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The Use of Advance Directives in Specialized Care Units: A Focus Group Study With Healthcare Professionals in Madrid

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Abstract Eight focus groups were conducted in four public hospitals in Madrid to explore healthcare professionals' perceptions of advance directives (ADs) in order to improve the understanding of their lack of success among physicians and patients. A purposive sample of sixty healthcare professionals discussed ADs and reasons for their infrequent use. Three main themes were identified: perceptions about their meaning, appraisals of their use in clinical practice, and decision-making about them. Healthcare professionals perceived a lack of clarity about their definition and implementation. There is insufficient awareness of their efficacy in

improving the quality of clinical relationships and decision-making, and they are often perceived only as a bureaucratic procedure. Advance directives are not integrated in the clinical practice of Madrid's healthcare specialist services because their application is exceedingly complex, because of insufficient education about them (for both professionals and citizens), and because of lack of procedural clarity. Consequently, healthcare professionals are not aware of how ADs could improve clinical decision-making, of when and for whom their use is appropriate, and of who has responsibility for providing ADs-related information to patients. These

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circumstances contribute to patients' lack of interest in completing these documents and to physicians' sceptical views about their usefulness.

Keywords Advance directives · Living will · Advanced care planning · Shared decision-making

Introduction

Advance directives (ADs) were introduced in the healthcare system of the Madrid autonomous community in 2005. Madrid's 3/2005 Law is part of a national strategy (Basic Law 41/2002¹) to harmonize healthcare legislation in matters of human rights and patient's dignity with that of other EU Member States, as defined in the Oviedo Convention (Andomo et al. 2015; Simon Lorda, Tamayo Velazquez, and Barrio Cantalejo 2008). In Spain, a person expresses their will in advance, to be fulfilled when the person is not able to express it themselves, through ADs about their care and treatment and about the eventual fate of their body and organs. In addition, a representative may be appointed for decision-making. These documents cannot include decisions that go against good clinical practice or the legal system. In Madrid, three requirements are established to be able to formulate an AD: being of legal age, not having been legally incapacitated, and free expression of will. Requirements for registration are detailed by each autonomous community in its regulations. In the community of Madrid, ADs require a notary and three witnesses and are listed on an official register. Once registered, physicians can consult ADs if necessary on a specific web platform with private passwords that expire every three months.

Theoretically, ADs are useful because they offer patients the opportunity to express themselves in order to inform clinical decision-making when they are incapacitated (Molina et al. 2011). They allow patients to have a discussion with their physician about death, end-of-life care preferences (Valle Sanchez et al. 2009), and the use of body and organs after death (Perez et al. 2016), and then express their preferences through a written declaration (AD) available to healthcare providers (Contreras Fernández et al. 2017). However, despite extensive and

specific legislation, the number of citizens who express their wishes about future healthcare through ADs is low. In the region of Madrid, the rate of ADs per inhabitant (0.4 per cent) is consistently lower than in other regions, such as Navarra (1.1 per cent), the Basque Country (1.1 per cent), or Catalonia (1.1 per cent) (Ministry of Health 2019), despite regional legislation following the same national framework.

The implementation of national legislation regulating ADs in Spain has increased the number of empirical studies in the last decade across the country. Some of them have explored the role of patients (Llordés et al. 2014; Antolín et al. 2010; Monzón et al. 2008) and family (Arauzo et al. 2010), and others the role of healthcare professionals (Velasco Sanz and Rayon Valpuesta 2016; Navarro Bravo et al. 2011; Champer Blasco, Cartig Monfort, and Marquet Palomer 2009; Simón Lorda et al. 2008; Mateos Rodríguez, Huerta Arroyo, and Benito Vellisca 2007). All these studies show an insufficient knowledge of ADs among both professionals and patients, as well as an infrequent use of them in Spain, especially in Madrid. To improve the understanding of the lack of success of ADs among doctors and patients from Madrid, we performed a qualitative study exploring healthcare professionals' perceptions.

Methods

We performed a focus group (FG) study to explore healthcare professionals' perspectives toward the use of ADs in four public hospitals of Madrid: University Hospital Fundación Alcorcon, University Hospital Rey Juan Carlos, University Hospital Clínico San Carlos, and University Hospital Infanta Cristina.

