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ORIGINAL ARTICLE

Characteristics and use of advance directives in a tertiary hospital.



A. Antolín^{a,*}, S. Jiménez^a, M. González^{a,b}, E. Gómez^a, M. Sánchez^a, O. Miró^a

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KEYWORDS

Advance directives; Prior instructions; Bioethics; End of life

Abstract

Objective: To evaluate the characteristics of patients who provide written advance directives and the use of the documents in healthcare practice.

Methodology: An observational, descriptive, retrospective study of all written advance directives registered at a university hospital between 2001 and 2011. The clinical-demographic characteristics of the patients at the time they provided the documents were studied, as was the later use of the documents through an electronic medical history analysis.

Results: A total of 130 advance directive documents were registered. At the time of their provision, the average patient age was 61 years; about 64% were diagnosed with a neoplastic illness; 73% were completely independent (Barthel), and 36.4% presented no comorbidities (Charlson). The women were slightly older than the men (63 vs. 60, p=0.17) and they were more likely to provide advance directives (61.5% vs. 31.5%, p=0.01) than men; the women's illnesses were less relevant (p=0.001) and they presented less comorbidity (p=0.01). A total of 361 medical acts were reviewed (193 hospital admissions and 168 emergency visits). At the end of the study, 74 patients were alive (57%), 37 had died (28%), and in 19 cases (15%), their evolution was lost. Of those who died, 13 (35.1%) were functionally incapacitated in the terminal phase of their illness, and in 9 (69%), the advance directives were applied in the final phase of their illness.

Conclusions: The number of registered advance directives is low; they do not interfere in the care process, and the documents are considered in the final decisions of life.

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^a Área Urgencias, Hospital Clínic, Grupo Investigación «Urgencias: procesos y patologías», Fundació Clínic, Barcelona, Spain

^b Servicio de Atención al Usuario, Hospital Clínic, Barcelona, Spain

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^{*} Corresponding author.

PALABRAS CLAVE

Voluntades anticipadas; Instrucciones previas; Bioética; Final de la vida

Características y uso del documento de voluntades anticipadas en un hospital terciario

Resumen

Objetivo: Evaluar las características de los pacientes que otorgan documentos de voluntades anticipadas (DVA) y su uso en la práctica asistencial.

Metodología: Estudio observacional, descriptivo, retrospectivo, de todos los DVA registrados en un hospital universitario en el periodo 2001-2011. Se investigaron las características clínico-demográficas de los pacientes en el momento de su otorgamiento y, mediante el análisis de la historia clínica (HC) electrónica, el uso posterior de los DVA.

Resultados: Se registraron 130 DVA. En el momento de su otorgamiento, la edad media era 61 años, un 64% estaba diagnosticado de enfermedad neoplásica, un 73% era totalmente independiente (Barthel) y un 36,4% no presentaba comorbilidad (Charlson). Las mujeres tenían, respecto a los hombres, una edad ligeramente superior (63 vs. 60, p=0,17), otorgaban en mayor medida (61,5% vs. 31,5%, p=0,08), su enfermedad era menos relevante (p=0,001) y presentaban una menor comorbilidad (p=0,01). Se revisaron 361 actos médicos (193 ingresos hospitalarios y 168 visitas a urgencias). Al finalizar el estudio, 74 pacientes estaban vivos (57%), 37 habían fallecido (28%) y en 19 casos (15%) se había perdido su evolución. De los fallecidos, 13 (35,1%) presentaban incapacidad de decisión en la fase terminal de su enfermedad y en 9 (69%) se realizaron uso y referencia expresa a los DVA en la fase final de su enfermedad.

Conclusiones: El número de DVA registrados es escaso; no interfieren en la práctica asistencial y los mismos son considerados en la toma de decisiones al final de la vida.

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Background

The bioethical principle of autonomy applied to medicine translates to the right of all individuals to be informed and to be freely and autonomously able to decide about the medical acts that involve them. This principle, embodied in informed consent, has as its prime example the prior instructions, living will or advance directives, which are legal instruments by which patients state their will concerning certain decisions to be made at the end of their life in the event that they cannot make that decision at that time. Coming to the forefront at the end of the 1970s in the U.S., its legislation in Europe was started in 1997 with the Convention on Human Rights and Biomedicine of Oviedo.1 This convention was ratified by Spain in 2000, and its implementation and legal regulation were started in Catalonia in 2001² and thereafter in the rest of the country.³ At present, there are central registries that can be consulted from anywhere in Spain where healthcare is provided.4

Despite the time elapsed and the considerable legislative development, advance directives have not met expectations in terms of their presence and use in healthcare practice. In the U.S., even their actual usefulness has been questioned. ⁵⁻⁸ In our community, ⁹⁻¹⁶ authors have focused more on determining the awareness of these advance directives, from the point of view of medical personnel at various healthcare levels (primary care, intensive care, palliative care and emergency departments) and patients (elderly and chronically ill). Although there seems to be a broad acceptance of advance directives and a favorable predisposition to granting them, there is still a lack of practical knowledge on the use of advance directives and little involvement of physicians in this process. Less than 10% of patients with

chronic diseases report having received information from their physician about advance directives.

Recently and thanks to the study conducted by Nebot et al. in 2010 in the community of Valencia, ¹⁷ a number of the actual characteristics of advance directives have been established, although their usefulness and the degree to which they are subsequently considered in the healthcare process are still unknown. The aim of the present study was to specifically address these 2 issues: (1) determine the number and characteristics of patients who issued advance directives who were registered in our center from 2001 to 2011 and (2) determine how these directives influenced the subsequent care and whether they were considered in this care.

Patients and methods

The present study had an observational, retrospective, descriptive-analytical design with no intervention and reviewed all advance directives delivered by patients from 2001 to 2011 to the Department of Customer Care of a tertiary urban university hospital. This center has a reference population of 540,000 and, for a number of highly complex diseases, acts as a reference center for all of Catalonia.

The study population consisted of all individuals who contacted the Department of Customer Care to deliver their advance directives, regardless of whether these directives would have been followed in any community in Spain. This department is responsible for centralizing the receipt of all advance directives in the hospital. For all cases, the advance directives were then added to the medical records hard copy along with the other clinical documentation. The document was also scanned and saved in portable document

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