

ETHICAL-NORMATIVE CONCEPTUAL EVALUATIONS IN ASSISTING PEOPLE AFFECTED BY ALZHEIMER'S DISEASE

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Abstract

Advance patient directives are various forms of anticipatory medical directives made by competent individuals for the eventuality of future incompetence. They are therefore appropriate instruments for competent patients in the early stage of Alzheimer's disease to document their self-determined will in the advanced stages of dementia. Although there are many restraints, from a medical and psychological point of view, the patients must be informed about their disorder and prognosis at an inchoate level of disease, when the patient is still competitive for making self-determined decisions.

Key words: *Alzheimer's disease, dementia, ethics, self-determination, cognitive.*

Occupying a central place in contemporary psychiatry, Alzheimer's disease is a priority of this science due to the theoretical interest and the reflection of the affection in present-day pathology. Described by Alois Alzheimer in

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1907, Alzheimer's disease became a "topic of interest" turning into a "medico-social emergency". Alzheimer's disease can be considered on the one hand as aiming at "brain psychiatry", and on the other, it raises great challenges concerning its approach, from an ethical and legal point of view, taking into account its specific peculiarities.

Clinical-evolutive aspects of Alzheimer's disease

Alzheimer's disease is a form of dementia which can begin both at a pre-involitional age (before 65 years old) and at an involitional age (after 65 years old) and it represents, according to specialized literature, more than 50% of all types of dementia. It is a primary degenerative dementia, morphologically manifested by generalized cortical atrophy, but with an obvious temporo-parietal accentuation, by the presence of amyloid plaques and by neurofibrillary tangles caused by abnormal tau proteins.

The dementia syndrome is present when memory impairments and the aphasia-apraxo-agnosic phenomena are defining. This syndrome can be associated with confusion, state of depression, delirious ideas or behavior disorders.

The clinical record distinguishes among three stages: the prodromal stage, the symptomatic (manifest) stage and the final stage. The beginning of the disease is insidious and, in the first stages, it can pass unobserved. Depression can be a precocious manifestation in Alzheimer's disease. With the evolution of the disease, the memory impairment, language disorders and the dramatic decrease in the intellectual functions become more and more obvious. The cognitive abilities are gradually lost, which will also be reflected in the changes in the patient behavior and in the

loss of various functions. In the final stages the patient experiences verbigeration, echolalia and mutism, while the neurological record aggravates.

The identification of the cognitive functions that have been affected or even abolished in the patient can prove to be useful to the physician in order to explain to the family the patient's specific behavior, and in order to find the most appropriate ways to assist patients suffering from dementia.

In any medical treatment that involves human beings, the Occidental medicine broadly accepts the fact that the doctor has to inform the patient about any intervention in the area of medical assistance, and that the patient has to consent voluntarily, autonomously and without ambiguity to the procedure (5).

Because of the progressive deterioration evolution in Alzheimer's disease, the patients lose the capacity to understand the information necessary to make an autonomous decision concerning their personal situation, in order to reach a personal opinion on the basis of their independent reasoning, and also to express this opinion. This loss of the ability to give an informed consent or the loss of competence will render much more difficult the care and treatment administered to the patient without injuring his/her own opinions (8).

The right to knowledge

The term of knowledge designates the process that puts the subject in relation to the world and the result of putting knowledge into action.

The myths, the primary events taking place at the beginning of time, teach and warn us that thorough knowledge can constitute a danger: the danger of knowing the future.

The myth of Adam, who ate from the "tree of knowledge of good and evil",

represents the usurpation of a right through sin, and the claim to decide on one's own what does right and wrong mean, and to act accordingly: claiming moral autonomy by which the person does not recognize his/ her state of creation.

Equally, the same concept is also present in the myth of Faust who sells his soul to the devil in exchange to the gift of knowledge and the power to enhance truth, Faust becoming thus the symbol of man's continuous aspirations and endeavor to know the true sense of life and of the surrounding world.

What we should accept without any doubt is reflected in the power of the human mind to know reality. We can speak about the limitations of our knowledge, and why these limitations exist, or we can submit to knowledge only the phenomena: what is shown, revealed or manifested in experiences. It is certain that in order to know reality, we have to use our cognitive capacities, including reasoning.

