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Introduction

ADs were introduced in the health care system of the Region of Madrid in 2005. Despite an extended and specific legislation, their use is scarce and the number of citizens who expressed their wishes about a future healthcare plan is low. In the Region of Madrid the rate of ADs per inhabitants is consistently lower (0,4%) than in other regions, such Navarra (1,1%), the Basque Country (1,1%) or Catalonia (1,1%) (Ministry of Health, April 2019), though regional legislations follow the same national legal framework.

Madrid's 3/2005 Law is part of a national strategy to harmonize health care legislation of the EU Member States in matters of human rights and patient's dignity in medicine, defined in Oviedo Convention^{1 2 3}. ADs offer patients the opportunity to express themselves in order to inform clinical decision-making when the circumstances do not allow it due to lack of capacity⁴. In the context of their use patients can have a discussion with their physician about death, end-of-life care preferences⁵, the use of body and organs after death⁶ and express their preferences through a written declaration available to healthcare providers⁷.

The implementation of a national legislation regulating ADs in Spain increased the number of empirical studies in the last decade across the country. Some of them have explored the role of patients^{4 6 8 9 10} and family,¹¹ and others the role of healthcare professionals^{7 12 13 14 15 16}. All these studies show an insufficient knowledge of ADs documents both among professionals and patients, as well as infrequent use of them in Spain, specifically in the Region of Madrid. We performed a qualitative study to explore professionals' perceptions in order to improve the understanding of the lack of success of ADs among doctors and patients from Madrid.

Methods

We performed a focus group (FG) study to explore participants' perspectives toward the use of ADs in 4 public Hospitals of Madrid: University Hospital Fundación Alcorcon, University Hospital Rey Juan Carlos, University Hospital Clínico San Carlos and University Hospital Infanta Cristina.

Sample

Sample procedure was carried out following the literature criteria, recommending 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 question¹⁷. We included between 5 and 10 participants in each FG, recruited in the hospital units where the use of ADs could have been feasible due to the

patients' clinical circumstances. We envisaged 2 FGs per hospital to obtain within-group and between-group saturation¹⁸. Lead investigators administered a questionnaire in each hospital to recruit health-care professionals of interest (*Table 1*). From a survey of 135 questionnaires a purposive sample of 60 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 1 year in a public hospital of Madrid; 3) clinical expertise in decision making processes where ADs can be potentially used; 4) ages between 25 and 65.

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 (*Table 3*) designed to explore topics identified in a previous literature review, and supported by an observer who took note about the circumstances of the discussion to clarify and support the data analysis when required. Recruitment was performed through the role of a coordinator assigned to each hospital, who collected a list of professionals, identified those corresponding to the selection criteria, and 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 who accepted to participate previously signed the informed consent.

The moderator started the discussion inviting participants to introduce themselves and next 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 ADs?* After a moderated discussion, three case vignettes (showing an increasing clinical complexity) were presented in order to stimulate reflection about ADs practical application. Using the projection technique, we represented an external scenario to direct healthcare professional. 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 and perceptions related to agreement and disagreement between the members.

Data analysis

FGs 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 iterative¹⁹.

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 2 independent researchers, who analysed 4 transcripts each and verified the feasibility of codes and themes identified.

Codes selected were between 82% and 95% of agreement among all the researchers involved in the analysis (EV, BH, JM) and codes where there was a disagreement between researchers eliminated. A second reading consisted in refining themes identified, collecting significant quotes and eliminating 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 analysis²⁰, and the coding strategy was focused on inductive approach²¹, patterns coded were organized as themes and emerged directly from transcripts in the first and second reading.

Results

The analysis of findings consists in identifying three main themes related to the healthcare professionals' views about the use of ADs: meaning, decision-making and appraisals. *Table 5* contains a summarised description of quotes related to the meaning of ADs. Many healthcare professionals expressed concern over their perception of patients' misconceptions of ADs. Some patients have negative views on ADs because they associate them with organ donation, with the rationalisation criteria to allocate resources and reduce costs or with euthanasia or medical aid in dying. Healthcare professionals' appraisals of the use of ADs are focused on the circumstances of the information shared with the patient, the quality and duration of the clinical relationship and the confidence in the professional competence (summarised in *Table 6*). Many professionals consider primary care is the most adequate context to talk about ADs, while others think specialized care is more appropriate for chronic patients with degenerative illnesses and for patients at the end of life.

