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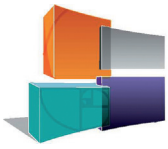

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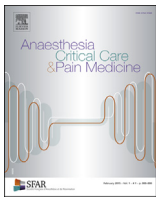

Original Article

# Impact of a stay in the intensive care unit on the preparation of Advance Directives: Descriptive, exploratory, qualitative study

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ABSTRACT

*Background:* Our objective was to assess, through a qualitative, exploratory study, the thought processes of patients regarding the formulation of advance directives (AD) after a stay in the ICU.
*Methods:* The study was conducted from May to July 2016 using telephone interviews performed by four senior ICU physicians. Inclusion criteria were: patients discharged from ICU to home > 3 months earlier. Semi-directive interviews with patients focused on 5 main points surrounding AD.
*Results:* In total, among 159 eligible patients, data from 94 (59%) were available for analysis. Among all those interviewed, 83.5% had never heard of "advance directives". Only 2% had executed AD before ICU admission, and 7% expressed a desire to prepare AD further to their ICU stay. Among the barriers to preparation of AD, lack of information was the main reason cited for not executing AD. Patients noted the following in their AD: withdrawal of life-support in case of vegetative/minimally conscious state or when there is no longer any hope, in case of uncontrollable pain, and if impossible to wean from mechanical ventilation.
*Conclusion:* The ideal time to engage patients in these discussions is most likely well before an acute health event occurs, although this warrants further investigation both before and after ICU admissions.


## 1. Introduction

Advance directives (AD) were first developed in the 1970s in the United States of America (USA), and were born of a twofold need. Firstly, they are rooted in the principle of the right to die with dignity without unreasonable obstinacy, and secondly, they are an extension of the patient's right to self-determination, particularly the right to refuse unwanted care [1]. The Patient Self-Determination Act passed in the USA in 1990 promoted the use of AD by mandating all healthcare establishments to provide written information to patients about their rights regarding the health decisions they may have to make [2]. In particular, this includes the right to participate in healthcare decisions, and to decide on the care they wish to receive, the right to refuse certain treatments, and the right to formulate AD. Currently, it is estimated that around 70% of Americans prepare AD before death [3], compared to only 8 to 10% of German, Dutch or British people [4–6]. The rate is reportedly even lower in Australia (0.2–7.9% of patients [7]), and Spain, where one study reported that no patient had filled out AD [8].

In France, since the introduction of the so-called "Leonetti Law" of 22 April 2005 relating to the rights of patients regarding end-of-life, any adult (healthy or ill) can formulate AD in writing to express their wishes regarding their end-of-life care. If that person later becomes incapacitated and unable to make their wishes known, the AD would be consulted and implemented by the physician, and the validity of AD was set to 3 years. The dispositions of this

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legislation were recently modified in France by a new law passed in February 2016 (the so-called Claeys-Leonetti law [9]) that introduced new rights for terminally ill and end-of-life patients. While AD retain precedence over patient preferences as reported by a surrogate decision-maker, the 3-year validity of AD was revoked, and AD have become more constraining. Indeed, physicians are now obliged to respect AD, since they explicitly express the patient's desires. However, despite this legislation, surveys of practices in France in recent years found that only 2.5% of patients who died actually had AD [10,11]. The explanations put forward to explain this low rate include poor awareness of AD among the medical profession and the general public, and the fact that the general public appears to think that AD will not be implemented [12]. Another possible theory is that it is difficult for patients to consider their own demise when they are in good health, or if they are not suffering from any severe and/or incurable disease.

To promote public debate and more frequent use of AD, the French National Health Authority (Haute Autorité de Santé, HAS) now provides free examples of forms and documents aimed at the public and health professionals. These documents allow for both AD and designation of a surrogate decision-maker (documents available online (in French) at: http://www.has-sante.fr/portail/jcms/c_2619437/fr/les-directives-anticipees-concernant-les-situations-de-fin-de-vie) (access date 5 October 2016). Indeed, surrogates are garnering increasing attention as key players in end-of-life situations. In the documents proposed by the HAS, it is clearly indicated that healthy people and patients who have a serious illness, are terminally ill, or who are approaching end-of-life may formulate AD regarding whether or not they would wish to be artificially maintained alive, use (or not) of medical or surgical treatments likely to artificially prolong life (e.g. assisted ventilation, chronic dialysis, etc.), or initiation of terminal sedation.

