

Advance Directives in Palliative Care: The French Case

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Abstract

"Advance directives" are an important tool for documenting the wishes of end-of-life patients who are no longer in a position to take decisions relating to their medical care. In France, the legal status of advance directives was enacted in 2005; the recent update of the project was abandoned due to controversies. This article aims at discussing how such advance directives should be drafted; they are difficult for patients to write precisely because of their health condition. However, they are essential documents for physicians allowing them to take medical decisions in accordance with the will of terminally ill patients. Discussion of such issues during palliative care should help patient state their wishes and their advance directives. Implementing these directives is an important issue under discussion in France.

Keywords: Advance directive, End of life, Legal status

Introduction

If the notion of advance directives was put forward as early as 1969 in the USA, in Europe it was only introduced in 1997 by the European Convention of Human Rights and biomedicine [1]. Article 9 of this Convention stipulates that patients' anticipated wishes concerning their medical treatment should be taken into account when the patients become unable to express their wills at the time of medical intervention. These wishes may or may not be followed [2].

In France, "advance directives" defining the rights of terminally ill patients about issues concerning treatment limitation or interruption were drafted by the April 22, 2005 Act, which was enacted in a context of heated debates among the medical community, the general public and law professionals [3-5]. This law was a crucial step in the French healthcare system since, for the very first time, it prompted patients to officially express their wills and to have a say in the medical decisions concerning their own condition.

It had been preceded by the enactment of the 2002 Patients' Right Act and quality of the healthcare system [6]. The two key points of the 2002 Act were 1/ to allow patients to have access to their own medical file and to all the medical information concerning them 2/ to make it mandatory for physicians to inform patients about their health state and to obtain the patients' agreement before any diagnosis or therapeutic decision is taken. Such information concerns prevention, investigation and medical treatment, as well as questions of treatment efficiency, emergency level and results. The question of risks must also be discussed and alternative acts must be considered, with their strengths and weaknesses. Patients have a right to refuse a diagnosis or a therapeutic act; they must give their consent to any undertaken investigation or treatment. Patients may also refuse to be informed of

some diagnosis or prognostic concerning their own condition, if this does not endanger other people's lives. Another key-point of the 2002 Act was to implement the notion of 'person of trust' whose role is to interact with physicians, especially when the patients are no longer able to express their wills. Choosing a person of trust comes in addition to drafting advance directives, they are not a substitute to advance directives.

One important aim of the Act was to involve patients in the medical decisions concerning their own condition, to promote joint decisions, and to alleviate the pervasive paternalistic attitude in the French healthcare system. But the specific issue of terminally ill patients was not mentioned in this Act. Only the issue of palliative care, first introduced in the 1999 Act, was included in the 2002 law. The 2005 Act goes one step further towards promoting the patients' right to self-determination, enabling them to express their own end-of-life wills. Physicians take these wills into account, but are legally free to follow them. In Europe, the legal status of patients' end-of-life wills varies considerably among countries, it is sometimes submitted to strict formal and procedural conditions.

This Act also strengthens the legitimacy for palliative and support care. It makes it legal to refuse unreasonable medical obstinacy and makes it mandatory to implement collegiate procedures when it comes to limit or interrupt medical treatment. Finally, it legalises advance directives.

This article assesses the draft of advance directive in the French context of palliative care. It also discusses possible evolutions in the status of advance directives.

Advance Directives: Their Context and Implementation

Article 7 of the law stipulates that any adult person may write their end of life advance directives, in case they might no longer be able to express their wishes concerning limitation or interruption of their medical treatment. Legal texts stipulate that advance directives be stated less than 3 years before a state of irreversible unconsciousness. They are revocable at any time. Physicians must take them into account before deciding any investigation, intervention, or treatment. These texts define their conditions of validity, confidentiality and conservation.

This confidential document must be written, dated and signed, it must specify the place and date of birth. Two witnesses, including the appointed 'person of trust' may write and sign the document if the patient is unable to do so himself. This document has 3 year validity, it may be modified, in part or totally, at any time. It must be made available to the physician or any other practitioner chosen by the patient.

The 2005 Act strongly stressed the notion of medical « relief of human suffering » and the relevance of limiting and/or interrupting medical treatment once some consensus has been reached, and avoidance of unreasonable medical obstination. This Act was favourably welcomed, in particular by anaesthetists and intensive care specialists, as an appropriate response to most situations encountered in their daily practices [7]. Written advance directives do not prevent consulting the 'person of trust', but they do prevail over the latter's view.

Whether the person is still healthy or has a serious medical condition, the writing of advance directives raises questions about the reliability of the options chosen at the time of writing, as choices are highly context dependent and also dependent on conditions of information [8].

The keystone of the 2005 Act is the refusal of unreasonable medical obstination and the promotion of the consensus approach, which allows effective consultative meetings, in particular multidisciplinary consultative meetings with other staff members [7]. Yet very often, only therapeutic acts are discussed during such meetings and the patients' wills are not taken into account [9,10]. Physicians often consider advance directives as merely indicative, and their therapeutic decisions may differ if they are medically justified.

Nearly a decade after the unanimous vote of the April 22, 2005 Act, difficulties still arise concerning the drafting and implementation of advance directives by a person still in a healthy condition or diagnosed with a serious medical condition.

