

ISSUES OF PROFESSIONAL ETHICS IN THE TREATMENT AND MANAGEMENT OF PATIENTS WITH LATE DEMENTIA

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<https://doi.org/10.5281/zenodo.10335648>

Abstract. *The ethical problems of late dementia cover a wide range of issues related to the positions and attitudes of medical professionals, as well as the behavior of caregivers. This report is devoted to the professional problems of Biomedical Ethics in working with elderly and elderly patients with dementia. The ethical aspects of late dementia are becoming increasingly important with increased public attention to this pathology, which is becoming more and more common among the population of older age groups.*

Keywords: *dementia, late life, treatment, Alzheimer's.*

Introduction. According to Josephstiglitz, Nobel laureate in economics, "there is no more important topic than population aging and social protection of the elderly. This affects the nature of our society and applies not only to the elderly, but also to all segments of the population. Protecting the rights of people with dementia is recognized as a health priority [1]. The United Nations Convention on the rights of persons with disabilities obliges states to ensure that all human rights and fundamental freedoms of all persons with disabilities are fully implemented and that their human dignity is respected. By the middle of the century, the number of people with dementia is expected to increase significantly and the global burden of Alzheimer's disease (AD) is expected in the World [2]. Consideration of the ethical aspects of dementia often focuses on "major" problems such as refusing treatment and deciding to end life. Although these issues are very important, there are other ambiguous situations that constantly arise in applied medicine as a product of the development of Biological Sciences and medical knowledge, requiring constant discussion both in the medical community and among the general public. At the same time, an analysis of 12 national guidelines for clinical practice in the treatment of dementia [3] showed that only 49,5% of deontological norms are taken into account, and 11 of the 12 guidelines do not address issues such as giving the other person the right to make important medical decisions at all, legal incompetence, the use of surveillance methods, control of suicidal behavior. The solution of these issues is relevant both for doctors and for the patients themselves, their relatives and the general public [4]. Moral problems arise during the life of a person with dementia, from the moment of diagnosis. The development of Neurology in understanding the individual branches of dementia pathogenesis, the idea of neuropathological changes in brain structures long before the appearance of symptoms of the disease, the development and attempt to introduce drug treatment methods of cognitive decline serve as the basis for considering ethical problems, preclinical stage [5]. The ethical aspects of the preclinical stage of AD pose the greatest challenge to consider, while the importance of not only early diagnosis but also the assessment of the risk of disease in healthy people gradually increases explains the increasing focus on discussing these problems.

Alzheimer's is a clinical diagnosis. However, Alzheimer's pathology begins long before clinical manifestations, and the number of studies is increasing to assume that biomarkers such as positron emission tomography and fluid tests directly prove this pathology [6]. It is assumed that the diagnosis can be distinguished from the clinical expression of Alzheimer's disease [6]. Preclinical AD is being discussed as changing the boundaries between "normal cognitive aging" or "healthy brain aging" and disease, which should change the notion that AD is the most feared aging disease among late age-specific diseases, fear of getting sick. New diagnostic criteria proposed using biomarkers to confirm and improve the accuracy of the diagnosis of mild cognitive decline (MCI), as well as to assess the risk in asymptomatic people [7] remain a topic of debate, as they are only of research significance and cannot be made available to the public at this time. The scientific community refers to the concept of preclinical AD as a risk condition identified by biomarkers and the separation from other risk factors and clinical signs of the disease. The ethical aspects of determining risk factors are considered for their commonality and for individual groups of biomarkers, among which structural and biochemical characters, as well as genotypes, stand out [8]. Neuroimaging (MRI, functional positron emission tomography, amyloid imaging) is used to early confirm a specific diagnosis in people with mild or unclear symptoms (MCI) and to identify Alzheimer's pathology in asymptomatic people. It is believed that the combination of neuroimaging methods will be most effective in predicting a diagnosis [9]. Putting them into practice is not without difficulties, but because cultures and values have changed within the scope that determines benefits and risks, planning the moral and social impact of predicting aging brain disease is very important and benefits leading researchers, patients and families in the field, health organizers and politicians [10]. Biochemical signs that are most likely to detect the presence of Alzheimer's pathology in the brain include indicators of beta-amyloid, Tau protein, and phosphorylated Tau in the cerebrospinal fluid. Ethical problems with biomarkers still apply to the volume of diagnostic and predictive data presented about the results of the unreliable study [11]. In the field of genetic testing or genotyping of AD, ethical problems lead to a balance between a person's desire to know the risk of developing dementia and the clinician's desire to mitigate the possible harm of this information. Genetic problems are important in very rare cases of familial AD that began early (up to 65 years of age) due to the presence of certain mutations. Genotyping, the main risk gene for Apo E – sporadic AD, is widely debated, which may be necessary in the context of creating new nozomodizing drugs [12]. Information on the presence of the APOE E4 genotype in asymptomatic patients has been shown to reduce anxiety in undamaged and even negative carriers. The impact of APOE E4 + carrier knowledge has been less than expected. This is due to the inclusion of individuals who initially took their risks in the study. Knowing the APOE genotype, it was also important for individuals to change their insurance orders, lifestyle and eating patterns, resort to vitamins, exercises, training, even knowing that these methods were not proven [13]. Revision of laws and guidelines can effectively monitor patients with preclinical AD, monitor the dynamics of their ability to perform high levels of activity, and at the same time minimize stigma, help patients maintain personal immunity and maximize independence. Another ethical dilemma is the position of a doctor or researcher who requires a genetic examination of a patient or relative with dementia [14]. Although preventive treatment is not available, moral consensus is achieved in providing the possibility of genotyping, as it is a manifestation of respect for the individual and this information can be useful in planning the future. However, genetic testing for AD is fundamentally different from this procedure in other hereditary diseases (such as Huntington's chorea), and the difference

