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BIOETHICAL PROBLEMS OF RENDERING MEDICAL AID TO PATIENTS WITH DEMENTIA

ABSTRACT

Currently, there is a steady increase in the number of elderly patients with cognitive impairment in need of specialized and high-tech medical care worldwide. We aim to outline the main bioethical problems of scientific research and medical care for patients with dementia in the Department of neurodegenerative diseases of the Hospital of the Yakut science center of complex medical problems. Patients with different stages of dementia accounted for about 18 % of the total number of patients treated in the hospital of YSC CMP, and elderly patients with dementia – 10%. Ways to solve complex issues should be taken to develop ethical rules for the provision of specialized medical care, taking into account the psychosocial, cultural and ethnic characteristics of the population in the Republic Sakha (Yakutia).

Keywords: patient, bioethics, dementia, neurodegenerative diseases.

At present, there is a constant, steady increase in the number of elderly patients with cognitive impairment in need of specialized, high-tech medical care throughout the world. The problem of injustice in health care, primarily in the availability of high-quality medical care and modern achievements of biomedical science is of prime concern in contemporary bioethics [4].

Degradation of memory, thinking, behavior, and the inability to perform daily activities are the most common symptoms of dementia [6]. According to WHO, there are 47.5 million people with dementia worldwide, and 7.7 million people are diagnosed with it each year [2]. Dementia is a multifactorial pathology, including both the primary degenerative processes in the nervous system (Alzheimer's disease) and secondary degenerative changes in the cerebral circulatory system (vascular dementia). In addition, dementia, as a syndrome, is characteristic of several hereditary neurodegenerative diseases, such as Chorea Huntington, myotonic dystrophy, hereditary spastic paraplegia and others.

"Dementia 2012", a WHO report [10], has a separate chapter devoted to ethics. Protecting the rights of persons with dementia is one of the highest priorities of the medical community and our society. It is emphasized that patients with dementia and their caretakers share the same human rights as everyone else. The UN Convention on the Rights of Persons with Disabilities obliges governments to ensure the realization of all human rights and fundamental freedoms of all people with disabilities. Different examinations of the ethical aspects of dementia often focus on such major problems as the right to refuse treatment and euthanasia.

While these issues are very important, there are also other problematic ethical situations that arise in the course of scientific research, the routine treatment of patients and daily care [12,13]. These include: autonomy, capacity, consent, advance directive, disclosing truthful information, confidentiality, artificial feeding and hydration, genetic screening, behavior control, car driving, wandering, research, determination of diet, problems associated with the decision to leave this world, namely, euthanasia and voluntary death with the assistance of special painkillers that is approved by the attending doctor [9].

An analysis of the bioethical aspects of old age dementia is most fully reflected in the review [4], which presents contemporary foreign and Russian research on the ethical issues of gerontology.

Various ethical problems are described in these studies [15,18], they are divided depending on the stage and severity of the clinical signs of the disease.

Predictive stage - the development of a wide range of molecular and neurobiological biomarkers can provide the ability to identify not only preclinical, but also the presymptomatic state of the illness [7]. In particular, the safety and effectiveness of the diagnosis of preclinical state of the Alzheimer's disease (AD) is the most challenging issue in bioethics. One of the first questions is: who is to be considered as candidates for testing and for the diagnosis of preclinical AD. The ethical challenge is that receiving the results of Alzheimer's biomarker tests can potentially be traumatic, with subsequent manifestations of anxiety, depression, or even suicidal thoughts in patients. Surveys have shown that among Americans, the fear of Alzheimer's disease is superi-

or to the fear of heart disease, diabetes, stroke, and in people over 55, this fear is stronger than, for example, the fear of cancer [4].

The mild and moderate stages of dementia - here the bioethical problem of decisions made by the patients themselves is most frequently discussed. So-called joint decision making is perceived as most ethically acceptable. It is defined as a partnership that clarifies possible treatment options, provides information about options, results and uncertainties, taking into account the patient's own set of values and preferences, which allows clinicians, patients and caregivers to make joint decisions on treatment [1, 11, 14, 20].

The severe stage of dementia - the complex moral aspects of maintaining the life of the patient at the end of his life are discussed, especially in those countries where euthanasia of hopelessly ill patients is legalized [21]. Studies of this issue in Russia show that the attitude of relatives of patients with dementia and AD to euthanasia is ambiguous. Respondents are less likely to see a medical problem in euthanasia, highlighting its ethical and legal aspects more. They positively assess the moral level of medical workers, paying attention to the imperfections of modern medicine. The attitude of people towards euthanasia is determined by the existence of multidirectional ideas about euthanasia in the field of legal, socio-cultural, spiritual and personal aspects of this problem [5].

