ADVANCE DIRECTIVES AND THE CONCEPT OF COMPETENCE: ARE THEY A MORAL BARRIER TO RESUSCITATION?

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The ethical reflection on the principle of respect for autonomy has evolved from protecting the patients’ right to direct health care decisions affecting them, to describing essential conditions necessary to recognize the patients’ consent as being really informed. Some specific problems arise with patients who are not autonomous or whose autonomy is doubtful at the time of undertaking medical treatments. The advance directives are seen as a means which permits to respect the patient’s autonomy even in such difficult situations. Such directives are understood as the declarations made by patients in which they express the will concerning treatment preferences, in particular, resuscitation recommendations, in case of their potential future lack of ability to act autonomously. This paper attempts to answer to the question of whether the advance directives fulfill (and if so, on what basis) the standards established by the concept of competence.

Keywords: advance directives, competence, informed consent

INTRODUCTION

Research ethics and, in particular, the necessity to protect human subjects in clinical trials, is indicated as a key source of the emerging bioethics, as a new discipline in the late 1960s and early 1970s (1). Bioethics could even be seen as a certain form of reaction against the practice of misuse of human subjects in the guise of medical research which took place under the Nazi regime, but also in some democratic countries (2). Probably, the most commonly known example of the violation of human rights outside a Nazi-Germany remains the so-called Tuskegee Syphilis Study (3). Regrettably, it is the most well known example, but not the unique one (4). In this context, it seems to be worth noticing that ‘The
Belmont Report’ (5), the worldwide known and highly appreciated document focusing on protection of human subjects in medical research, and the fundamental work of four-principle approach to bioethics „Principles of Biomedical Ethics“ (6), which although being subject to criticism still remain the mainstream of bioethical reflection (7), were developing simultaneously, with reciprocal influences and (partially) by the same authors (8).

In this way, ethical standards elaborated for research ethics have gone into use in a broader field of medical ethics. Although they have been adjusted to the needs of medical practice, their essential structure has remained unchanged. In particular, in both research and medical ethics, the principle of respect for autonomy (with its two main issues of ‘informed consent’ and ‘respect for patients’ privacy/confidentiality’) seems to play – both in theory and practice - the central role (9, 10). Consequently, the so called substantive rules, which aim at specifying this principle, remain the subject of the main interest in the bioethical discourse. In fact, as an example of the substantive rules, Beauchamp and Childress cite the rule which serves doctors as a guidance to deal with the problems connected with patient’s advance directives (“Follow a patient’s advance directive whenever it is clear and relevant”) (6, p. 39). The authors admit that ‘advance directives’ should be considered to be the procedure rooted mainly in the principle of respect for autonomy (6).

It is worth noticing that during the almost forty years of the history of bioethics as a separate discipline of knowledge, discussions over the principle of respect for autonomy has undergone essential evolution. Initially, this reflection was concentrated on protecting the patients’ right to direct health care decisions affecting them. The physician’s obligation to disclose information about the nature and consequences of the given treatment to patient was emphasized. Nowadays, the bioethicists ask rather how to inform patients’ to guarantee that disclosed information will be understandable to them and, in consequence, to enable them to consent to and authorize the proposed treatment procedure (6). Increased attention is given to the problems related to standards for surrogate decisions for incompetent patients. In this context, not only the standard of ‘advance directive’, but also ‘of ‘substituted judgment’ and ‘best interests’ are discussed.

METHODS

This study is based on a literature review. The PubMed and ProQuest on-line databases were browsed using as keywords: ‘advance directive AND competence’. The search was done in April 2007. Coherentism was used as a method of the ethical reasoning.

RESULTS AND DISCUSSION

In the Medical Subject Headings (according to Bioethics Thesaurus) ‘advance directives’ are defined as „declaration by patients, made in advance of situation
in which they may be incompetent to decide about their own care, stating their treatment preferences or authorizing a third party to make decisions for them” (11). There are essentially two main types of advance directives (6). The first, in which the patient specifies medical procedures that should/should not be provided in certain potential situations in the future, is known as ‘living wills’. The second, ‘durable power of attorney’ (DPA) consists of authorizing a third party to decide in the name of the patient in the period of his/her incompetence.

