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HEALTHCARE, MEDICAL SCIENCE AND EDUCATION ORGANIZATION

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EXPERIENCE IN CREATING A SPECIALIZED MEDICAL CARE CENTRE FOR PATIENTS WITH NEURODEGENERATIVE DISEASES BASED ON THE CLINIC OF SCIENTIFIC INSTITUTION

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The article presents the experience of creating a specialized center of medical care for patients with neurodegenerative diseases on the basis of the clinic of the Federal State Budgetary Scientific Institution of the Yakutsk Scientific Center for Complex Medical Problems (YSC KMP). The aim of this work is to present a model for creating a specialized center for patients with neurodegenerative diseases, as an improved model for providing specialized care for patients with neurodegenerative diseases in the Republic of Sakha (Yakutia) and an example of the consolidation of a federal medical research institution and the regional ministry of health. The materials in the work were the register of patients with SCA 1 and MND, reporting data of regional neurologists from 2016-2018, regulatory documents of the Ministry of Health of the Russian Federation and the Republic of Sakha (Yakutia). Clinical, comparative analysis and organizational modeling were used for the study. The result of the analysis was the opening of the Center for Neurodegenerative Diseases at the YSC KMP.

Key words: neurodegenerative diseases, specialized care, type 1 spinocerebellar ataxia, medical and social care

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Relevance. Currently, one of the urgent problems of public health and social protection is the provision of high-quality medical and social assistance to the population of patients with diseases of the nervous system, including neurodegenerative diseases. It is known that neurodegenerative diseases (NDD) are age-dependent and affect people of the older age group. In most of these diseases, the etiology and pathogenesis remain unclear, despite many years of scientific research in the world [3,4,6]. Solving the issue of providing medical and social assistance to this a group of patients at the outpatient hospital stage is a difficult task for healthcare in Russia, including healthcare in the Republic of Sakha (Yakutia). The financial crisis that health care is going through affects primarily the vulnerable segments of the population suffering from various diseases, which limit their ability to receive adequate medical care.

The lack of specialized departments for patients with neurodegenerative diseases deprives this category of patients of medical care not only in the hospital, but also at the outpatient stage, because most of these patients have problems with motor, speech, and cognitive functions. Thus, patients with neurodegenerative pathology are practically deprived of medical care. In addition, this problem is interdisciplinary in nature, since neurodegenerative diseases cause disturbances not only on the part of the nervous system, but also on the part of other systems of the body, impairing vital functions. All of the above requires the organization of a set of measures in the field of practical health care and social services for citizens. In our opinion, scientific institutions of a medical direction, which have their own clinics, in which both medical care at the outpatient hospital stage and scientific research can be carried out, can make their contribution to the provision of specialized care. It is the consolidation of medical science and practical health care that could bear fruit in this direction. In this article, we want to show a joint solution to this problem by the efforts of a scientific institution of the federal state Yakutsk Scientific Center for Complex Med-

ical Problems and the Ministry of Health (MH) of the Republic of Sakha (Yakutia).

Despite the fact that to date, the epidemiological situation of neurodegenerative diseases has been studied only for individual diseases in the republic, the epidemiological indicators obtained indicate that the percentage of NDD is relatively high among all diseases of the nervous system [5]. The most studied are type 1 spinocerebellar ataxia (SCA), oculopharyngeal myodystrophy (OPMD) [7], Charcot-Marie-Tooth disease (CMT) [1], Parkinson's disease (PD) [6], amyotrophic lateral sclerosis (ALS) [2]. Yakutia is the territory of the greatest prevalence of type 1 spinocerebellar ataxia in the world, 34.4 cases per 100 thousand population [8]. The situation with Alzheimer's disease, which ranks 1st in the world among neurodegenerative diseases [9], as well as various genetic and inherited diseases of the nervous system common in Yakutia, remains unexplored. Taking into account the age-dependent nature of neurodegenerative diseases, their frequency in Russia, as well as in the world, is steadily increasing and creates a medical and social problem for the health care and social protection authorities, since the number of patients with aging of society increases rapidly. The key to the success of the development of the direction of brain research is the combination of scientific potential and health authorities. The provision of specialized medical care to patients with neurodegenerative diseases in the Russian Federation is a very urgent problem against the background of the overall optimization of hospital beds in healthcare. Therefore, the opening of a specialized department for patients with neurodegenerative diseases in a scientific medical institution is a very significant help to regional health care and is a concrete example of the consolidation of practical health care with medical science.

