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## ORIGINAL ARTICLE

# Knowledge and attitudes of critically ill patients and their families on advance directives and the decision making process at the end of life<sup>☆</sup>

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## KEYWORDS

Critical patient;  
Family;  
Advance directives;  
Living will;  
End-of-life care

**Abstract** Most patients admitted to intensive care units have alterations in their usual state of consciousness, with the family or relatives serving as substitutes. It is important to determine the knowledge, as well as the attitudes adopted by patients and their representatives as regards the decision-making process at the end of life.

**Objetives:** To determine and examine the knowledge and attitudes of critically ill patients and their families about advance directives and know how family involvement in decision making at the end of life.

**Method:** A review was conducted using 9 integrated databases with a combination DeCs and MeSH, limiting the search to 11 years. Relevant documents that dealt with knowledge and attitudes of critically ill patients and their families about advance directives and the decision-making process were selected. Critical reading was performed using CASPE lists.

**Results:** Twenty articles were selected, of which 8 were descriptive studies, 5 analytical, and 7 were studies performed using qualitative methodology. In these articles, it was found that both the knowledge and the rate of signing of advance directives (AD) are low, and that the decisions of the family is a stress factor that is alleviated by the existence of AD, as well as communication between health professionals and family.

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**Conclusions:** AD are poorly understood by both patients and their relatives, although both showed interest in learning about this tool that can help in decision-making at the end of life. Health professionals also see the AD, along with good communication, as tools for decision making.

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## PALABRAS CLAVE

Paciente crítico;  
Familia;  
Instrucciones previas;  
Directivas  
anticipadas;  
Cuidados al final de la  
vida

## Conocimientos y actitudes de los pacientes críticos y sus familiares respecto a las directivas anticipadas y la toma de decisiones al final de la vida

**Resumen** La mayoría de los pacientes ingresados en las Unidades de Cuidados Intensivos presentan alteración de su estado de conciencia habitual siendo sus familiares o allegados los que ejercen como sustitutos. Resulta importante conocer los conocimientos y actitudes que adoptan los pacientes y sus representantes respecto al proceso de toma de decisiones al final de la vida.

**Objetivos:** Explorar los conocimientos y las actitudes del paciente crítico y sus familiares respecto a las directivas anticipadas y conocer la forma de participación de la familia en la toma de decisiones al final de la vida.

**Método:** Se realizó una revisión integrada en nueve bases de datos, con una combinación DeCs y MeSH, limitando la búsqueda a once años. La selección se realizó sobre documentos relevantes que trataban de los conocimientos y actitudes del paciente crítico y de sus familiares sobre las directivas anticipadas, así como del proceso de toma de decisiones. La lectura crítica se realizó mediante listas CASPE.

**Resultados:** Se seleccionaron veinte artículos, de los cuales ocho son estudios descriptivos, cinco son analíticos y siete son estudios realizados con metodología cualitativa. En ellos se encuentra que tanto los conocimientos como el índice de otorgamientos de las directivas anticipadas (DA) son bajos y que la toma de decisiones de los familiares resulta un factor estresante que se ve aliviado por la existencia de DA y la comunicación entre profesionales sanitarios y familiares.

**Conclusiones:** Las DA son poco conocidas, tanto por los pacientes como por sus familiares, aunque ambos muestran interés por conocer este instrumento que puede ayudar en la toma de decisiones al final de la vida. Los profesionales sanitarios también ven las DA junto con la comunicación, como buenas herramientas para la toma de decisiones.

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## What is known/what is the contribution of this?

Advance directives (ADs) allow a person to previously express their willingness on how to be taken care of their health. Therefore, this will be fulfilled if, in certain clinical situations, they are unable to express their will. Many patients admitted to the Intensive Care Unit (ICU) suffer from altered state of consciousness. Therefore, surrogate decisions are frequent. Knowing the will of the patient facilitates decision-making at the end of life to both family members and health professionals.

The conclusions of this study lead us to point out that ADs are very helpful in respecting the autonomy of the critically ill patient, but they are not sufficient, especially when complex decisions have to be made, such as those in the ICU.

## Implications of the study

It is evident that the existence of ADs improves decision making by surrogates in the field of critical care. ADs include patients' preferences. Therefore, the decision burden decreases and trust of patients, representatives and health care teams improves. Studies like this are aimed at promoting visibility and knowledge about ADs.

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