

Ethics and aging: focus on living will for patients with dementia

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Abstract

Today dementia certainly represents a public health priority with a huge global impact on worldwide population. However, clinical and social issues related to dementia have long been marginalized. The actual high prevalence of dementias requires also to face issues from a bioethical perspective, regarding how to deal with demented patient's disposition.

There are currently no specific guidelines on the national territory regarding whether to draw up a living will by a patient with dementia, neither about the informative role of physicians during the progressive story of the disease.

Introduction

In 2015 more than 46 million people were affected by dementia. This amount is estimated to almost double every 20 years, increasing to 131.5 million by 2050.¹ Alzheimer's disease (AD) is the most common form of dementia and it possibly contributes to 60-70% of cases. In 2006 the worldwide prevalence of AD was indicated in 26.6 million. It was also estimated that this number would quadruple by 2050, so that 1 out of 85 subjects would be living with the disease.²

These numbers well point out how today dementia certainly represents a public health priority with a huge global impact on worldwide population.

However, clinical and social issues related to dementia - especially to AD - have long been marginalized by the international scientific community and society in general. Dementia was often configured as integral part of aging or rather a *taboo subject*. Moreover, the absence of a cure, net of symptomatic therapies currently in use, has certainly played a decisive role, which has led to simply conceive dementia as an inescapable destiny. We should not forget that dementia, by definition,³ is a syndrome

caused by a number of progressive illnesses that affects on different levels cognitive functions, behavior and the ability to independently perform everyday activities.

In this context, the risk is to receive a diagnosis of dementia only at an advanced stage, often when even *behavioral and psychological symptoms* are already exacerbated and the burden both for patient and caregiver has increased.

The actual high prevalence of dementias (especially AD) requires to face with new problems and to decide as well on issues for which there are no immediate answers. It is especially difficult for family members and caregivers who often have to make these decisions on behalf of the patient. As a matter of fact, subjects with dementia, compared for example to patients affected by different medical conditions, likely have little space to express their will, due to the progressive cognitive impairment which makes them less and less aware of their pathological status.

Discussion

From a bioethical perspective, self-determination clearly represents a cardinal principle in the doctor/patient relationship. The question of self-determination in subjects with dementia is actually an area of debate.⁴ While, according to the law, the right to self-determination of every adult citizen must be respected, on the other side cognitive disabilities progressively affect their capacity to make decisions.⁵

A widely accepted definition of decision-making capacity⁶ is based on the following strongholds. The patient should: i) understand relevant information on the treatment, including the risks and the benefits; ii) be able to assess the situation and its consequences; iii) be able to evaluate the different therapeutic alternatives; iv) know how to communicate a choice.

Generally to evaluate these skills two different approaches can be taken in account: to create *ad hoc* tools (questionnaires and interviews) or to adapt neuropsychological test batteries normally used in the assessment of cognitive impairment.⁷ A proper evaluation, indeed, should not leave aside those cognitive functions known as *executive functions*, involved in several aspects of daily life. Neuropsychological tests of complex abilities such as attention, memory, frontal functions, language and visuospatial abilities should be incorporated into capacity assessments.

Moreover a deep psychopathological assessment it is also crucial to exclude the

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presence of a psychiatric condition or personality disorder which could affect subject's self determination.

In the precise order to respect the patient's right to self-determination, scientific community and international politics have recently begun to discuss the proposal for a living will even to subjects with dementia. This will basically configures the possibility to decide before being no longer able to do so and its use is well known especially in cases of euthanasia.

In this context, living will appears to be one of the most suitable instruments to ensure greater respect for the will of a demented patient along his disease's progression. However, as previously pointed, dementia is a story that is written over many years (on average, ten) during which is gradually established an inability to make even the most basic decisions of daily life.

It is therefore necessary to evaluate when a living will should be proposed to a patient who has been taken in care for cognitive impairment (Figure 1). It could be a proper choice by the physician to discuss this opportunity early in the disease, when the subject is still able to understand and perhaps make plans.

It should also be remembered that precisely in the early stages of the disease the patient appears to be more vulnerable, due to several changes he/she is experiencing which involve his/her cognition and generate a real psychological burden. It would be strongly recommended a specific work on the disease awareness in order to make wise and weighted decisions about the future. In this context could play a key role not only the quality of the doctor/patient relationship, but also a correct diagnosis disclosure by the physician, the trust and support from his family and eventually a psychotherapeu-

tic process aimed to the acceptance of the disease.

Another point regards the topics on which the patients would express their premature will. During the disease decisions to be taken are many, diluted over time, having a strong influence on quality of life. Not to mention the emotional impact of patients who might no longer be able to modify their will due to advancing cognitive decline.