is that in ad this marker is only a statement of predisposition. Until recently, it was not considered necessary to report the results of genotyping in the absence of symptoms of the disease, which is usually alerted during scientific research [15]. This paternalistic approach exaggerates the moral significance of protecting patients from traumatic information. An acceptable model for explaining non-disclosure of findings to participants, family members, and physicians is that these findings are not critical to treatment [16]. But many patients want to know the results, even positive ones, although they can exaggerate the importance of the initial scientific evidence. The doctor or researcher requires careful explanation of genetic information, keeping in mind that providing it can improve compatibility and affect the search for previous help [17]. The safety and effectiveness of reporting a preclinical AD diagnosis presents the most difficult problem in terms of biomedical ethics. One of the first questions involves examining the preclinical AD and considering whom to nominate for diagnosis. The ethical problem is that the results of the Alzheimer's-gob-marker test are potentially traumatic information, and anxiety, depression, or even suicidal thoughts can develop. Surveys have shown that fear of AD prevails over fear among Americans [18]. In people with heart, diabetes, vascular disease, and over 55 years of age, fear of AD is stronger, such as fear of cancer, which reflects the popular phrase: "senior Alzheimer replaced Senior R(AK)". Nevertheless, it is morally correct to report the results of the study to the "biomarker positive". The "evidence-based medicine" answer to the question of how patients with preclinic AD should be treated cannot be obtained at the moment, since it is envisaged to prescribe treatment if the benefit of this treatment is indicated, but there are still no "golden standards" about the benefit of this intervention [19]. When treatment in clinical studies is shown to reduce the risk of progression from the preclinical stage to clinical manifestations of ad or intermediate states such as ISS, the clinical decision-making process and the development of diagnostic and treatment facilities change radically. The logic of this approach is based on the interrelationship of two different arguments: the argument predicting that biomarker reliably implies the risk of a clinical event, and the goal of therapeutic intervention is to reduce the risk of dementia [20]. To date, there are constant contradictions about how widely treatment for diseases with risk factors should be used. To mitigate these contradictions, scientists, clinicians, and health policy makers must develop national education programs on Alzheimer's disease. These programs should focus on how to transfer the preclinical phase of AD research findings to clinical practice, including adapting professional practice, social policy, and laws to preclinical AD diagnosis [21]. The value of the Alzheimer's label is expected to change as the preclinical AD diagnosis is put into practice. Relevant laws must be revised to prevent Stigma and discrimination. The discovery of preclinical AD may indicate how ready society is for the "tsunami" of Alzheimer's dementia. The emergence of new drugs that can delay the transition from the Prodromal stage to dementia requires rules of caution for their use [22]. Because the operational research criteria of preclinical AD are not focused on clinical diagnostics, and the predictive benefits of these biomarkers for individuals remain unclear, information press targeting for early detection of high-risk groups for AD development has been shown. In particular, it is recommended to perform an amyloid brain test every 5 years from the age of 50 [23]. The ethical aspects of informing adults and children with dementia about the risk of AD for them, although first of all there is concern about the condition of a sick relative, in second place there is a risk of getting sick. It is known that in the case of one sick relative (parents or sibs), the risk increases by 2-4 times. Usually, doctors report an increase in risk, but note that age-related risk exists for everyone both when there is a family history and