ADs are perceived as a legally and ethically useful tool to improve the quality of decision-making, but the lack of clarity and operationalised procedures to fill in and consult the document is regarded as a barrier for its implementation. Due to the lack of information, patients tend to use informal decision planning through family or relatives. On the other hand, physicians generally do not consult ADs because consultation procedures are frequently too

complex or because the keywords to access the online database have expired or are available only to a small number of clinicians who cannot be present at the moment its use is required. These circumstances contribute to some professionals' belief that ADs are a mere bureaucratic procedure without real impact on clinical practice.

Medical education and training programs available for healthcare professionals are considered insufficient to increase awareness about the usefulness of ADs. Some participants believe the responsibility to promote the use of ADs and improve patients' education lies with the healthcare authorities and policymakers.

The role of the family in decision-making is matter of concern because ADs contents can be different than relatives' wishes and as a consequence, healthcare professionals can be a potential target of complaints and reports. On the other hand, healthcare professionals who are knowledgeable on the subject know ADs are a way to avoid conflict with the family because the legal regulation supports their use and protects patient's rights. Some physicians consider patients' fear can be a barrier to talk about the subject.

Physicians and nurses believe that some families perceive the discussion about ADs as something potentially harmful to the patient, because the subject can scare them, fosters uncertainty or because ADs are perceived as a tool to downscale or withdraw therapeutic measures for patients. Cultural factors associated with familial influence in decision-making, especially in patients with a lack of capacity, are relevant in Spain, even though some religions support the use of ADs because they can be a tool to respect the believer's convictions or can be an argument to strengthen the refusal of treatment when this is required by their value systems.

Discussion

This study is the first instance of qualitative research about the use of ADs in Spain with healthcare professionals and aims to explore the subject from a new angle. As noted, the meaning of ADs is blurry and unclear to healthcare professionals and patients. This can be a key issue in the promotion of their use in clinical practice, and in order to offer patients all the guarantees that they are in their best interests.

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 than the place where information about ADs is given, the key issue is to do it in accordance with the clinical situation and the

patient's needs. All physicians should have a user-friendly access to consult ADs and, in addition, should explore whether patients have provided any kind of important information related to decision-making, both to relatives or to other healthcare professionals. In Madrid, to check if a patient has ADs, 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 USA or Germany. Healthcare authorities and policymakers in Madrid must provide adequate training programs to professionals, design more operational procedures to improve the use of ADs and promote suitable information about ADs for patients.

The lack of information and training related to ADs for healthcare professionals is an issue in the whole of Spain^{6 15}, and this phenomenon extends to patients both at a national^{4 8 22} and international level^{23 24 25 26}. The quality of the clinical relationship is positively associated with the information about and implementation of ADs²⁷, even though for some physicians it is difficult to discuss this subject with patients^{28 29} and family³⁰. The need to identify groups of patients with a potential interest to fill in an AD is an aspect previously explored^{6 15 31} and could be considered as part of the strategy to increase the rate of ADs in Madrid. Though some professionals consider the discussion about ADs should be opened on the patient's initiative⁵, many studies establish it is the physician's responsibility to start the discussion on ADs with patients, some of them in primary care^{13 32 33} and others in specialized care³⁴.

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. If health policies are required to improve the availability of information among citizens and strengthen training programs for healthcare professionals, a bottom-up approach is essential to provide policymakers with evidence-based support and design empirically informed procedures to facilitate the use of ADs.

The FGs were carried out in 4 of the 24 public hospitals of Madrid Region and, though the perspectives identified are common in the 4 hospitals involved, findings cannot be extrapolated to be representative of all the procedures available to obtain or consult ADs in Spain.

