Knowledge and Attitudes of Medical Staff in 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 specialized 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 specialized 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 specialized 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.
Introduction

Attempts 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 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." 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, and what there is, is mainly theoretical. There have been few studies carried out in our country on the knowledge and attitudes of the population 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 physicians in internal medicine, 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 dichotomous 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.

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±8.08 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.

### Knowledge and Attitudes of Medical Staff of the 2 Health Areas

<table>
<thead>
<tr>
<th>Question</th>
<th>Malaga NHA</th>
<th>Almeria NHA</th>
<th>Student t Test</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Knowledge of AD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very poor 0</td>
<td>2 3 4 5 6 7 8 9 10</td>
<td>Excellent 5</td>
<td>2.90 2.526</td>
</tr>
<tr>
<td>2. ADs are regulated by the law in Andalusia</td>
<td>135 (69.6%)</td>
<td>60 (65.9%)</td>
<td>75 (72.8%)</td>
</tr>
<tr>
<td>Yes</td>
<td>135 (69.6%)</td>
<td>90 (66.9%)</td>
<td>45 (42.8%)</td>
</tr>
<tr>
<td>No</td>
<td>121 (62.4%)</td>
<td>62 (68.1%)</td>
<td>59 (57.3%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>52 (26.8%)</td>
<td>25 (27.5%)</td>
<td>27 (25.2%)</td>
</tr>
<tr>
<td>3. Have read the Andalusia AD document</td>
<td>73 (37.6%)</td>
<td>29 (31.9%)</td>
<td>44 (42.7%)</td>
</tr>
<tr>
<td>Yes</td>
<td>73 (37.6%)</td>
<td>29 (31.9%)</td>
<td>44 (42.7%)</td>
</tr>
<tr>
<td>4. Good idea to plan and write health wishes</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>5. Useful tool for professionals</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Not useful</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Very useful</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>6. Useful tool for families</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Not useful</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Very useful</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>7. The representative helps professionals to make decision</td>
<td>7.66 2.516</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>8. You would recommend your patients to make an AD</td>
<td>7.88 2.394</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Would not like that at all</td>
<td>7.88 2.394</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>9. You would comply with their AD</td>
<td>7.88 2.394</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Would not like that at all</td>
<td>7.88 2.394</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Very likely</td>
<td>8.31 2.107</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Would like that a lot</td>
<td>8.31 2.107</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Would not like that at all</td>
<td>8.31 2.107</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>10. You would make an AD next year</td>
<td>7.88 2.769</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Would not like that at all</td>
<td>7.88 2.769</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Yes</td>
<td>84 (43.6%)</td>
<td>37 (40.4%)</td>
<td>47 (45.1%)</td>
</tr>
<tr>
<td>Would like that a lot</td>
<td>84 (43.6%)</td>
<td>37 (40.4%)</td>
<td>47 (45.1%)</td>
</tr>
</tbody>
</table>

*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.
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. 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. 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 making.

In Canada, Hughes et al. 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.
- The doctors expressed very positive attitude and respect for the directive and training on it.
- 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 and Australia 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 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.

Acknowledgements
To the medical staff of the North Malaga and North Almeria Health Areas for filling in the questionnaire, to the nursing staff and social workers of these areas who helped collect the data, and Ricardo Ocaña (Professor of Statistics EASP) for the help requested during the statistical analysis.

Investigators of the “In the end, you decide” project

References
19. Santos Unamuno C. Conocimiento y actitudes de los médicos de familia ante el testamento vital. Rev Calidad Asistencial [en prensa].
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.

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 were able to con-
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."

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.

References

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.
- “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.”

Conclusion: that 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.
### Knowledge and Attitudes on Advance Health Care Directives (AHCD) or Living Wills

**PLEASE FILL IN THE FOLLOWING DETAILS**

<table>
<thead>
<tr>
<th></th>
<th>MALE □</th>
<th>FEMALE □</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DOCTOR □</td>
<td>NURSE □</td>
<td></td>
</tr>
</tbody>
</table>

We present 12 questions below. You only have to mark your response with a cross.

1. What score would you give for your knowledge of advance directives (AD) (living wills)?
   - Very poor
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Excellent

2. Are ADs regulated by the law in Andalusia?
   - YES
   - NO
   - DON'T KNOW

3. Have you read the Andalusia AD document?
   - YES
   - NO

4. Do you agree that patients should plan their health care wishes by writing them in an AD declaration?
   - Don't agree
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Strongly agree

5. Do you believe that the AD Declaration is a useful tool for health professionals when making decisions on a patient?
   - No use
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Very useful

6. And for patients’ families?
   - Don’t like it at all
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Very likely

7. Do you believe that if a patient names a representative in the AD, it would help making decisions easier for health professionals in those situations where the patients cannot express themselves?
   - No
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Always

8. Would you, as a professional, recommend your patients to make an AD?
   - Never
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Always

9. Although it is a decision for their families, would you prefer that they had made their AD?
   - Unlikely
   - 0
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6
   - 7
   - 8
   - 9
   - 10
   - Very likely

10. Would you personally, as a potential patient, fill in an AD?
    - Unlikely
    - 0
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10
    - Very likely

11. You would respect the express wishes of a patient in an AD declaration.
    - Never
    - 0
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10
    - Always

12. Do you think it is likely that you would make your own AD in the next year?
    - Unlikely
    - 0
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10
    - Very likely

Thank you very much for your help.