The living wills can be divided into two subgroups: ‘a value statement’ and ‘an instruction directive’. “A value statement gives the patient’s general preference or values with respect to medical treatment as a whole, but does not address specific forms of treatment or illnesses”, while “an instruction directive expresses preference for or refusal of specific medical treatment in the context of specific illnesses” (12, p. 141). Taking into account the content of ‘a instruction directive’ it seems that living wills of this type can be classified as ‘a limited instruction directives’ or ‘an unlimited instruction directives’ (13, 14). The limited instruction directives focus practically exclusively on potentially life-prolonging treatment, in particular, cardiopulmonary resuscitation (CPR). Moreover, their validity is limited to only the very precisely described set of circumstances (‘imminent death’ or ‘persistent vegetative state’ PVS) (15). The unlimited instruction directives are used to decide in advance about the wide spectrum of health procedures (and not only about withdrawing/withholding CPR), in particular, those related to psychiatric care. The psychiatric advance directives may include, for instance, “preferences about medication, electroconvulsive therapy (ECT), restraint and seclusion, hospitalization, method of de-escalating crises”, etc. (16, p. 501). It is worth noticing that new models of living wills (such as „Five Wishes“, „Let Me Decide“, „Respecting Choices“ Respecting Choices & Physician Orders for Life-Sustaining Treatment (POLTS)) tend to include wide range of health choices and even wishes which are not strictly related to medical procedures.

Taking into account how advance directives were stated, they can be divided into two groups: ‘an oral instruction’ and ‘a written instruction’. This division, although it seems to be important from a legal point of view (12), is relatively unimportant in the ethical discourse.

Using living wills, patients can in advance refuse to or request for treatment, in particular CPR. Traditionally, living wills existed only in the form of the advance refusal, which expresses patient’s wishes for the limitation of treatment. However, the above mentioned new models of living wills permit patients to indicate that they wish to receive a given treatment, especially CPR. Naturally, taking into account the physician’s right to the objection of conscience, “patient cannot demand […] a treatment that the doctor considers contrary to the patient’s clinical needs” (12, p. 141-142). It should be noted that the advance requests still seem to make medical professionals uneasy (17).
Bearing in mind (i) that advance directives are considered the prominent means of extending patients’ autonomy to situations when they are incompetent (18) and (ii) that the principle of respect for autonomy is commonly seen as the central, fundamental, most important or, at least, as the ‘first among equals’ (9), it should not astound that in many countries appropriate legal regulations in the matter have been introduced. As early as December 1991, the Patient Self-Determination Act went into effect in the U.S. (6). Five years later, the New Zealand Code of Health and Disability Services Consumers’ Rights declared patients to be in the right to refuse and/or to withdraw treatment procedures (13). In the decade 1997-2007, similar regulations went into effect or are expected to come into force, for instance, in England and Wales (12), in Scotland (19), France (20) and Germany (21).

It is worth noticing that it is estimated that Patient Self Determination Act entailed a start-up cost of over 100 million USD on health care (22). These expenses do not include the cost related to the administration of the program. Taking into account the financial dimension of the implementation of this regulation, Fagerlin and Schneider observe: “If programs to promote or provide living wills showed signs of achieving the goals cherished from them, we would have to decide whether their valuable but incalculable rewards exceeded their diffuse but daunting costs. However, since those programs have failed, their costs plainly outweigh their benefits” (22, p. 38). What seems to be particularly interesting, is the authors’ statement that this failure is not or, at least, not primarily caused by the lack of appropriate social education in the matter, or by the lack of intelligence or skills of people responsible for it. The problem lies in the very human nature, in particular, in the fact that people are unable to be competent decision-makers in regard to the advance health care planning, especially, end-of-life decisions.

Competency is regarded, alongside with voluntariness in deciding, as one of the two essential preconditions of informed consent (6). Although the term “competence”, appearing in the context of various disciplines of human knowledge and activity, assumes different meanings, the ‘core’ meaning which is “the ability to perform a task” (6, p. 134) could be identified. Taking into account the specificity and variety of tasks to be preformed, ‘to be competent’ always means to be competent to make this (specific) decision or, at the very least, decisions belonging to the particular class of such decisions (6, 18, 19). Generally, it could be said that a given person has to demonstrate three essential kinds of abilities to be recognized as a competent moral agent: (i) ability to state a preference; (ii) ability to understand decision-related information, and (iii) ability to give reason for decision (6).

Keeping in mind the very nature of a task to be performed, i.e., making in advance a decision regarding refused/requested treatment procedures, it seems necessarily to specify what in this context ‘ability to state a preference’ and ‘ability to understood adequate information’ mean (should mean). Regarding
the first of these abilities, it is assumed that patients’ decisions will be accurately and lucidly stated (22) and that patients’ choices will be (relatively) consistent and stable (18, 19). Patients should be able to understand (i) “the nature and purpose of an advance directive […] and (ii) the possible future clinical situations” (18, p. 494).