The right to know is an issue related to human dignity. By informing the patients, the physician gives them the chance to plan an optimal life experience in the years their capacities are still intact; they can thus prepare a solid care plan that might be implemented in the case of possible future incompetence.

Without any doubt, the desire for suicide will increase if we cannot assure these individuals that their rights and desires will be respected.

Anticipatory health care instructions

In the United States, the so-called "advance directives", the anticipatory health care instructions began to be used in the 1960s. These documents contain written directives in which patients decide on whether or not to accept a

certain number of medical, surgical or ICU interventions for the moment when they will probably be unable to make such decisions. The anticipatory health care instructions were conceived to fix the problem of the right to self-determination in the case of patients who are no longer capable to exercise it for various reasons. They can provide the legal support for the individuals who are still enjoying a good health, in order to give them the possibility to exercise their right to self-determination in the case of medical treatment. In Western countries, all medical institutions are compelled to inform the patient about his / her right to self-determination in these respects (11).

Initially, the written forms of the anticipatory health care instructions have been used to specify the special desires of an individual in a particular medical circumstance, such as extended and persistent vegetative state (9). They mentioned the point up to which the patient accepts the artificial prolongation of life in these conditions and the medical interventions that are not accepted. Because of some similarities, these documents have also been called "living wills".

Besides this type of written instructions, there is also the possibility to appoint a person to make the decisions on behalf of the person who nominated it, decisions concerning personal care and medical treatment. This person will be authorized to make decisions instead of the person in concrete medical situations. Both ways could be combined in view of respecting the rights of the incompetent patient (3, 7, 11).

The anticipatory health care instructions are also increasingly accepted in Europe (4, 13). Many countries accept the advance appointment of a person, authorized to make decisions on behalf of the patient. Nevertheless, the

“living wills” are not an obligation from a legal point of view; they are considered as important directives of the patient’s will, but they cannot be taken into consideration in the situations where medical treatment is required.

Some professional organizations are skeptical about the validity of the “living will”, and this skepticism is based on the doubts that can be formulated on the authenticity and credibility of such a document.

The action of an individual is authentic if it is written by the very person, being the outcome of his / her will. In medical ethics, there are different concepts concerning authenticity and various demands in order to determine whether or not the decisions of a patient are really authentic. Nevertheless, it is generally accepted that “authentic” cannot be assimilated to “acceptable” or “reasonable”, and there still remains the problem of a valid definition of “authenticity”(10).

In the legal acceptance of the anticipatory health care instructions, a person has the right to refuse a medical treatment (s)he does not want, as many advantages it could have. From an ethical point of view, the situation is much more complicated. When determining the validity of these directives, the doctor can no longer question their authenticity, with the sole argument the person’s decision is irrational or mentioning the existence of a better treatment. Many of these decisions made by various individuals by exercising their right to self-determination can seem irrational, but they are applicable as long as they do not violate the right to self-determination within a democratic society.

The assimilation of “authenticity” with “rationality” is consequently unconvincing and cannot serve as a basis for justifying the validity or the invalidity

of these directives. Equally, the validity of these directives cannot be refuted by proving the existence of some treatments “of a higher performance” than those stipulated in the patient’s instructions, for the simple reason that the aim of the action itself is precisely the choice of the individual not to benefit from certain treatments at a certain point in the evolution of the disease or in certain medical circumstances (1).

Starting from these theoretical considerations, we need to mention that, from an ethical point of view, there are considerable differences between the care instructions for a patient with Alzheimer dementia and those for a patient suffering from any other disease.

As a general rule, more often than not, the patients suffering from Alzheimer dementia are aged persons, who have had many experiences during their life, have structured a personal attitude and are able to establish priorities within their system of values and life situations. More frequently than a younger individual, aged persons have generally been through the experience of disease, convalescence, pain and its relief, the need for help and support. Statistically speaking, aged persons use medical services more frequently and have generally been in contact with hospitals, doctors and medical institutions. They had the experience of death, mourning and the pain of losing a family member or a friend.

This life experience can be considered as a solid basis for expressing one’s own will concerning personal care in the form of some written directives, on the basis of personal experiences and values.

Alzheimer’s disease is a chronic, progressive disease, determining during its evolution the gradual loss of the patient’s cognitive capacities. The fact

that at precocious stages of the disease, the patient preserves his/ her capacity to make self-determined decisions, taking into consideration the occurrence of incapacity in the advanced stages of the disease, turns Alzheimer's disease and other chronic affections into an ideal indication for the advance health care instructions. Consequently, we can say that the persons suffering from Alzheimer's disease formulate their care instructions with the advantage of life experience and in the presence of concrete symptomatology.