In conclusion, ADs are not integrated in the clinical practice of Madrid's healthcare specialist services because its application is exceedingly complex and due to a lack of clarity in the whole procedure. As consequence healthcare professionals are not aware of how they impact

clinical decision-making, when and for whom their use is appropriate, and 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 the usefulness of ADs.

Bibliography

¹ Andorno, R., Shaw D.M., and Elger B. 2015. Protecting prisoners' autonomy with advance directives: ethical dilemmas and policy issues. *Med Health Care and Philos*18(1):33-9.

² Simon Lorda P., Tamayo Velazquez M.I., and Barrio Cantalejo I.M. 2008. Advance directive in Spain. Perspectives from a medical bioethicist's approach. *Bioethics* 22(6):346-354

³ Basic Law 41/2002 of 14 November, governing the autonomy of the patient and rights and obligations with regard to clinical information and documentation

⁴ Molina J., Pérez M., Herreros B., Martín M.D., and Velasco M. 2011. Conocimiento y actitudes ante las instrucciones previas entre los pacientes de un hospital público de la Comunidad de Madrid. *Revista Clínica Española* 211(9):450-454.

⁵ Valle Sanchez A., Farras Villalba S., Gonzalez Romero P.M., Galindo Barragan S., Rufino Delgado M.T., and Garcia Marco MT. 2009. Documento de voluntades anticipadas: opinión de los profesionales sanitarios de atención primaria. *Semergen* 35(3):111-4

⁶ Perez M., Herreros B., Martín M.D., Molina J., and Kanouzi J. 2016. Do Spanish hospital professionals educate their patients about advance directives? A descriptive study in a university hospital of Madrid, Spain. *Journal of Bioethical Inquiry* 13: 295-303

⁷ Contreras Fernández E., Barón López F.J., Méndez Martínez C., Canca Sánchez J.C., Cabezón Rodríguez I., and Rivas Ruiz F. 2017. Validación del cuestionario de conocimiento y actitudes de los profesionales sanitarios en el proceso de declaración de voluntades anticipadas. *Aten Primaria* 49(4): 233-239

⁸ Llordés Llordés M., Muñoz E., Serra Morera I., and Giménez N. 2014. Conocimientos, expectativas y preferencias respecto al documento de voluntades anticipadas entre los pacientes de atención primaria. *Med Clínica* 143(7):309-313

⁹ Antolín A., Sánchez M., Llorens P., et al. 2010. Knowledge about disease course and living wills among patients with heart failure. *Revista Española de Cardiología* (63) 12:1410-8

¹⁰ Monzón J.L., Saralegui I., Abizanda i Camposc R., et al. 2008. Recomendaciones de tratamiento al final de la vida del paciente crítico. *Med Intensiva* 32(3):121-33

¹¹ Arauzo V., Trenado J., Busqueta G., and Quintana S. 2010. Grado de conocimiento sobre la ley de voluntades anticipadas entre los familiares y los pacientes ingresados en un servicio de medicina intensiva. *Med Clin (Barc)* 134:448-51

¹² Velasco Sanz T.R., and Rayon Valpuesta E. 2016. Advance directives in intensive care: health professional competences. *Med intensive* 40(3):152-62