The aim of this work is to present a model for creating a specialized center for patients with neurodegenerative diseases, as an improved model for providing specialized care for patients with neurodegenerative diseases in the Republic of Sakha (Yakutia) and an example of the consolidation of a federal medical research institution and the regional ministry of health.

Research methodology and organization. To organize a center for neurodegenerative diseases (CNDD) at the YSC KMP Clinic, a comprehensive program was drawn up, including the following stages:

1. Analysis of the initial organizational model for the provision of neurological care to patients with neurodegenerative diseases in the RS (Y);

2. Study of the base of the Clinic of the YSC KMP to determine the potential for opening the CDCH;

3. Determine the structure of the CNDD;

4. To propose an improved model of the organization of specialized medical care for patients with neurodegenerative diseases at the Collegium of the Ministry of Health of the Republic of Sakha (Yakutia);

5. To agree on the opening of the CNDD with the Ministry of Health of the Republic of Sakha (Yakutia) and draw up an order on the procedure for routing patients with NDD at the outpatient hospital stage in the CNDD;

6. To evaluate the medical effectiveness of the implementation of the improved organizational model for the provision of neurological care to patients with NDD and the social significance of the proposed model from 2019-2021.

Materials and research methods. The materials for this study were the register of patients with SCA 1 and MND, reporting data from regional neurologists from 2016-2018, regulatory documents of the Ministry of Health of the Russian Federation and the Republic of Sakha (Yakutia).

Clinical, comparative analysis and organizational modeling were used for the study. The clinical method included studying the register of patients with SCA 1 and MND, reports of regional neurologists of the republic on other NDDs, and this method was also used to determine the list of diseases and criteria for selecting patients for hospitalization in the newly created neurological department of the CNDD. The method of comparative analysis and organizational modeling included the study of the initial organizational structure of the provision of health care to patients with NDD and the proposed improved model, as well as the study of the base of the YSC KMP Clinic, where it was planned to organize the Center NDD, as a new organizational model for providing specialized care to patients with NDD.

Results and discussion. At the first stage of the comprehensive program, the initial organizational structure of medical care for patients with NDD was studied, which revealed a number of shortcomings in both outpatient and hospital care.

For outpatient specialized care, patients can apply to municipal polyclinics and the Medical Genetic Center (MGC) Republican Hospital №1 National Center of Medicine. Primary patients go to the neurologist of the polyclinic in the direction of the therapist and narrow specialists in the order of the general queue, the repeated and those who are registered at the dispensary can contact immediately, bypassing these specialists. In the MGC, patients with NDD are referred to by a neurologist or therapist. But due to specific neurodegenerative processes leading to motor and cognitive disorders, disorders of the psycho-emotional sphere, this category of patients cannot receive sufficient assistance at the outpatient stage, because they require a long examination by a neurologist at an appointment and getting prescribed treatment on an outpatient basis for many patients is a difficult task due to the manifestations of a neurodegenerative disease. Despite the fact that by order of the Ministry of Health of the Russian Federation in 2015, the time for an outpatient visit by a neurologist to one patient was increased to 22 minutes. [10], this time is still not enough to admit a patient with a neurodegenerative disease, which affects the quality of the patient's examination by a neurologist and the establishment of a preliminary diagnosis.

Hospital stage. In the republic in the health care system there are 2 neurological hospitals for round-the-clock stay, which are based in Republican Hospital N 2 - Center for Emergency Medical Aid (RH 2-CEMA)

1. Neurological department for patients with acute cerebrovascular accident in the Regional Vascular Center (RVC) 50 beds;

2. Department of General Neurology for 30 beds for the provision of emergency care to neurological patients, of which 5 beds are allocated for patients with NDD for the entire republic. Patients with severe pain syndromes, epilepsy or a series of epileptic seizures, acute inflammatory diseases of the nervous system, exacerbations of demyelinating diseases and other conditions, except for stroke, are hospitalized in this department. Thus, the Department of Emergency Neurology, which is the only department for patients with a general neurological profile, hospitalizes patients from all over Republic the, including patients with NDD. The available 5 beds in the neurological department of the Republic of RH 2-CEMA for patients with NDD cannot cover the needs of these patients throughout the republic.