In order for advance directives to be suitably acceptable by professionals, the conditions of drafting and the amount of provided information must clearly be specified. In 2012, a study of the consultations conducted in relation to advance directives, also taking into consideration ageing conditions and death, showed that nearly 20% of interviewed people aged over 75 expect their will to be respected [11]. They also insist on the paramount importance of exercising their autonomous and free choice concerning their end-of-life decisions.

French physicians consider it difficult to ask patients to draft their advance directives. Another study published in 2012, concluded that only 2,5 % of deceased patients had drafted their advance directives

[12]. Such data are convergent with those published by the preceding study showing that 83% of persons aged over 75 were not willing to draft advance directives [11]. 42% considered it « too early », 36% thought them « useless » and 22% refused to anticipate death or discuss it. Over half of them preferred to talk about their remaining life-time, or about their life-quality rather than anticipate on their conditions of death.

In other countries, the notion of advance directives seems much more appropriate both for patients and physicians. A German study [13] conducted in a unit of intensive care showed that advance directives, even though mandatory since 2009, did not much change conditions of death, but allowed deeper thoughts on end-of-life issues. This obligatory procedure is used to prompt discussions between the patient, his relatives and physicians. In the USA, a 2009 study conducted with end-of-life homeless patient revealed that when patients are prompted to draft advance directives, the ratio rises when one-to-one talks are conducted between the patient and a member of the medical team, and when a document summarising the purposes of the procedure has been presented to the patient [14]. In France, such information documents for patients have been devised, but it remains necessary to reinforce recommendations on advance directives by training healthcare professionals, and to increase public awareness by organising public debates. As to patients in a state of minimal consciousness or cognitively impaired patients, whose faculty to assess their wishes or whose ability to assess reality may be seriously jeopardised, it is important not to exclude them from the process of drafting their advance directives [15,16]. In such situations, the role of the person of trust is paramount.

Expression of end-of-life wishes fluctuates with the patients' health conditions. The patients' environment, evolution of medical condition, loss of autonomy and vulnerability have an impact on end-of-life choices [17-19].

Palliative care improves the lives of patients and families who are confronted to the dire consequences of a life-threatening disease; they prevent and alleviate human suffering, control pain thanks to early identification and precise diagnosis; they also treat other correlated physical, psychological and spiritual problems [20]. Palliative care has proven its worth and constitutes some significant improvement, they provide less aggressive treatment and permit longer survival if they have been used from an early stage [21]. Advance directives can only be offered to patients through constant and regular dialogue with the medical team [7]. Announcing a chronic disease to a patient who felt healthy so far or announcing some irreversible deterioration is both a difficult and brutal situation however cautious one tries to be.

From Anticipated Discussions to Advance Directives

Prompting a patient to draft his advance directives requires to be rigorous, tactful and attentive. Anticipated discussions are indispensable and must take into account complex situations [17]. If advance directives are so difficult to draft, despite the many information documents available to the patients, the main cause remains the difficulty to plan ahead one's own end-of-life [22]. In such an uncertain context, a relationship of mutual trust must be built between the physicians and their patients, also including paramedical staff [23].

Autonomy in drafting advance directives is one way for patients to remain involved in their medical treatment. Discussions with medical professionals ease the drafting of advance directives [24]. Some teams

recommend such talks when the prognosis is shorter than a year [25]. In 2009, a Spanish study bearing on 171 pairs of patients and person of trust showed the benefits of information and training on both of them and on the respect of advance directives [26].

Currently, advance directives are unheeded in France, rarely suggested and generally uneasy for patients to draft. When implemented, physicians consider that they have been an important element for 72% of their medical decisions in end-of-life situations. That survey, based on 5217 questionnaires supports the view that advance directives genuinely help doctors take decisions for end-of-life patients [12].

Other social issues at stake in France

Advance directives may only be drafted by adults aged over 18 years. They may not be used in pediatrics, though teen-agers and older children are clearly able to express their wishes in relation to choice of medical treatment or end-of-life plans. Multi-disabled children may also be concerned. Presently, parents act as proxies [27].

Another major stake concerning advance directives is their legal evolution, from their present consultative status towards enforceable legal rights.

Two distinct and contrasting situations may arise: that of conscious patients still in a position to discuss a reasonable end-of-life project, and that of unconscious patients for whom enforceable advance directives would not constitute an alternative.

An emerging issue in France is that of medically assisted suicide [28]. Various European countries among which some neighbouring French-speaking countries have already passed legislation in favour of medically assisted suicide. Consequently, some French patients seek such benefits in those countries, since it is totally illegal in France. A bill was debated in 2012, but did not come through due to strong oppositions [29]. An article of that bill stipulated that patients might express their wishes to limit or interrupt treatment in their advance directives. A registry should have collected all advance directives, in order to keep control over such practices. Another article of that bill suggested creating a national commission in charge of supervising such practices relating to the right to a dignified death in the conditions defined by the law.

Conclusion

Advance directives are little-known and rarely used in France. They confront individuals to their own human finiteness. Questioning this keypoint of the Act is immaterial, but there may be some benefit in improving the ability of patients and professionals alike to exercise their wills. Individual and collective information and awareness-raising of the general public would allow better understanding and acceptance of the goals of this process promoting a more peaceful end-of-life [30,31]. Enforceable advance directives might then evolve towards some form of legalised euthanasia.

The April 2005 Act was a milestone, it triggered some crucial awareness that the patients' wishes be heard and respected [32]. Will it become possible some day in France to promote the notion of anticipated dialogues with the patients to support and guide them towards expressing and fulfilling their wishes?

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