Sample

Sampling was carried out following the criteria recommended in the literature, with a small size of participants in each FG to allow enough data saturation and at the same time account for the complexity of the research question (Krueger and Casey 2014). We included between five and ten participants in each FG, recruited from the hospital units where the use of ADs could have been feasible due to the patients' clinical circumstances. We envisaged two FGs per hospital to obtain within-group and between-group saturation (Onwuegbuzie

¹ Basic Law 41/2002 of 14 November, governing the autonomy of the patient and rights and obligations with regard to clinical information and documentation

Table 1 Counts of healthcare professions in sample

SERVICE	PARTICIPATING UNIVERSITY HOSPITALS (N)				TOTAL
	Fundación Alcorcón	Rey Juan Carlos	Infanta Cristina	Clínico San Carlos	
Internal medicine	3	2	7	1	13
Nephrology	1				1
Haematology	1	2			3
Anaesthesiology	1				1
Emergency		1	2	1	4
Laboratory	1				1
Urology	1				1
Palliative care			1	1	2
Pneumology		1			1
Preventive Medicine		1		1	2
Neurology			1		1
Paediatrics				2	2
Surgery				1	1
Intensive care unit		2		1	3
Geriatrics		1		1	2
Residents	6				6
Nurses	4	3	6	2	15
Physiotherapists	1				1
TOTAL	19	13	17	11	60

et al. 2009). Lead investigators administered a questionnaire in each hospital to recruit healthcare professionals of interest (table 1). From a survey of 135 questionnaires, a purposive sample of sixty participants of

different specialties (table 2) was recruited with the following criteria: 1) employment as medical doctor, resident or nurse in one of the hospitals included; 2) professional experience of at least one year in a public

Table 2 Focus groups characteristics

	FG1 (N%)	FG2 (N%)	Total
Hospital			
- Fundación Alcorcón	10 (52.6)	9 (47.4)	19
- Rey Juan Carlos	7 (53.8)	6 (46.2)	13
- Infanta Cristina	9 (52.9)	8 (47.1)	17
- Clínico San Carlos	5 (45.5)	6 (54.5)	11
Sex			
- Female	18 (54.5)	15 (45.5)	33
- Male	13 (48.1)	14 (51.9)	27
Age Average (Standard Deviation)	40 (10)	40 (11)	40 (11)
Professional category (N%)			
- Physicians	18 (48.6)	18 (51.4)	38
- Residents	4 (50)	4 (50)	6
- Nurses and physiotherapists	9 (60)	6 (40)	16

Table 3 Topic guide for the focus group study

QUESTIONS
PROMOTION OF ADS
<ul style="list-style-type: none"> • <i>What patients are suited for the use of ADS?</i> • <i>What professionals are more appropriate to suggest ADS?</i> • <i>What is the role of health policymakers?</i> • <i>What is the healthcare professionals' individual strategy to encourage the use of ADS?</i>
INFORMATION
<ul style="list-style-type: none"> • <i>What information process is more feasible?</i> • <i>What information should be provided?</i>
DECISION-MAKING
<ul style="list-style-type: none"> • <i>What is the relevance of ADS in the future?</i> • <i>What are the reasons to promote ADS in order to improve decision-making?</i>

hospital in Madrid; 3) clinical expertise in decision-making processes where ADS can be potentially used; 4) aged between twenty-five and sixty-five.

Our FG study started in September 2013 and concluded in June 2014. The aim of the discussion was to ascertain attitudes toward and experiences with the use of ADS. Groups were led by an experienced moderator using a topic guide (tables 3 and 4) designed to explore topics identified in a previous literature review and supported by an observer who took notes about the circumstances of the discussion to clarify and support the data analysis when required. Recruitment was performed through a coordinator assigned to each hospital

Table 4 Professionals' knowledge and attitudes toward ADS

	FG1 (N%)	FG2 (N%)	Survey only (N%)	Total (N%)
Knowledge				
- yes	1 (3.2)	0 (0)	1 (1.3)	2 (1.5)
- not sure	4 (12.9)	3 (10.3)	14 (18.7)	21 (15.6)
- no	26 (82.9)	26 (89.7)	60 (80)	112 (83)
ADS Expertise				
- never	19 (61.3)	18 (62.1)	58 (77.3)	95 (70.4)
- once	3 (9.7)	5 (17.2)	6 (8)	14 (10.4)
- more than one	9 (29)	6 (20.7)	11 (14.7)	26 (19.3)
ADS Usefulness				
- yes	3 (96.8)	26 (89.7)	70 (93.3)	126 (93.3)
- not sure	0 (0)	1 (3.4)	2 (2.7)	3 (2.2)
- No	1 (3.2)	2 (6.9)	3 (4)	6 (4.4)

who collected a list of professionals, identified those meeting the selection criteria, contacted them by email in order to invite them to participate, and elucidated the aim and the methods.

