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Review Article

Anosognosia in Alzheimer's Disease: Clinical Psychology and Medico-Legal Issues. Informed Consent in Healthcare

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Received date: March 07, 2024; **Accepted date:** March 18, 2024; **Published date:** March 28, 2024

Citation: Letteria Tomasello, Miriana Ranno, and Claudia Pitrone, (2024), Anosognosia in Alzheimer's Disease: Clinical Psychology and Medico-Legal Issues. Informed Consent in Healthcare, *J. New Medical Innovations and Research,* 5(2); **DOI:**10.31579/2767-7370/093

Abstract:

Insight or deficit awareness have been used interchangeably to refer the lack of knowledge or recognition of one's deficit. Our aim was to investigate if this lack could influence Alzheimer's disease patients' ability to understand and making.

Disease awareness is a phenomenon that in recent years is obtaining an increasing interest in a clinical and research point of view. It has important implications on patient cure and management. The present study is aimed to contribute to the comprehension of disturbance awareness in patients with Alzheimer disease, and provided a starting point on a complex disease linked to medical and psychological scopes but also involve Bioethics and Law.

Keywords: anosognosia; Alzheimer's disease; ethical approach to care

Introduction

Due to the progressive increase in the elderly population, there is now an increase in the number of people at risk of chronic disabling diseases related to age. These include neurological diseases, where dementia is one of the most important causes of disability in the elderly. Alzheimer's disease begins, in the vast majority of cases, with a deficit of declarative memory, associated with a time disorientation, slowly progressive, in conjunction with deterioration of another cognitive area, more often language or executive functions. This configuration is called "amnesic-disesecutive syndrome" [1]. The disease affects different cognitive functions and their deficits manifest in each individual, with different levels of clinical severity. In dementia, the mental ability to control stimuli decreases, confusion expands and the patient feels frightened, vulnerable and no longer able to control and manage emotions, with subsequent difficulty to interpret the surrounding events and to relate to them in a suitable way [2]. The main psychological symptoms are dominated by anxiety, often associated with depression and psychotic manifestations, with delusions of impairment, neglect and the so-called "myopia of the future" [3,4]. In addition to cognitive symptoms, there are non-cognitive symptoms, which affect the sphere of personality, affectivity, ideation, vegetative functions and behavior, such as apathy, irritability, agitation, aggression, disinhibition, hallucinations, delusions and eating disorders [2]. The non-cognitive symptoms are so heterogeneous and represent the greatest burden in patient management by the caregiver [3,4]. Sometimes, these symptoms can already be present in the early stages of the disease, are heterogeneous, fluctuating and influenced by both somatic and environmental variables. Impairment of the functional abilities of everyday life has a dramatic impact on the quality of life of both patients and their caregivers [5]. The treatment of behavioural disorders is one of the main outcomes in the care of the demented patient and is often a challenge that requires a multimodal approach, including the education of family members and caregivers [6]. Dementia is a disease that changes constantly, not only from patient to patient, but also and above all over time, and this leads, necessarily, to adapting goals and methods of rehabilitation, depending on both the clinical stage and the history of the person. It is a "social" disease, in which an entire family becomes ill more than a single person, and the supporting role of the caregiver is almost as important as that of the patient. Disease awareness is a phenomenon that, in recent years, is gaining increasing interest from a clinical and research point of view. It has important implications in patient care and management [3]. Awareness is a multidimensional construct, divided into insight, awareness and anosognosia

