0 1 2 3 4 5 6 7 8 9 10 agree
. Do you believe that the AD Declaration is a useful tool for health professionals when making decisions on a patient?
Very lo use 0 1 2 3 4 5 6 7 8 9 10 useful
. And for patients' families?
on't like Like it at all 0 1 2 3 4 5 6 7 8 9 10 a lot
. Do you believe that if a patient names a representative in the AD, it would help making decisions easier for health professionals in those ituations where the patients cannot express themselves?
lo 0 1 2 3 4 5 6 7 8 9 10 Alot
. Would you, as a professional, recommend your patients to make a an AD?
lever 0 1 2 3 4 5 6 7 8 9 10 Always
. Although it is a decision for their families, would you prefer that they had made their AD?
Inlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely
O. Would you personally, as a potential patient, fill in an AD?
Inlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely
1. You would respect the express wishes of a patient in an AD declaration.
lever 0 1 2 3 4 5 6 7 8 9 10 Always
2. Do you think it is likely that you would make your own AD in the next year?
Inlikely 0 1 2 3 4 5 6 7 8 9 10 Very likely
hank you very much for your help.