The project was assessed by the Research Ethics Committee (REC) of the University Hospital Fundación Alcorcon, who approved the protocol and the informed consent form (n.11/46). All the participants signed the informed consent.

The moderator started the discussion by inviting participants to introduce themselves and then asked the following questions: *What are your thoughts on ADS? What clinical experience do you have with ADS? Have you had patients with ADS? How did your patients become aware of the possibility to make ADS?* After a moderated discussion, three case vignettes (showing increasing clinical complexity) were presented in order to stimulate reflection about the practical application of ADS. Using the projection technique, we represented an external scenario requiring decision-making by healthcare professionals. Participants expressed freely what they would have done in the same circumstance. The moderator explored the attitudes of professionals following the topic guide and using the Socratic method to clarify opinions, perceptions, and agreement and disagreement between the members.

Data analysis

Focus groups were recorded and the audio files transcribed by a researcher who uploaded them on QSR N-Vivo 10. The analysis started immediately and was ongoing and iterative (Glaser 1965). Transcripts were coded line-by-line and processed iteratively to categorize the most relevant codes. In order to verify the feasibility of the categories identified, a second reading was performed by two independent researchers, who analysed four transcripts each and verified the appropriateness of codes and themes identified.

Codes selected had between 82 per cent and 95 per cent agreement among all the researchers involved in the analysis (EV, BH, JM), and the codes that were cause for disagreement between researchers were eliminated. A second reading was conducted to refine identified themes, collect significant quotes, and eliminate redundancies. A steering meeting among the researchers involved in the team project and hospital coordinators discussed the findings and validated the themes extracted. The data analysis was performed through thematic

analysis (Braun and Clarke 2006), and the coding strategy used an inductive approach (Frith and Gleeson 2004); coded patterns were organized as themes and emerged directly from transcripts in the first and second reading.

Results

The FG study was conducted from September 2012 to April 2013 and involved sixty participants: thirty-eight senior clinicians from fifteen different medical specialties, six residents, fifteen nurses, and one physiotherapist (table 1). Two FGs were performed in each of the four hospitals participating in the study: nineteen participants were from the University Hospital *Fundacion Alcorcon* (UHFA), thirteen were from the University Hospital *Rey Juan Carlos* (UHRJC), seventeen were from the University Hospital *Infanta Cristina* (UHIC), and eleven were from the University Hospital *Clinico San Carlos* (UHCSC) (table 2). An internal researcher from each participating hospital in the study managed the recruitment strategy: BH at the HUFA, LMR at the UHRJC, GGC at the UHIC, and AS at the UHCSC. The determination of codes and themes is illustrated in tables 5 and 6 (see [online supplementary materials](#)). Significant quotes have been selected and organized in codes, themes, and sub-themes following the participants' discussions. All quotes have been translated from Spanish.

We identified three main themes related to the healthcare professionals' views about low use of ADs: professionals' perceptions about the meaning of ADs, professionals' appraisals related to the use of ADs in clinical practice, and decision-making about ADs.

Healthcare Professionals' Perceptions About the Meaning of ADs

The concept of ADs is not clear enough to healthcare professionals and patients, and this can constitute a barrier to promoting their use and understanding their utility in clinical decision-making. Healthcare professionals' lack of clarity about the meaning of ADs has an impact on the information received by patients. This misunderstanding is due partly to the variety of terms used in Spain to define advance care plans. Some professionals consider the definition of ADs not clear enough:

C211 (physician, preventive medicine, female): *my first opinion is on the language itself, the term*

advance directives is unclear ... the truth is that the term is difficult to understand.