The terms insight or awareness of deficits have been used interchangeably, referring to lack of knowledge or recognition of one's deficits [7]. Anosognosia similarly means lack of knowledge of disease, but has been used more often to describe a failure to acknowledge a particular deficit, usually the motor [7]. Babinski first used the term in1914 to describe an absence of awareness in a hemiplegic patient who had suffered a stroke However, the term is now used more generally to include all neuropsychological and neurological deficits [8]. Some authors use the terms anosognosia and unawareness interchangeably [7]. Anosognosia, lack of awareness of neuropsychological symptoms (cognitive anosognosia), behavioral disorders and impaired function. Awareness, in psychiatry it designates the consciousness of mental illness, insight, it’s about introspection [8], awareness is the cognition of an ongoing change, the awareness of a specific symptom (such as a memory disorder). The patient takes note of the meaning and consequences of the symptom, that is, of "having a disease" [9]. Referring to dementia, the term anosognosia indicates the absence of awareness of neuropsychological and behavioral symptoms (Behavioural and Psychological Symptoms) and reduced functionality. With the term "Clinical Competence" or with the British equivalent "mental capacity" (10), means the ability to act or natural capacity, defined by jurists as the ability to decide or to take actions that may have legal significance for the person himself or for others. Disease awareness in Alzheimer’s disease has important implications in both the treatment process and patient management. Most of the works in the literature examine the awareness of neuropsychological deficits (memory, attention, executive functions, with less attention to the functional state and behavioral disorders). Less numerous are the works that examine the awareness of disease following diagnosis. There is a relationship between capacity and cognitive level, measured e.g. with the Mini Mental State Examination [11] and between neuropsychological capacities and deficits [12,13]. The ability to act, as well as the choice to adhere to a certain treatment, are lacking if the awareness of disease is lacking [14]. In a document, drawn up in June 2014, the National Committee of Bioethics recognizes a partial autonomy to the patient with diagnosis of AD [15]. In the early stages, the patient may have lost some of their cognitive functions and may not be able to manage certain aspects of their life independently, but may have sufficient decision-making skills in some fields (for example, therapeutic decisions or participation in trials and research). Decision-making autonomy in the patient must be considered a variable dynamic concept, at different stages of the disease and in relation to the type of decision to be taken. To date, there are still no standardized tools that define the competence of an individual with dementia [16]. It will therefore be the task of research in the neuropsychiatric field to define protocols that evaluate the different dimensions and functional aspects underlying the decision-making process, in order to involve, as far as possible, the patient in therapeutic and care decisions [15]. One of the aspects, to be taken into account in clinical research and healthcare treatments, involving patients with dementia, concerns cognitive disorder and poor judgment, present in the evolution of the disease and which may interfere with the ability to make informed decisions. Various approaches have been recommended for this assessment. A guideline, approved by the Association of American Psychiatrists in 1997 and the Research Council, indicates four "capacities" to determine whether subjects are able to make decisions:

- ability to make a choice;
- ability to understand consent information;
- ability to give due weight to the situation and its possible consequences;
- ability to use information rationally.

AIFA, in its statement of 28 December 2006 (17), raises the issue of the consent of the patient, suffering from dementia, in relation to the prescription of neuroleptic drugs that do not have a specific indication in their data sheet. The psychological and behavioural disorders of these patients are a major management problem for the caregiver and are often the main cause of access to the emergency room or to the clinic for emergency visits. Despite this, their treatment provides for a pharmacological intervention, considered like any health treatment not mandatory, according to specific provisions of law. The pharmacological treatment of patients suffering from Alzheimer’s disease is based on the constitutional principle (Art. 32) that "no one can be obliged to a certain medical treatment". Therefore, in these patients, it is necessary that every medical act is preceded by those acts of information that make personal consent valid. Specialist doctors at Memory Clinic centres often come into contact with patients with serious cognitive and behavioural disorders who, almost regularly, do not have a legal representative (i.e., are not banned) or a support administrator. In the case of incapacitated patient, suffering from behavioural disorders and with urgent need of treatment, with drugs able to control these aspects, but without legal representatives, the doctor is required to intervene according to the provisions of art. 36 (Emergency Assistance) and 37 (Consent of the legal representative) of the Code of Medical Ethics. Art. 36 declares that: "When conditions of urgency exist, taking into account the wishes of the person if expressed, the doctor must take action to ensure the necessary assistance". Art. 37 states that: "... if there is danger to life or serious risk to the health of the child and the incapacitated, the doctor must still proceed without delay and as necessary to the necessary care". Neurodegenerative and Alzheimer’s diseases are among the most infamous forms and it is desirable that the patient is assisted throughout the therapeutic path and not only for the administration of atypical neuroleptics, by a supportive administrator.