To at least partially overcome these problems, the appointment of a *health care proxy* could be a useful proposal. This person would be chosen by the patient and should be well informed about his/her med-

ical history. Generally the one pointed as proxy is a member of family or anyway a person in whom the patient places the utmost confidence in order to interpret his/her will when he/her will no longer be able to fulfill it. This *health care figure* should be proposed not simply when a diagnosis of dementia is made by the physician, but rather after mental capacity of the patient has been fully assessed. In fact, while on the one hand it is true that people with dementia have a higher risk of impaired abilities than non-affected, on the other hand a diagnosis of dementia by itself does not necessarily mean that a person has

lost his capacity to self-determination.⁸

The questions which have been described however clash with several socio-political realities not yet ready to meet with these needs. Italy, for instance, is a sensitive country though divided between secularism and religion. A recent national report⁹ pointed a prevalence of almost one million individuals affected by dementia. The Italian Government still tries to reach the solution of these complex issues. However, the *right to health*¹⁰ enshrined in the Constitution lends itself to several interpretations.

There are currently no specific guidelines on the national territory regarding whether to draw up a living will by a patient with dementia, neither about the informative role of physicians during the progressive story of the disease.

Conclusions

In conclusion, for an adequate health care planning, even in dementia, it is our opinion that the writing of a living will should be proposed to the patients in the early days of their medical care. The need to improve the quality of life of patients with dementia goes also hand in hand with recent scientific findings^{11,12} showing that subtle changes or preclinical disabilities may affect daily autonomy even in presence of a mild cognitive decline.

In this context, shared bioethical guidelines are necessary¹³ so that physicians who deal with patients affected by dementia should discuss every implication as soon as possible after a diagnosis is reached.

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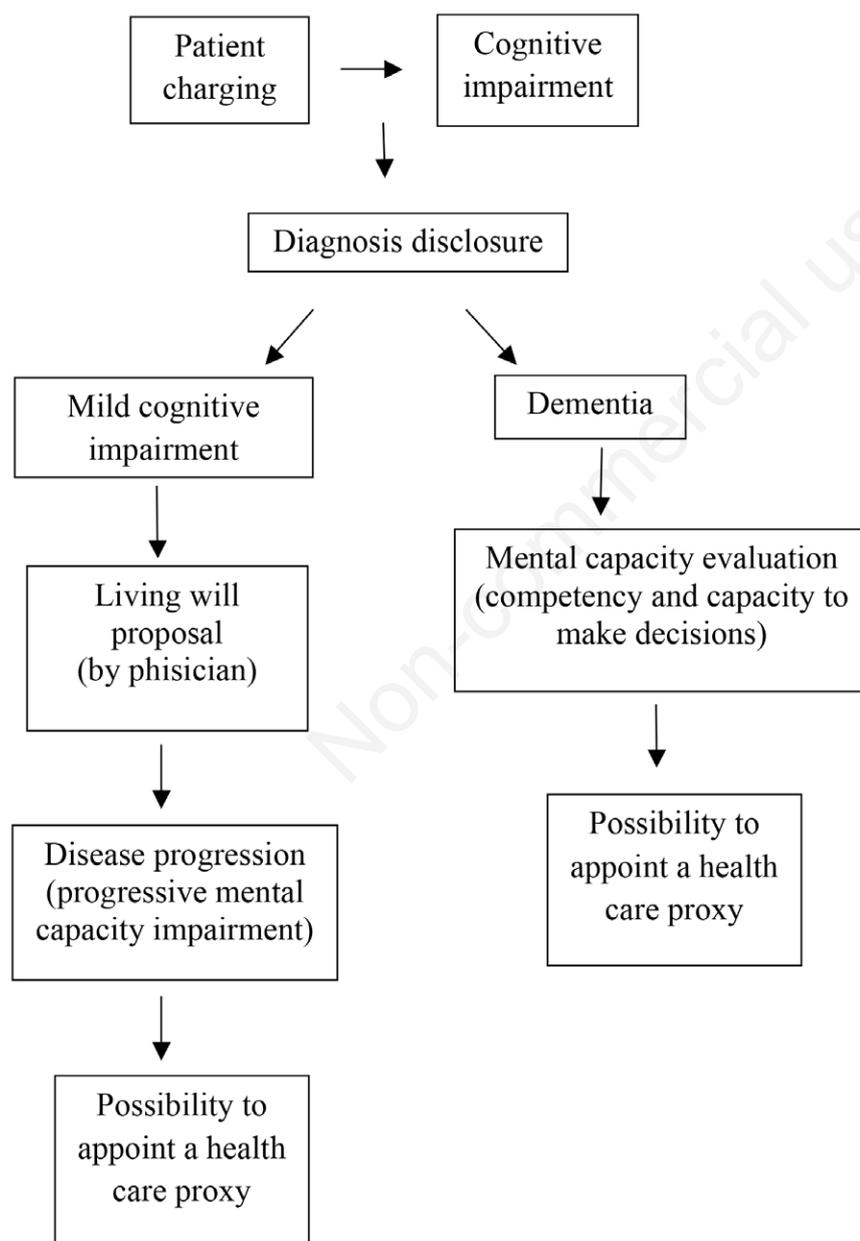


Figure 1. Living will and clinical practice.

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