Others consider the use of the expression ADs more appropriate than the expression living will:

C107 (physician, emergency, male): *from terminology to use, many things attract my attention, like the living will, of course, the will is done in life, but in this and anything else, the term advance directives seems more appropriate in the sense of clarifying situations.*

Some professionals associate ADs with organ donation:

P105 (physician, geriatrics, male): *I am an organ donor, but I do not have ADs. I became a donor with a separate card, and I believe society also benefits from someone having ADs. Whether you put the cross in the box for "I am an organ donor" or whether you do not want to be an organ donor, it is good for society to know who does and who does not. Because of that it is very useful, not only for the person, also for society.*

Others associated them with a strategy to reduce costs, even though there is enough evidence to affirm their cost-effectiveness:

C209 (physician, internal medicine, male): *I think it is a discussion that is not easy with the health system we have and with the demand of the population. I believe that ADs in any case should not be used to reduce health spending, that is for me the first reasoning. I believe that ADs have to help make decisions, but of course it should not be an instrument because if so, we are getting into a very complex dynamic and probably of natural selection typical of other times.*

Healthcare professionals highlight that the misunderstanding about the meaning has an impact on patients and families, who frequently, after a conversation about the options available concerning ADs, are afraid about the irreversibility of the process and its ultimate value:

C106 (physician, palliative care, female): *I think the easiest is in primary care. Let's see, a patient comes to palliative and suddenly I show them a paper and say "look at this"; they will say, "Goodness, what do these people want to do with*

me?" People are afraid that if they leave something written on a paper, then it is irreversible, and, of course, I can change my opinion, my circumstances may change and what I have been thinking for a lifetime, maybe when I'm in a critical situation, I no longer believe it.

The contents discussed in ADs can have a negative impact on patients' emotional well-being and induce them to lose any hope about the treatment or healthcare:

M201, (physician, haematologist, male): *what to do or not to do, I think that both the family and professionals think that doing that makes the patient suffer, that having that conversation with them will increase their pain, and it's probably not so, but that is the majority perception.*

The lack of clarity about the meaning, the variety of terminology, and the negative impact on patients and their families are some of the reasons for the scarce use of ADs in the community of Madrid.

Professionals' Appraisals Related to the Use of ADs in Clinical Practice

Professionals' perceptions about the value of ADs in clinical practice are mixed: some have a negative view about their usefulness in improving decision-making, others consider them a good tool to improve patients' satisfaction. Negative views usually define ADs as a bureaucratic procedure without any impact on practice. Some participating healthcare professionals claim the procedure to fill them out is not sufficiently operationalized and this is a further obstacle to assigning them some utility:

C102 (nurse, palliative care, female): *I believe that there is a lack of real awareness that this exists because we have not really internalized it. I believe that the people who do it are very clear that they want to do it, that it is an offer that there is, and that the people who want it, they cling to it and it is true that it is a bit cumbersome, but also because many assumptions of whether it is a terminal illness are collected, at what time, when, how, perhaps they have tried to tie so many things into them that the document has been made a bit extensive.*

Others think the use of ADs has an essentially legal justification. It is the consequence of the legal framework and does not offer any improvement to the standard clinical procedures:

A103 (physiotherapist, occupational therapy, male): *I have a double perspective. Like her, I belong to the ethics committee, and we started spreading awareness among professionals as to what ADs are, and the perspective I have is that staff or professionals see it as a more legal type of thing because there is an obligation of something written, to comply with what's in there. It also forces them to see if there is something written and then consult it if the patient's clinical situation obliges it; because of the complexity or the complex surgery on all Jehovah's Witnesses about transfusions, they perceive it negatively and prefer that the patient does not have it, so the normal clinical course could be followed. The clinician does not perceive it as something that will help them decide.*

Healthcare professionals with specific training and experience of the use of ADs tend to have a positive view and consider them as a tool to promote patients' autonomy and respect their rights:

M101 (nurse, preventive medicine, female): *I have been working for four years and I have not had any relationship with ADs. I have not had any cases, and I have always been working with patients. Now, my opinion about the reception of them is that they are important, as it is important to adjust to the patient's opinion.*

The ambivalence in these professionals' views is due to lack of training and information about the use of ADs. Even when clinicians have been provided with the appropriate information about ADs, they are not aware of their usefulness because patients do not receive information about the subject and decision-making is frequently up to the patient's family:

M205 (nurse, palliative care, female): *I came into contact with ADs in university. We already had a subject that introduced us a little into the subject of the validation of ADs, but it is true that I think that in general there is a lack of knowledge in the general population that they have this option ... The population we serve does not know it, and I do*

not know whether professionals have internalized it very well.