In order for the patient suffering from Alzheimer dementia to have the opportunity to exercise his / her right to self-determination, (s)he has to be informed, at an early stage of the disease, about the diagnosis, and also about the character of the affection, the evolution and the therapeutic possibilities and prognosis. Some psychiatrists or physicians from other branches, who oppose to the patients' informing, accuse the special diagnosis procedure in Alzheimer dementia (which is made through a process of excluding other possible diagnosis, especially in the early stages of the disease) and the fact that a margin of error is also possible within this process. Against these objections, one may say that the margin of error does not automatically justify hiding the diagnosis from the patients. Such a procedure will prevent the patient to model his / her own life, taking into account the possibility of an affection which will determine the evolution towards incompetence. Postponing the presentation of this information to the patient, in order to obtain a greater certitude on the diagnosis, leads to the progression of the disease, while the capacity of exercising self-determination decreases accordingly (6).

The limited therapeutic possibilities

available nowadays, as well as the lack of curative treatment represent another ethically justified reason to inform the patient suffering from dementia about his/ her diagnosis at an early stage of the disease.

The patient's wellness and the principle "first, do no harm" oblige us to be cautious about the way in which we communicate this information. We should bear in mind the fact that patients suffering from dementia, particularly in the early stages of the disease, frequently suffer from a depressive syndrome, representing thus a vulnerable group (12). The stressful events and situations can precipitate the symptoms associated with dementia, or they can determine the apparition of catastrophic reactions. In this case, the stress caused by the discovery of the diagnosis can precipitate or accentuate the functional downhill, depression or psychiatric symptoms such as agitation, aggressiveness or paranoia (2).

Applying a neuropsychological evaluation screening to at-risk populations would increase the prevalence of dementia cases diagnosed at early stages.

In an era of increased capacity for detecting and managing diseases in an early stage, screening has become an accepted method for many medical conditions. Both the advised persons from the medical staff and the "public" accept screening for breast cancer, cervical cancer, colorectal cancer, diabetes, high blood pressure, obesity and high cholesterol level, osteoporosis and even depression.

Nevertheless, dementia screening, the most common invalidating condition of the old age, is avoided even nowadays.

We shouldn't forget that the prevalence of dementia worldwide doubles every 20 years, increasing from

24 million persons diagnosed with Alzheimer dementia in 2001, to 40 million in 2020 and probably 80 million in 2040.

From the perspective of autonomy, this screening would have the advantage of communicating the diagnosis at a point where the patient could still exercise his/ her right to self-determination. On the other hand, one should be aware of the possible danger of labeling the patient with this diagnosis and his /her stigmatization by society (2).

When we make the decision to inform a patient about the diagnosis of dementia, we have to analyze the benefits and the harm it could cause to the patient, in terms of medical ethics. For the clinical practice, we can state as a general rule that patients will have to be informed about their disease, and that exceptions to this rule will have to be justified from case to case by respecting the principle "first, do no harm".

Conclusions

An Alzheimer's disease diagnosis is the beginning of a long and difficult "journey" which will last approximately 10 years. Alzheimer's disease affects not only the patient, but also his/her family and friends. The family and friends are comrades in this journey, sharing this experience with the person directly affected.

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Even though patients make decisions concerning their last years of life, at the moment where they will be severely affected mentally and physically, the persons who are close to them will be the ones to provide financial support and to make decisions for their medical care. The choices they make can only be based on assumptions and suppositions which can be false, since the possibility to verify their truthfulness no longer exists, the person for whom the choices were made not being capable to confirm them. Irrespective of the decisions they make concerning the patients' wishes, they will be living with doubts, frustration, and guilt for the rest of their life. It is thus for their best interest to make all arrangements in due time (14).

The anticipatory health care instructions for patients, as a legal act, have to be used especially for the persons diagnosed with Alzheimer dementia.

Although there are reserves, both from a medical and psychological point of view, the patients must be informed about their disease and their prognosis, at an early stage of development, when they are still able to make informed decisions.

Due to their rich life experience, old patients are qualified to make decisions for their future on the basis of their preferences and their system of individual values.

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