The extent to which a given person should demonstrate possession of these abilities can be indicated using “the sliding-scale strategy” (6). This scale, in its traditional version, determines that the level of abilities should correspond to the risks related to the decision or rather to the consequences of this decision. Beauchamp and Childress rightly observe that the level of competence should vary rather with difficulty in decision-making than in accordance with the risks involved. They admit, however, that this problem “can be avoided by holding that the level of evidence for determining competence should vary in accordance with risk, although competence itself varies only along a scale of difficulty in decision-making” (6, p. 141).

Are people actually able to be the competent moral agents at deciding about their future treatment using advance directives? In the case of DPA, the necessary competence to make a decision seems relatively easy obtainable. As Fagerlin and Schneider observe, advance directives which have the form of DPA demand from patients “a few, familiar and simple” choices which “require little change from current practice, in which family members ordinarily act informally for incompetent patients” (22, p. 39). The patients’ task, and consequently related to this task competence, consists in choosing a person who will be a surrogate decision-maker when patients are incompetent. Patients, in fact, do not necessarily have to have adequate information about all these situations in which surrogate decisions possibly will be needed. It will be a task of surrogate decision-makers to be competent moral agents when they undertake proxy decisions. Obviously, it is far easier to be competent at deciding in a given concrete situation than to know and comprehend information indispensable to be a competent moral agent in all possible future situations. In other words, it is much easier to be a competent surrogate decision-maker, than to be competent at deciding about one’s own future, i.e., at making living wills. In fact, the question arises of whether it is at all possible to be competent at making living wills. To be a competent living-will maker, one should not only have adequate information about the nature of disease and used treatment procedures (medical knowledge), but also about as yet unknown circumstances which will be able to influence the possible future treatments and patients’ preferences (prophetic knowledge). Naturally, people can foresee same future events. However, as MacIntyre observes, unpredictability or fortune constitutes essential and irremovable element of human/social life (23).

The surrogate decision-maker also is in an advantage position when taking into account the problem of clarity of decisions’ statements. The surrogate decision-maker is able to explain how his/her decisions should be interpreted.
Living wills are subject to interpretation. Moreover, they are interpreted by people, primarily by physicians, who do not know which of the possible interpretations are right and which are wrong. In consequence, living wills seem to rest essentially ineffective (22). Their effectiveness is probably limited only to few situations in which there is no doubt about how living wills should be interpreted. What seems particularly interesting, withholding/withdrawing CPR may be regarded as an example of such a situation (24).

Assuming that only in some very specific and probably rare circumstances, living will can be used, a new, seemingly more profound problem, related to the concept of competence, arises. “A pressing ethical problem in their (living wills) use is that competent people may not always be well placed to make decisions concerning they future incompetent selves” (18, p. 493). A well-known in the ethical literature example which illustrates this problem is a fictitious “case of Margo” (19). Margo made, at the time when she was competent, a living will. She accurately and lucidly stated: “I refuse treatment in the event of my becoming demented”. Now, although she suffers from dementia, she seems to be a really happy person. She takes delight in small pleasures of everyday life. Because of her dementia, she does not remember what she has stated in her living will or even that she made a living will at all. Margo seems to be grateful for treatment received from the doctors and nurses. The question arises whether competent Margo, an author of a living will, and Margo who suffers from dementia should be considered the same person. Are there two different persons and the first of them has no right to decide in the name of the second? It is likely that the advance directives, in particular the living wills, are ultimately incompatible with the commonly accepted in the contemporary bioethics narrow, strictly functional conception of a human person.

**Conclusions**

The standard of ‘advance directives’ was thought to increase and extend patients’ autonomy. It was emphasized that both form of advance directives (DPA and living wills) would promote patients’ self-determination regarding the issues involved, in particular, in the end-of-life decisions. It was accentuated, however, that the living wills would be a better option than DPA to guarantee that patients’ wishes regarding withholding/withdrawing treatment would be honored.

Critical reflection over the concept of competence seems to reveal that only in very few cases the willing wills fulfill the criteria of a competent decision-making process. There are essential problems with the stability of decisions regarding end-of-life issues. Moreover, the very wording of the living wills is often too vague and confusing and, in consequence, the living wills are open to different interpretations. The most important argument against the living will is thought to be the lack of necessary information about the possible future situations. This lack of information makes it impossible, at least in most cases, to regard the living
wills as an expression of competent consent. It seems necessary to elaborate a satisfactory ethical standard to resolve the problem of futile or even harmful, from the patients’ point of view, treatment, in particularly CPR. The advance directives, both DPA and living wills, although due to different reasons, cannot be regarded as an efficient ethical barrier to unwanted treatment.

REFERENCES


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