Nurses also lack information about the use of ADs, though they could be a very useful support for clinicians:

M106 (physician, emergency, female): *I am aware that the nurse has no idea, and if the patient is in the unit the first one who has contact with him is the nurse, it does not matter and they have no idea.*

The negative perceptions about the use of ADs seem to be linked to the lack of information among the healthcare staff and the consequent expertise in clinical practice.

Factors Influencing Clinical Decision-Making and the Use of ADs

Healthcare professionals have clear preferences for the use of ADs even if they haven't used them before or they are not completely convinced about their usefulness. Among the reasons identified for proposing and discussing the use of ADs with a patient is the quality and the duration of the clinical relationship:

M201 (physician, haematologist, male): *perhaps those with whom I have spoken much more are patients with whom I have already had a little more follow-up in the office and who finally are admitted to the hospital because they are already shutting down, and more with young patients since they are fundamentally those who ask a little more openly "what prognosis do I have" or who say "I want to put my affairs a little more in order."*

The lack of confidence of the patient in the physician can be a barrier when discussing the contents of ADs and exchanging information. Some clinicians consider the chronic patient as the most suitable clinical profile to plan future healthcare:

C212 (physician, intensive care unit, male): *I believe that these documents are valid in the case of the patient with a chronic disease who knows what their evolution will be in the future, that is, degenerative neurological diseases, the patient with chronic lung disease, oncology ... those*

who can say if they want to be subjected to ventilation, the patient with ALS, the patient with chronic lung disease who may have been intubated once, if they want to go through that situation again.

An informed patient has more awareness of the utility of a discussion related to their future healthcare plan and can understand the relevance of planned choices in order to protect their individual wishes or beliefs. Jehovah's Witnesses are more frequently open to discussing and filling out AD forms:

A210 (physician, internal medicine, male): *the vast majority of people who have made ADs are Jehovah's Witnesses and people who are very clear on certain things, like "I do not want blood transfusions," but nobody else.*

Perceptions about the place where patients should receive information about ADs vary, but three essential places are considered appropriate to provide information. One is primary medicine:

C106 (physician, palliative care, female): *I said that primary care is for focusing on specific populations, although I think it should be for the general population, but since at the end this affects the patient, we should not fool ourselves, to reach the largest possible population in each autonomous community, I think that primary care is the way.*

When a diagnosis is available associated with degenerative illness, specialized medicine is recommended:

M103 (nurse, medical area coordinator, female): *I think it's good that there is advertisement about what ADs are in general, and that people know that they exist and that it is a possibility that you have. I think it is the doctor's obligation [...], not from primary care but of the specialist, the oncologist, the neurologist or us, of who is diagnosing a chronic disease ... I think it should be referred to the specialists who treat the chronic disease, of course the time to do ADs is not when the patient gets to intensive care, but when we anticipate a disease.*

Lastly, information should be provided through public service media campaigns:

C102 (nurse, palliative care, female): *for me the most important thing is the first level of dissemination to the population ... if previously there is no information and health illiteracy is very high ... we are asking for the completion of a document with very powerful importance in relationship with their life in a time before the disease or when the disease has begun, that is why at the beginning society itself has to be engaged.*

Professionals' views about the scarce use of ADs also relate to some practicalities of uploading the information to the digital platform used to register them. The first barrier is the password expiration, which happens periodically, and the process to obtain a new password is extremely complicated for clinicians working in the clinical units:

C209 (physician, internal medicine, male): *I attended the presentation when the legislation on ADs appeared. Then we had a specific session in our department where it was explained. I believe that we all made a username and password to use it, and this, we are talking about 2006 ... Probably the username and password, not only mine, but all the department's, it has expired. As far as I know in the department, during these years, nobody has used them.*

The regional regulations establish an archive for ADs separate from other medical records. ADs are uploaded on a different platform and linked to the medical record through a message received by the clinician. This difference was criticized by participants:

M106 (physician, emergency, female): *Why do ADs have to have a separate treatment and cannot be of easier access to the physician? In fact, sometimes a password is required to access medical records, I see a patient and I put there that I have spoken with the family and that in case of deterioration they should not go to intensive care, and, what is it? That's an AD, I've written it in the medical record, why can't that be written there?*

The existence of informal ADs expressed by the family is a further barrier to filling out or following existing ADs:

C213 (physician, geriatrics, male): *I believe that it does not substitute at all, nor will it substitute, the*

value of information transmitted verbally ... I believe that the signature of the ADs does not replace the verbal transmission.