Awareness in Alzheimer’s Disease

Research so far has shown that awareness is preserved in the early stages of Alzheimer’s dementia, variously compromised in the intermediate stages and absent in the advanced stages Informed consent (CI), which is relatively easy to apply, encounters difficulties if the conditions are lacking, according to the scheme of Beauchamp and Childress (2001) (18)

a) well-established information; or information from the point of view of the doctor;

b) information well understood; that is, information from the point of view of the patient, his ability to understand and integrate it in the knowledge of his or her overall condition;

c) freedom; or freedom to decide in the absence of conditioning factors or at least with awareness of their presence;

d) the ability to decide. This last element corresponds to the ability to deal with the present work.

Patients in the early stages of disease, are aware of their memory difficulties. Many studies have analysed the relationship between awareness and psychic symptoms. According to some studies, high levels of awareness would be associated with an increased risk of depression, apathy would be linked to a lower degree of disease awareness [19] Psychotic symptoms and unawareness are often present in the advanced stages of dementia and appear to be caused by dysfunction of the frontal cortex and its subcortical structures [20].

The problems, related to awareness, are often linked to those of the diagnosis and prognosis for the patient and his family. Communicating the diagnosis to the patient makes it possible to respond to one of the key principles of biomedical ethics, the "respect for autonomy", that is, the right of the person to make decisions about the proposed healthcare treatment. The CNB (2014) [15] recognizes that the decision-making capacity of the patient, with Alzheimer’s disease, must be evaluated in the various stages of the disease and in relation to the decision to be taken. In addition, he states that it is the task of neuropsychiatric research to define protocols that evaluate the functional aspects, underlying the decision-making process, to involve, as far as possible, the patient in therapeutic and care decisions. There are several legal instruments to protect individuals with dementia, which progressively make the subject unable to understand and want, to guarantee the rights and interests, not only patrimonial but also existential.

Assessment of the ability to decide and give consent to processing

The 1997 Oviedo Convention [21] and the 2006 Code of Ethics enshrine the principle of autonomy of care choices [22]. Dementia is characterized by the progressive loss of the capacity on which autonomy is based. Moreover, there is also a lack of awareness of the disease and its symptoms (cognitive deficits, behavioural disorders, alterations in the functional state). The Study Group of Bioethics and Palliative Care in Neurology of the Italian Society of Neurology [23] have examined the issue and have reached the conclusion that the examination of a patient with dementia and Behavioural and Psychological Symptoms, aimed at assessing their ability to consent to treatment, should be subject, in addition to clinical evaluation-medical history, including a neuropsychological evaluation and an investigation that assesses the perception of the disease status and decision-making. This survey should make particular reference to the ability to understand relevant information, assess the significance of the information in relation to your situation, to consider the relevant information in order to compare the risks and benefits of the various possible alternatives proposed and to make a choice.

Informed consent and decision-making skills

Informed consent is a fundamental prerequisite of every medical act and the autonomy of a patient, in the fullness of his ability to decide on treatments and possible therapeutic treatments. Presupposition of informed consent, beyond the information (well given and well understood) and freedom (absence of conditioning factors or at least awareness of their presence), is the ability to decide. The ability to decide on medical treatment is inherent in the legal concept of capacity to act (Art. 2 of the C.C.). The definition, proposed by Wong et al. (1999) (10), provides an indication of the relationships between the ability of the individual and the society around him: "capacity is what distinguishes a person, who is able to make a decision and whose choice must be respected, regardless of the reasonableness of the choice, by a person for whom decisions must be made by others". There are cases where a person may no longer be able to manage his or her current account but may be able to give his or her consent to simple medical treatment. The ability to decide must be presumed, until proven otherwise. Dementia is, therefore, a risk factor for incapacity, but it does not inevitably involve it. The ability (or inability) is always relative to a certain task. For example, a person may be able to make a decision for simple medical treatment but not be able to discern complex alternatives with different risk/benefit profiles.