A study of the annual reports of neurologists showed not only the lack of data on the primary appealability of such NDDs as Aligheimer's disease and other

dementias, many hereditary diseases, including SCA 1, myotonic dystrophy, oculopharyngeal myodystrophy, hereditary spastic paraplegia, dystonia, motor neuron disease and many other diseases ... There is no data on the volume of care provided (number of visits per year, treatment in a day hospital or at home, data on hospitalization). Patients suffering from NDD, as a rule, have motor, speech or cognitive impairments, which is an undoubted obstacle to attending polyclinics, and the lack of hospitals for rehabilitation or rehabilitation treatment deprives them of receiving medical assistance in case of illness.

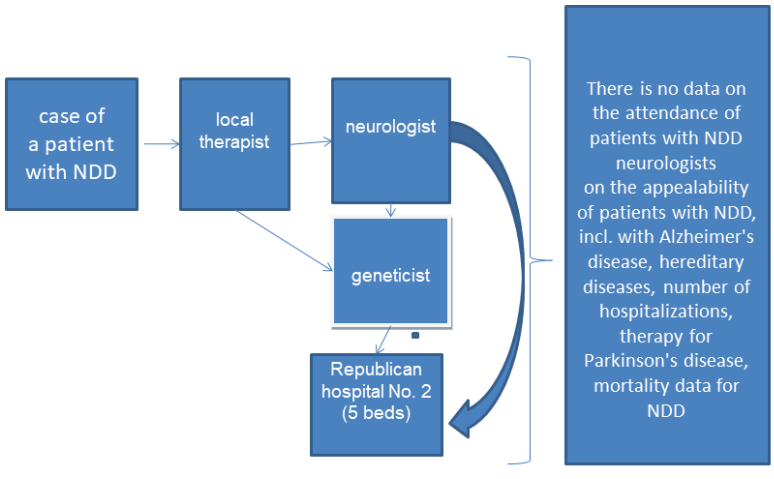

Fig. 1. Initial model of specialized care for patients with neurodegenerative diseases

Therefore, the predominant and comfortable type of medical help for such patients is treatment in a round-the-clock hospital. At the same time, it should be noted that outpatient care for patients with NDD in Yakutia became more effective after the opening in November 2017 of the Center for Extrapyramidal Disorders and Botulinum Therapy at the Clinic of the North-Eastern Federal University. The opening of such a Center in the Republic of Sakha (Yakutia) was a good alternative to providing MP to patients with NDD, despite the provision of compensated assistance. In Russia, there are examples of the opening of such specialized centers in the system of the Ministry of Science and Higher Education in medical research institutions. For example, specialized and high-tech medical care for patients with neurodegenerative diseases in Russia is provided by: Scientific Center of Neurology [11], Moscow, Institute of the Human Brain by N.P. Bekhtereva of the Russian Academy of Sciences, St. Petersburg. [12],

Thus, in the Republic of Sakha (Yakutia), if at the outpatient stage, patients with NDD have the opportunity to receive medical care, although not in full, then the issue of inpatient care is unresolved. Given the current situation, there is a need to improve the existing organizational model for the provision of neurological care to patients with NDD.

At the second stage of the comprehensive program, the base of the Clinic of the YSC KMP was investigated in order to identify the real possibilities of creating a CNDD. Not only the material and technical base was studied, but also personnel issues and issues of financing this category of patients from the Territorial Compulsory Medical Insurance Fund (TCMIF) were considered. It is known that medical organizations have single-channel funding from the TFOMI funds, and the main part of the NDH is included in the group of orphan diseases, which, due to the severity of the course, expensive treatment and examination, are among the highly paid clinical statistical groups (CSG) in the TCMIF system.

The clinic of YSC KMP occupies the 1st and 2nd floors of a 4-storey building of a standard hostel. The 1st floor is reserved for a polyclinic, and the 2nd floor is occupied by a round-the-clock hospital for 110 beds, including (at the time of the study) a therapeutic department for 40 beds, of which 10 are neurological, a gynecological department for 25 beds, a cardiology department for 35 beds. The Clinic has a physiotherapy department, a clinical diagnostic laboratory, which serve the clinic and the hospital. In addition, the structure of the YSC KMP includes the department of medical genetics, which includes a laboratory of hereditary pathology. The lack of MRI and the Department of Radiation Diagnostics at the Clinic is compensated by the conclusion of bilateral agreements with medical institutions that have this equipment. In general, given the availability of space for the proposed center for patients with NDD, this task could be successfully solved.