The role of family in end-of-life decision-making in Spain is significant:

C106 (physician, palliative care, female): *The truth is that in the day-to-day experience, the one who tells you the most about the patient's verbal ADs is the family. They tell you that when they have talked about this topic at home he has always said that he did not want such types of treatment or such others. I believe that as for the written document it is time to start to debate, and maybe it is not the time to start discussing.*

Frequently the reason why ADs are not filled out or applied is because the family intervenes in the doctor–patient relationship and expresses a specific preference.

P205 (nurse, internal medicine, female): *here in internal medicine we have a lot of cancer patients and the family rarely tells you that they have ADs. They tell you that he did not want to have such a medical test, that he did not want aggressive measures, but in writing, no.*

Discussion

This study aims to explore healthcare professionals' perceptions in order to improve the understanding of the lack of success of ADs among doctors and patients from Madrid. To achieve this objective, we performed a qualitative study with focus group in four public hospitals of Madrid. This study is the first instance of qualitative research on the use of ADs in Spain with healthcare professionals and tries to explore the subject from a new angle, not from the quantitative perspective of data and figures, but from the perception, opinions, and evaluations of healthcare professionals, the protagonists of decision-making.

During the study, three main themes were identified related to healthcare professionals' views about low use of ADs: 1) the meaning of ADs, 2) professionals' appraisals related to the use of ADs in clinical practice, and 3) decision-making about ADs.

The dimensions related to healthcare professional's perceptions about the meaning of ADs were its possibly

blurry significance, since there are terminological confusions among both patients and professionals, confusion about the possible goals in clinical practice (e.g., some participants relate ADs to economic costs), and problems with patients' ideas/perceptions with the ADs—because ADs can discourage them, patients can be afraid after being informed about ADs or ADs could have a negative impact on the patient's emotional well-being. As noted, the meaning of ADs is often blurry and unclear to healthcare professionals and patients. To reduce confusion about what ADs are, it is essential to improve training for both professionals and patients. Much of the wrong ideas derive from insufficient or inadequate information. This can be a key issue in the promotion of their use in clinical practice and in offering patients guarantees that they are in their best interests.

Regarding professionals' appraisals of the use of ADs in clinical practice, one dimension found is the perception of their limited usefulness, because ADs are seen as a bureaucratic procedure without any impact on clinical practice or are perceived only as a legal tool. There are also participants who consider that ADs are useful to respect patient's rights and to avoid conflicts with the family. In their application to clinical practice, there are professionals who have a negative view on the usefulness of ADs, while others value them positively. To improve the involvement of professionals in the application of ADs, the most problematic aspects of implementing ADs must be addressed (i.e., excessive bureaucracy and its reduction to a legal document), since if professionals consider them useful for their practice, they will contribute to their dissemination. Another dimension related to implementation of ADs in clinical practice is professionals' education about their use, since many of them do not have adequate training, without forgetting that the relatives of the patients do not have it either and this influences decision-making. The lack of information and training on ADs for healthcare professionals is an issue throughout Spain (Perez et al. 2016; Simón Lorda et al. 2008). Lack of information for patients applies both at a national (Molina et al. 2011; Monzón et al. 2008; Pérez et al. 2013) and international level (Strauss, Kuppinger, and Hartl 2017; Guyon et al. 2014; Carrion, Gallo, and Sanchez 2013; Platts-Mills et al. 2017). Healthcare professionals consider the enactment of law as necessary but not sufficient to improve awareness about the benefits produced by ADs in clinical decision-making. Health policies are required to improve the availability