The term "clinical competence" means self-determination in the healthcare sector [24].

Decision-making capacity is made up of parameters, outlined in 1977 and subsequently revised [25]

The parameters are related to:

- ability to express/manifest a choice;
- ability to understand choice information;
- awareness of the meaning of the choice and therefore of the possible consequences;
- ability to reason and logical processes; for example, being able to focus the problem, operate response options and likely consequences.

In Alzheimer’s disease there would be a relationship between capacity and cognitive level (MMSE) and between neuropsychological abilities and deficits, with reference to semantic memory and executive functions [26].

The conflict between freedom of care and protection is evident; therefore, to overcome a possible medical approach of the "paternalistic" type, it is necessary, as the only viable alternative, the appointment of a legal representative, in the figure of the supporting administrator, introduced in our legal system with l. n. 6/2004, The latter, unlike the traditional institutes for the protection of incapacitated persons (interdiction and incapacitation), does not perform a mere protective and conservative function of the beneficiary’s assets, but has, as its main objective, the promotion of the same, through the realization of interests of a non patrimonial nature [27]. Case-law has stated that: "the scope of the support administration must be identified in relation to the interdiction and incapacitation institutions, not because of the different and less intense degree of infirmity or inability to wait for the non-autonomous person’s own interests, but rather because of the greater suitability of this instrument to adapt to the concrete needs of the subject itself" (in this sense, Trib. Bari, 5 September 2008, n. 630) [28]. The principles on which this institution is based are flexibility and proportionality. flexibility, as there is no rigid predetermining of the sphere of autonomy of the beneficiary, remitted to the court, according to the protection needs emerged and with indication in the provision of the tasks of the administrator; proportionality means that the measure must be adapted to the conditions of the beneficiary, that is, the deprivation of the capacity to act is limited and has the limits strictly necessary to ensure the protection of his personal and property interests. This allows the balance between the opposing demands of freedom and protection of the person so cared for internationally. The New York Convention of 13 December 2006 (ratified by the internal legislator with l. n. 18/2009) on the rights of disabled people, recognizes art. 3 "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices", also specifying art. 12, paragraph 4, that "States must ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, which are free from any conflict of interest and any undue influence, proportionate and appropriate to the circumstances of the person, applied as soon as possible and subject to periodic review by a competent, independent and impartial authority or judicial body". "The line, followed by Italian law, is intended to enhance and promote the residual autonomy of the person and not to marginalize and exclude" [29]; law that, after its issuance, has obtained the favourable opinion of the National Committee of Bioethics ("Bioethics and the Rights of the Elderly"), which recognises the ethical significance of the supporting administrator’s role in relation to legal issues that may arise in old age. Dementias would be fully compatible with the institution of the support administration, since, as has been pointed out by several quarters, the use of the ban could even be harmful, since the risk of social exclusion of the elderly would run, having regard to the full substitute representation characterising this protection measure [27], "On the contrary, the administration of support can be a stimulus in the life of the elderly, who begin to relate to a new interlocutor and, whether or not he is able to dialogue in a conscious way, may feel an element of contrast to the feeling of loneliness or isolation, where present" [30].

The approach of care and care in such patients should be based on a multidisciplinary approach, not only aimed at the control of non-cognitive symptoms, but above all at the relationship and environmental context [31]. If this concept is not clear and shared by the multidisciplinary team (general practitioner, neurologist, psychologist) with the involvement of the main caregiver and the family, the patient will become the subject of treatment and no longer the subject of treatment [32] The ethical and solidarity duty of all professionals in the sector towards these patients must therefore be strongly affirmed. Only the analysis of real needs allows, in fact, to face the numerous ethical dilemmas that are evident in the course of the disease, respecting the principles of autonomy-self-determination, charity and social justice. The temptation on the part of today's cultural world to believe that dignity in the subject with dementia no longer exists is frequent. Man, as a "person", has his own original dignity, at every stage of his existence, and, to strengthen the concept that the patient with dementia, is still a "person" and, in any relationship with him, we must recognize this dignity [32].

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DOI:10.31579/2767-7370/093