Clearly, to be in a position to formulate AD in this context, it is necessary for the patient to possess a good level of knowledge of the disease, and of the accompanying therapeutic plan, as well as the prognosis of their disease. It is therefore easy to understand that a stay in the ICU can represent a good opportunity to raise the question of AD with some patients. Indeed, admission to the ICU is often a milestone on the healthcare pathway in acute disease, or in the progression of chronic disease. The frailty and uncertainty of clinical situations, the idea of vital organ failure or unfavourable prognosis inevitably prompt some patients and/or their families, to raise questions about, or simply to reflect on their disease, their future perspectives, and their wishes for future care choices. Thus, after discharge, it is possible that with the help of the healthcare team and/or family members, patients may express their wishes regarding end-of-life care in case of decisional incapacity, and consign these desires in writing in the form of AD.

In this context, the objective of this study was to assess, through a qualitative, exploratory study, the thought processes of patients and their close family regarding the formulation of AD after a stay in the ICU. The use of a qualitative approach appears to be more relevant and more suitable than a strictly quantitative approach for exploratory purposes, insofar as the purpose is to describe and carefully interpret patients' responses to questions on such a complex topic as the end-of-life.

## 2. Methods

This is a substudy of the IVOIRE cohort (prospective, multicentre cohort, funded by a grant through the National Program for Hospital Research (PHRC 2012) and registered with the French Health Products Safety Agency (ANSM) under the number 2013-A00095-40), which evaluated the influence of socio-economic vulnerability on the initial severity and on the prognosis of patients admitted to the ICU. The IVOIRE study and the current substudy were approved by the local Ethics Committee and by the National authority for the protection of privacy and personal data (CNIL and CCTIRS). Informed consent was obtained from all patients included in the initial IVOIRE cohort, and in the current substudy.

In this single-centre substudy, we included only patients (and families of patients) admitted to the ICU of the main participating University Hospital, due to the physicians' extensive knowledge of the patients' medical files, and the need for training in semi-directive interview techniques.

We developed and tested an ad hoc questionnaire to prepare the interviews held with the patients using a methodology previously described elsewhere [13–15]. Empirical data were used to construct the interview guide and were obtained from a preliminary exploratory qualitative study performed in around 20 patients who were hospitalised in the ICU. Patients attended follow-up sessions at 3, 6 and 12 months after discharge from the ICU, and were most often accompanied by a family member. Together with a sociologist and the ICU physicians, we approached the question of AD with these patients, and asked them about the impact (if any) of their stay in the ICU on the preparation of AD. The results of these preliminary interviews were used as a basis for constructing the final interview grid for the present study.

The current study was conducted from May to July 2016 (between 3 and 4 months after discharge for all patients), using telephone interviews conducted by four senior physicians from the ICU. These physicians were trained prior to contacting the patients by a sociologist who is specialised in interviews of this type [13]. Training consisted in workshop sessions with the participating physicians to learn about qualitative research methods and how to conduct semi-directive interviews, with simulations of interview situations with a qualified sociologist. Regular debriefing meetings were held to discuss any difficulties encountered, in particular with the first few telephone interviews. Interviews were conducted until saturation was reached (i.e. the point at which new interviews failed to bring forth any new elements on any of the points in the interview grid). Data were encoded to guarantee the anonymity of the participating patients and family members.

Inclusion criteria were: patients who were discharged from the ICU to home more than 3 months earlier. In addition, patients and any interviewed family members had to be able to hold a coherent discussion in French for about 30 minutes. Patients were included prospectively, in the order of their discharge from the ICU.

The semi-directive interviews with patients focused on 5 main points that comprised the final interview grid, namely:

- what does the term advance directives bring to mind for you? Do you know what they might be for?
- what was your position regarding AD before being admitted to the ICU?
- now that you have been out of the ICU for a while, what do you think about them?
- in your opinion, what are the barriers to writing AD?
- if you were to prepare AD, what would you put in them?

For the family members, there were two main questions, namely:

- can you tell me anything about advance directives?
- in your opinion, having been there for your loved one through a stay in the ICU, has that changed your view about AD for yourself?

All interviews were recorded and transcribed in their entirety. The corpus of discourse from all the interviews with patients and family members was analysed using textual content analysis as previously described by our group elsewhere [13].

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