of information among citizens and strengthen training programmes for healthcare professionals. To facilitate the use of ADs, a bottom-up approach is essential, as well as the design of empirically informed procedures to, finally, provide policymakers with evidence-based support. This study is an example of this. One more dimension related to clinical practice is the responsibility for knowing that ADs exist. Participants think it is the responsibility of the patient's representative or the public administration (the healthcare system), because they are the ones who have to provide information about their existence. It has been discussed whether physicians should have to inquire about ADs in each patient unable to decide on their own. If so, the clinical practice of physicians would be very complicated, because of the sheer number of patients unable to make decisions or communicate them. A more streamlined procedure would be, for example, that patient's representatives or the health system, through some kind of alert, be responsible for communicating the existence of ADs to the clinicians. Finally, there is a dimension about patient's circumstances to consider: socio-demographic characteristics, Mediterranean culture (where the role of the family in clinical decision-making is very important), religion and beliefs, etc. In Spain and in general in the Mediterranean countries, the influence of family and relatives in the decision-making process is essential. Advance directives are designed to defend the patient's right to decide about their life, and sometimes this is not well received by the family. That is why we return again to the importance of education for professionals: they should know that with ADs, in addition to protecting the rights of the patients, sometimes the patient is protected from family or from professionals who are not willing to accept the decision made by the patient themselves.

With respect to the dimensions associated with clinical decision-making, there is a dimension about when ADs are recommended: it is best if there is trust and a good relationship with the patient and if they are patients with chronic diseases. The quality of the clinical relationship is positively associated with the provision of information about and the implementation of ADs (Tierney et al. 2001), even though for some physicians it is difficult to discuss this subject with patients (Huges 1998; Santos et al. 2007) and family (Aitken 1999). The need to identify groups of patients with a potential interest to fill in an AD is an aspect previously explored (Simón Lorda et al. 2008; Perez et al. 2016; Jox, Bosisio, and Truchard 2018) and could be considered

as part of the strategy to increase the rate of ADs in Madrid. The other dimension associated with decision-making is information management (where and to whom the information should be given). This dimension has three parts: the patient, who, according to the participants, must be informed primarily in primary care, although specialized care also has a function, as do public information policies; the professional, who should have more tools at their disposal to be able to put ADs into practice, with the role of nursing reinforced; and the family, which has an essential role. Regarding information management, though some professionals consider that discussions about ADs should be initiated by the patient (Valle Sanchez et al. 2009), many studies maintain that it is the physician's responsibility to start discussion on ADs with patients, some of them suggest this should occur in primary care (Navarro Bravo et al. 2011; Heiman et al. 2004; Contreras Fernandez et al. 2015) and others in specialized care (Nishie et al. 2014). The suitable place for the patient to discuss the content of the document can be in primary care but should also be addressed in specialized care. More significant than the place where information about ADs is given is the requirement to do it in accordance with the clinical situation and the patient's needs.

The main limitation of our study is that the FGs were carried out in just four of the twenty-four public hospitals of Madrid and, though the perspectives identified are common in the four hospitals involved, they cannot be completely extrapolated to Spain as a whole, much less to other countries.

The results of our study affirm that the role of healthcare authorities and policymakers is essential and that adequate training programmes must be provided to professionals, more operational procedures must be designed to improve the use of ADs, and that suitable information about ADs for patients must be promoted. In Madrid, to check if a patient has an AD, health professionals must do it through a computer system whose passwords expire after three months—a Spanish particularity, since this computer registry does not exist in other countries like the United States or Germany. All physicians should have user-friendly access to ADs and, in addition, should explore whether patients have provided any other kind of important information related to decision-making, whether to relatives or to other healthcare professionals. Decision-making cannot be based solely on ADs. Due to the limitations that ADs have in making decisions at the end of life and since

such decisions cannot be based exclusively on them, it is necessary to talk about advanced care plans. Advanced care plans have arisen precisely because of the difficulties that ADs have. They are less binding but tend to be more supportive of doctor–patient discussions and the recording of patient goals. Advanced care plans go beyond legally binding restrictions on specific therapies (as happens sometimes with ADs), and there are studies that show them to be more promising (Korfage et al. 2015).

In conclusion, healthcare professionals' perceptions of ADs show that ADs are not integrated in the clinical practice of Madrid's healthcare specialist services. This is because their application is exceedingly complex due to insufficient education (for both professionals and citizens) and because of lack of clarity in the whole procedure. As a consequence, healthcare professionals are not aware of how ADs could improve clinical decision-making, of when and for whom their use is appropriate, and of who has the responsibility to provide ADs-related information to patients. These circumstances contribute to patients' lack of interest in filling in and signing these documents and to physicians' sceptical views about their usefulness.

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