without them. It is very important to explain that at the age of 65-70, the total risk is 2.5%, in the absence of a family history - about 1.5%, and in the case of a family history - from 3 to 6%. Thus, although the relative risk is increasing, the overall risk is still low enough [24]. There is no clear answer to the second frequently asked question of what can be done to prevent the disease, but attention should be paid to the recommendations of active activity, the benefits of which have been repeatedly confirmed. Being active, engaging in social and cognitive stimulating activities, and exercising are thought in many cases to slow down memory impairment and stabilize disease progression [25]. Therefore, the recommendation will have to change the lifestyle in favor of active activities. Vitamin deficiency should be replenished, but there is no reliable evidence of increased adherence to vitamins, food additives, herbal preparations and diet. Ethical problems in early dementia diagnosis include strict adherence to accepted diagnostic criteria and conscious interpretation of the entire dataset of clinical and neuropsychological examination, as well as neuroimaging results [26]. The transmission (disclosure) of the diagnosis to both the patient himself and his relatives requires adherence to biomedical ethical relationships. The implementation of the patient's right to know the diagnosis involves explaining the potential benefits of this knowledge, the guarantees of confidentiality, while maintaining the possibility of informing family members [27]. Correct information about the diagnosis can be sensitive to the patient, but this allows the patient with the initial stage of the disease not to be removed from participating in the planning of various measures – from participating in treatment programs to solving legal issues that allow maintaining the patient's quality of life. In the case of the patient, delay in diagnosis is considered acceptable in the presence of depression or anxiety disorders, or in the absence of support in the family [28]. The right to not know the patient's diagnosis is maintained if he announces it directly. However, this should not affect the possibility of treatment and gradually provide more complete information about the disease [29]. The role of the family is determined by cultural characteristics and a specific family situation. It is advisable to inform the Alzheimer's Association about its activities in society, its goals and the specific possibilities in helping and supporting patients and their families. Since the diagnosis of dementia, clinicians, patients, family members, caregivers and researchers have faced many ethical questions that vary depending on the stage of the disease and the severity of the manifestation [30]. Some nuclear ethical issues are addressed in the order in which they occur during illness. In the early stages, these are the limits for recognizing the independence of patients (referral for more accurate diagnostic tests, actions of a psychiatrist when patients require genetic testing, limits for discussing severe results with the patient when executing pre-issued commands) [31]. In the middle and late stage of the disease, a main conflict arises between paternalistic attempts to maximally maintain the independence of patients and protect them. This includes behaviors and actions against the will of patients, the transmission of intolerable information, especially in the later stages, when it is necessary to lie in order to avoid psychological stress. As death approaches, the problem of life-saving boundaries arises [32]. That is, the main tendency to maintain independence simultaneously determines the moral validity of the intervention for the most complete and as long as possible, and remains opposite when the situation worsens [33]. The psychiatrist then uses his moral concepts. When faced with these or other moral problems, it is important to understand that with the spread of the disease, relationships with relatives of patients become increasingly important, and not a loss of their cognitive abilities [34]. Recognition of not only moral, but also legal responsibility for the diagnosis of dementia is justified by the fact that medicine and health in