When analyzing the volume of financing of the Clinic from the funds of the TCMIF, the administration of the YSC KMP found effective ways to solve the release of funds and direct them to the solution of strategic tasks for the further development of the YSC KMP Clinic. First, a decision was made to reduce the catering unit and turn to outsourcing services for organizing meals for patients. Secondly, an unprofitable bed capacity of the gynecological and cardiological departments was identified. This was due to the fact that in the republic in 2011. Within the framework of the National Project "Health" on the basis of RH 2-CEMA the Regional Vascular Center (RVC) was opened, equipped with the most modern equipment, designed to provide specialized high-tech round-the-clock medical care for patients with acute cerebrovascular accidents and acute coronary syndrome (ACS). Thus, the cardiology department of the YSC KMP Clinic, excluding patients with ACS, began to admit patients with chronic ischemic heart disease, hypertension and other diseases of the heart and blood vessels, which are referred to as “therapy” during hospitalization. In addition, in Yakutsk in March 2018 year the Republican Perinatal Center (RPC) was opened, with a hospital for 130 beds (department of pregnancy pathology, obstetric physiological department, maternity department, department of pathology of newborns and premature babies), a consultative and diagnostic department for 150 visits per shift, an intensive care and intensive care department for women and newborns, as well as a follow-up department for young children, etc. The opening of the RPC also affected the unprofitability of the beds of the gynecological department of the YSC KMP Clinic.

The above objective reasons led to the decision to reduce the gynecological department and 25 beds in the cardiological department and place the Center for Neurodegenerative Diseases on their base.

The third stage of the comprehensive program was to define the structure of the CNDD, as a module that would include both outpatient and inpatient care, and provide assistance in social issues. Therefore, it was decided to allocate a separate block on one floor for the central oil refinery. In the structure of the CNDD, an important role is played by the location of the office for cognitive disorders, the office for bioethics and medical and social care and the inpatient neurological

department on the same floor, which is important for patients with limited mobility. As a result of this location, the CNDD is an integral section, isolated from other premises of the Clinic. Figure: 2 The structure of the CNDD

The CNDD is the main link in our proposed improved organizational model of specialized care (IOMSC) for patients with NDD and is a single unit for the provision of specialized care, where all stages of the provision of medical aid are interconnected. Figure: 3 Perfect the model.

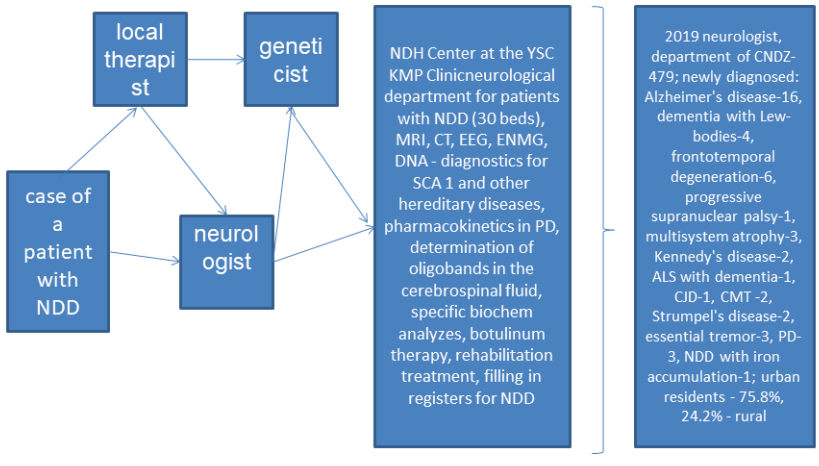

Fig. 2 An improved model of medical care for patients with neurodegenerative diseases in the RS (Y)

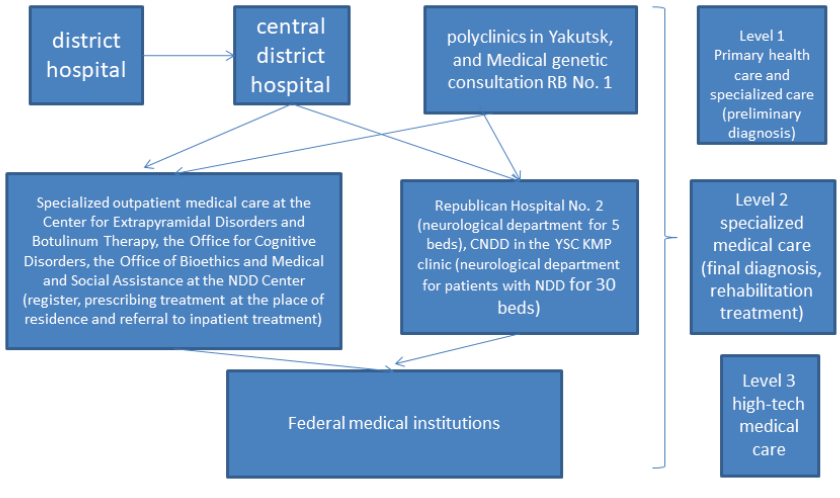

Fig 3. Patient routing scheme in an improved model of MP delivery to patients with neurodegenerative diseases