Stigmatization of patients with dementia is the constant subject of research in the International Alzheimer's Association studies [22], including the research of criticism in patients and caregivers, various attempts to address different aspects of

stigma and search for ways to overcome it. Stigma is seen as one of the main barriers in understanding the problems of the disease, seeking help, getting a diagnosis and accessing support services. This closes the path of open discussion of the disease and makes doctors think that they have nothing to offer [4].

Factors predisposing to the development of the disease are still not completely clear, but the severe moral and social consequences of dementia are obvious [17, 3]. The primary goal of this publication is to outline the main bioethical problems of scientific research and medical care after patients with dementia in the department of neurodegenerative diseases of the Hospital YSC CMP.

Since November 1st, 2018, the Department of Neurodegenerative Diseases has been functioning in the Hospital YSC CMP, in the span of three months from December 3, 2018 till March 5, 2019, 11 patients with different stages of dementia, from mild to severe, received medical help, of which 5 people were middle aged (30-55 years) and 6 people were of old age (63-79 years); nationality: Yakuts - 7 people, Russians - 2 people, other nationalities - 2 people; place of residence: Yakutsk - 7 people, districts of Yakutia - 4 people. Patients had the following diagnoses: frontotemporal dementia - 1 person, neurodegenerative diseases (NDD) - 6 people, Parkinson's disease - 2 people, neuromyelitis optica - 1 person, polyneuropathy of unclear genesis - 1 person. Patients with different stages of dementia accounted for approximately 18% of the total number of dementia patients who received treatment in the inpatient department of the YSC CMP, and elderly patients with dementia - 10%.

Elderly patients with dementia belong to the group of vulnerable patients who need special treatment and care, both from family and medical staff. You can include at least three questions into the framework of the modern ethical approach towards deciding on medical intervention for an elderly patient:

- 1) clearly identify the purpose of the intervention;
- 2) assess the effectiveness of the procedure or intervention;
- 3) determine whether the risks and benefits of the intervention will be balanced.

If all three questions are answered positively, the intervention and quality of care regarding the proper treatment and examination of an elderly patient will be ethical [19].

In the initial stages of dementia, it is

important for patients to be under the care of the caregiver and remain involved in the society as much as possible. The provision of relatives with accurate information about the disease, their involvement in the treatment plan and medical care, discussion and preparation of advance directives beforehand is of the highest ethical priority. As the disease progresses, the goal is to ease the stress for the patient and relatives. The method of providing negative information is up to the individual choice of the attending physician. The role of the doctor is not to make decisions for the patient, but to facilitate and participate in joint decision-making by the doctor, patient and family members. In addition, an important aspect is that the doctor or the researcher should consider the educational, cultural, ethnic and religious characteristics of the patient.

The treatment of patients with cognitive impairment in the conditions of the inpatient department of the YSC CMP is carried out according to the standards of medical care and the principle of equitable distribution of resources. It is known that in some cases, in the conditions of resource shortage, elderly patients are in a disadvantageous situation. Several hidden forms of discrimination against elderly patients is the refusal of hospitalization and appointment of expensive treatments [3,4]. In the future, palliative care is planned for the disabled and hopelessly ill patients of the YSC CMP.

Participation of patients with dementia in scientific clinical research is one of the more complex bioethical problems. Patients with cognitive disorders and elderly patients belong to the vulnerable group of participants in clinical trials, epidemiological and genetic studies. The issue lies in obtaining informed consent. The process of informed consent requires: confirmation of the ability to make decisions, disclosure of sufficient information, understanding of the information provided, voluntary choice between the options and, on these grounds, consent to or refusal of medical intervention [8,16]. Patients with cognitive impairment cannot fully comprehend large amounts of complex information, therefore researchers and the Ethics Committee should carefully weigh the risks and benefits for these patients and consider modifying clinical research protocols to protect patients, and that is the reason why family members or so-called "Surrogate" caretakers should actively participate in obtaining of informed consent. The term "surrogate decision maker" is a legal term for the

healthcare authority or agent who is the advocate for an incompetent patient. It is used in Western countries, but in Russia this practice finds itself in the concept of guardianship.

Conclusion

Apparently, about 20% of the total number of patients admitted for treatment and examination in the neurological department of the YSC CMP will be patients with various disorders of cognitive function, and elderly patients with dementia will account for 10% of it. Accordingly, it will be necessary to create certain conditions for patients in the hospital: constant around the clock monitoring and the provision of special equipment that facilitates patient care. In addition, special training is needed for medical personnel to care for elderly patients and people with disabilities.

Currently, the field of research on bioethical issues of application of new medical technologies in medical practice is expanding due to the study of new pathologies and the possibility of applying clinical trials of new diagnostic and treatment methods. It is necessary to outline a range of basic bioethical problems that undoubtedly arise in clinical practice and research of a number of diseases which impair cognitive functions, including senile dementia in elderly patients. We can resolve such problems with the development and adoption of ethical rules for the provision of specialized medical care, while also considering the psychosocial, cultural and ethnic characteristics of the population of the Republic of Sakha (Yakutia).

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