modern society exist in a new legal space [35]. In the context of the transition from medical deontology to medical law and civil liability (for actions and inaction), the ethical aspect of long-term therapy is discussed. Certain moral contradictions concern the professional activities of a doctor who is currently engaged in the treatment of an incurable disease using ineffective therapeutic intervention methods. Certain moral problems arise as a result of contacting various specialists, first of all, neurologists, receiving incompatible medical recommendations [36]. Excluding the stigmatizing effects of diagnostic disclosure involves combining efforts by neurologists and psychiatrists in managing patients with dementia. It is known that the diagnosis of AD is clearly established after death, but in the future it may change. Neuroimaging allows you to see amyloid plates throughout life, but plaque accumulation occurs only at an advanced stage [37]. The moral imperative of the clinical diagnostic procedure is recognized as the patient's right to clarify the diagnosis as much as possible [38]. Initially, other cases with similar symptoms, often reversible, are excluded, while it is equally important to seek to reduce the risk of false positive and false negative results. The first and most important clinical and moral duty of a psychiatrist or physician is to exclude the possibility that it is a manifestation of normal aging, or of dealing with relatively good and treatable diseases [39]. When the patient complains of memory for the first time, the psychiatrist should be careful about AD. It is believed that cognitive tests of young individuals over 65 years of age and with family weights should be carried out almost every year. One of the main ethical problems is the degree of completeness of information about the probability of AD [40]. Recently, medicine has not been able to offer much to patients with AD. There are concerns that the patient may find out about a possible AD and take his own life. Psychiatrists believe that avoiding suicide is more important than maintaining independence. In fact, a balance between these approaches is required [41]. Although suicidal reactions are very rare, the risk of suicide is still present today and should be considered, especially in people who are highly educated, maintain criticism and recognize that there is no improvement in therapy, even when depression and other risk factors are not present. In contrast to these views, two arguments speak in favor of continuing the test [42]. The first is associated with the use of medications and psychological intervention in the past. Although early intervention does not change the final outcome of the disease, it can slow down the process [43]. The latter is a rare occurrence of depressive reactions to the diagnostic message. This makes it possible to solve other ethical issues – the discussion of genetic tests and pre-issued orders [44]. Only one moral exception is recognized-if patients do not want to know this information and continue in it. The psychiatrist should take this position by respecting the patient's independence and even realizing that the lack of information for the patient can be harmful, but should warn about the risk of insufficient Examination, given the possibility of patients returning to the doctor later [45]. Another ethical problem of diagnostics, according to the researcher, is the decision to give everyone or only those who wish the opportunity to take tests [46]. It is believed that following the principle of equal opportunities, the right to choose is supported by self-esteem. Thus, the psychiatrist paradoxically not only more broadly supports patients' self-esteem, but also improves the quality of care at the same time [47]. Currently, there are various methods of diagnosis by specialists, taking into account the ability to understand and/or hold information, psychological impact and therapeutic nihilism [48]. The moral process of reporting a diagnosis should take into account the level of understanding, biography, belief, psychological state and desire to know the diagnosis, take into account the composition of the family and the degree of its involvement in care, be aimed at

clarifying the diagnosis, provide the opportunity to discuss the possibility of treatment and support [49]. Planning the future, including financial and legal issues, care problems, the ability to observe, including psychological support when necessary [50]. The ethical problem of conveying his diagnosis to the patient has two aspects – the disclosure of the diagnosis or the accuracy of the data and the experience of the person diagnosed with dementia. Dementia is not always a patient-oriented problem when disclosing a diagnosis [51]. Doctors do not always accurately and directly reveal the diagnosis and the relatives of patients. It is believed that the negative consequences of revealing the diagnosis (depression, suicidal tendencies) are not characteristic in these cases. Positive thoughts are discussed, such as visualizing cognitive disorders as symptoms of the disease, planning treatment, and later life, rather than the result of age-related changes [52]. The diagnosis should be discussed many times, not only to facilitate adaptation (coping) strategies, but also to address practical issues. The results of a specially conducted study showed that [53] of 233 caring family members, all participants wanted to know the diagnosis, but 58% did not want the doctor to deliver the diagnosis to a sick relative. At the same time, 96% want to know the diagnosis if they have developed dementia, and 66% want to know the diagnosis from the very beginning in order to have time to develop a life situation management strategy [54]. Disclosure of the diagnosis should be carried out in a supportive environment when there is enough time to answer questions and correct emotional reactions [55]. It is recognized that it is necessary to comprehensively discuss various problems: treatment, the course of the disease, the nature of the disease and the presence of various forms of support that will be needed in the future, and even to discuss orders for maintaining life at the terminal stage [56]. Reporting a specific diagnosis and its consequences can cause great discomfort for both the patient and the family, and these issues should be gradually raised on subsequent visits or discussed only with the family member responsible for the patient [57].

Conclusion. Great importance is attached to the choice of phrases when disclosing a diagnosis, both in the oral message and in the written form. The use of clear phrases, respectful tone, involvement in a joint discussion will allow patients with dementia to avoid condemning discrimination. The ethical aspects of diagnosing dementia and opening it are closely related to the stigma problem. According to WHO research, stigma, as a result of ignorance of the nature of dementia, prevails in most countries and is valid both for the whole society and for the patients themselves, their family members and even for health and social care workers. Not understanding the nature of the disease leads to fear of developing dementia. The idea that nothing can be done leads to a feeling of frustration that can affect people's well-being. Stigma and discrimination refer to caring family members and causes avoidance of communication. This health fear is second only to the fear of cancer.

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