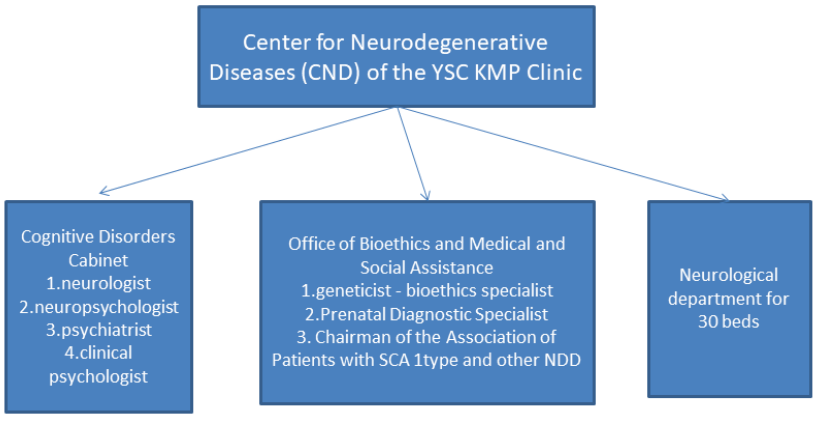

Fig 4. Structure of the Center for Neurodegenerative Diseases of the Clinic of the YSC KMP

At the fourth and fifth stages of the comprehensive program, joint work was carried out with the Ministry of Health of the Republic of Sakha (Yakutia) and the TCMIF, for the Republic of Sakha (Yakutia) to clarify the amount of funding for neurological beds. The functional structure of the CNDD was presented by us at the Collegium of the Ministry of Health of the Republic of Sakha (Yakutia) in December 2018. Considering that the neurological department will serve patients from all over the republic and for its full functioning, at the College of the Ministry of Health of the Republic of Sakha (Yakutia), it was recommended to draw up a draft order on the procedure for routing patients suffering from neurodegenerative diseases. Thus, based on the Decree of the Head of the Republic of Sakha (Yakutia) dated December 27, 2016. "On the approval of the regulations of the Ministry of Health and its collegium" (Appendix 1, paragraphs 3.11, 3.19, 3.20) and in pursuance of the order of the Ministry of Health of the Russian Federation dated November 15, 2011 No. 926n "On the approval of the Procedure for providing medical care to the adult population with diseases of the nervous system, the order of the Ministry of Health of the Republic of Sakha (Yakutia) No. 01-07 / 184 dated 02.14.2019 was drawn up and approved. "On the procedure for routing neurological patients suffering from neurodegenerative diseases at the outpatient and hospital stages."

The above-issued order of the Ministry of Health of the Republic of Sakha (Yakutia) allows you to gradually concentrate patients in one medical institution, which will make it possible to create a unified database of neurodegenerative diseases, track new cases, consult patients and maintain direct communication with neurologists using telemedicine. The data of the created registers will also make it possible to provide restorative and rehabilitative treatment to patients in need, monitor their condition in dynamics, identify the peculiarities of the clinical picture, and track families with genetic diseases. On the basis of this knowledge, an assessment will be made of the current state of the epidemiological situation of NDD in the regions of Yakutia and the prospects for the development of early (preclinical) diagnostics, approaches to personalized treatment of neurodegenerative diseases, primarily Parkinson's disease, Alzheimer's disease and type 1 spinocerebellar ataxia, have been developed.

The moral and ethical side of this problem is also an important factor, since the introduction into healthcare practice

of this order on the routing procedure and the creation of the CNDD, in fact shows that there is a search in solving the problems of providing health care to this category of patients, who until that moment were practically deprived of it, will make them feel like full-fledged members of society, which means that will improve their quality of life.

The preliminary results presented above show that the implemented improved model of specialized care for patients with neurodegenerative diseases may justify itself in the future.

Conclusion. Thus, the opening of the specialized center for patients with neurodegenerative diseases is the example of the consolidated interaction of a federal scientific medical institution and regional healthcare in solving a medical and social problem.

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