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- ¹³ Navarro Bravo B., Sánchez García M., Andrés Pretel F., Juárez Casalengua I., Cerda Diaz R., and Párraga Martínez I. 2011. Declaración de voluntades anticipadas: estudio cualitativo en personas mayores y médicos de atención primaria. *Aten Primaria* 43:11-7
- ¹⁴ Champer Blasco A., Cartig Monfort F., and Marquet Palomer R. 2009. Conocimientos y actitudes de los profesionales de los equipos de atención primaria sobre el documento de voluntades anticipadas. *Aten Primaria* 42(9): 463-469
- ¹⁵ Simón Lorda P., Tamayo Velázquez M.I., Vázquez Vicente A., Duran Hoyos A., Pena Gonzales J., and Jiménez Zurita P. 2008. Conocimientos y actitudes de los médicos en dos áreas sanitarias sobre las voluntades vitales anticipadas. *Aten Primaria* 20(02):61-8.
- ¹⁶ Mateos Rodríguez A.A., Huerta Arroyo A., and Benito Vellisca M.A. 2007. Instrucciones previas: actitud de los profesionales de emergencia. *Emergencias* 19:241-244
- ¹⁷ Krueger R.A., and Casey MA. 2014. Focus groups a practical guide for applied research. London: Sage.
- ¹⁸ Onwuegbuzie A.J., Dickinson W.B., Leech N., and Zoran AG. 2009. A qualitative framework for collecting and analysing data in focus group research. *International Journal of Qualitative methodology* 8(3): 1-21
- ¹⁹ Glaser B. 1965. The constant comparative method of qualitative analysis. *Social Problems* 12:436-445.
- ²⁰ Braun V., and Clarke V. 2006. Using thematic analysis in psychology. *Qualitative research in psychology* 3(2):77-101
- ²¹ Frith H., and Gleeson K. 2004. Clothing embodiment: men managing body image and appearance. *Psychology of Men and Masculinity* 5(1): 40
- ²² Pérez M., Herreros B., Martín M.D., Molina J., Guijarro C., and Velasco M. 2013. Evolución del conocimiento y de la realización de instrucciones previas en los pacientes ingresados en medicina interna. *Rev Calid Asistencial* 28(5):307-312
- ²³ Strauss S., Kuppinger D., and Hartl WH. 2017. Quality of dying processes after commencement of the German Living will Act: experiences of surgical intense care unit. *Chirurg* 88(3): 251-252
- ²⁴ Guyon G., Garbacz L., Bauman A., et al. 2014. Trusted person and living will: information and implementation deficit. *Rev Med Interne* 35(10):643-8.
- ²⁵ Carrion C., Gallo P., and Sanchez E. 2013. Barriers and facilitators to research translation into health care decision-making: reviewing the evidence. *Evidence Live*. 25-26 March. England: Oxford.
- ²⁶ Platts-Mills T.F., Richmond N.L., LeFebvre E.M., et al. 2017. *J Palliat Med* 20(01):74-78
- ²⁷ Tierney W.M., Dexter P.R., Gramelspacher G.P., Perkins A.J., Zhou X.H., and Wolinsky FD. 2001. The effect and discussion about advanced directives on patients satisfaction with primary care. *J Gen Intern Med* 16(1):32-40

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- ²⁸ Huges R. 1998. Ethical problems in living will legislation. *J Relig Aging* 5(1-2): 35-50
- ²⁹ Santos C., Forn M.A., Pérez R., Corrales A., Ugarriza L., and Sales C. 2007. ¿Estamos preparados los médicos de familia para ayudar a nuestros pacientes a hacer el testamento vital? *Rev Calid Asistencial* (22)5: 262-5.
- ³⁰ Aitken P.V. 1999. Incorporating advance care planning into family practice. *Am Fam Physician* 59(3):617-20.
- ³¹ Jox R.J., Bosisio F., and Rubli Truchard E. 2018. Dementia from palliative care perspective: why a disease-specific advance care planning is necessary. *Ther Umsch* 75(2): 105-111
- ³² Heiman H., Bates D.W., Fairchild D., Shaykevich S., and Lehmann LS. 2004. Improving completion of advance directives in the primary care setting: a randomized controlled trial. *Am J Med* 117(15):318-24
- ³³ Contreras Fernandez E., Rivas Ruiz F., Castilla-Soto J., and Mendez Martinez C. 2015. Knowledge and attitudes of health professionals to the living will declaration process. *Aten Primaria* 47(8):514-22
- ³⁴ Nishie H., Mizobuchi S., Suzuki E., Sato K., Toda Y., Matsuoka J., and Morimatsu H. 2014. Living will interest and preferred end-of-life care and death locations among Japanese adults and over: a population-based survey. *Acta med Okayama* 68(6):339-48