

STRUCTURAL ANALYSIS OF THE RARE DISEASES' OFFICIAL LIST IN UKRAINE

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Introduction. Rare diseases are a large group of pathologies, the prevalence of each of which in the general population does not exceed 1 patient per 2000 people (this is the criterion adopted in the European Union, or 1 patient per 1250 persons according to the US criteria). According to the World Health Organization data, more than 7,000 nosologies have been defined. The total number of patients with rare diseases is quite large and accounts for more than 5% of the world's population. The significance of rare diseases for the health care system is determined also by the high cost of medicines for pathogenetic therapy. However, the social significance of rare diseases is also in the fact that for the overwhelming number of orphan diseases there are no medications that allow to influence the cause of the disease development, and for many people the treatment is limited only to symptomatic therapy.

Aim. To analyze current legislation in rare diseases by structure with estimation of part of each one.

Materials and methods. Legislative regulation of pharmaceutical providing of patients with rare diseases has place in Ukraine. Thus, there is an order of the Ministry of Health (MH) of Ukraine № 778 "On approval of the list of rare (orphan) diseases" dated 27.10.2014, as amended in accordance with the Ministry of Health Order No. 919 of 30.12.2015; No. 731 dated 29.06.2017, where the list of rare diseases is given.

Results and discussion. The total number of rare diseases, declared in the order, is 275. Eleven (11) groups of rare diseases of different etiology are given in the order of MH, of which 23.27% are rare neoplasms, 19.6% endocrine diseases, 13.8% birth defects. The least rare diseases are in such areas eye diseases (0.7%), skin disease and mental disorders (1.1%), and infectious and parasitic diseases (1.8%). Many rare diseases, including infections, some rare cancers, and some autoimmune diseases, are not inherited. While researchers are learning more each year, the exact cause of many rare diseases is still unknown.

Conclusions. Analyses of legal acts has shown that regulation of rare diseases issues has place in Ukraine. Structural analyses of established list of rare diseases has indicated 11 general groups of rare diseases in Ukraine. Given results can be used in future researches for improving of pharmaceutical providing of patients with rare diseases in Ukraine and abroad.

ANALYSIS OF FOREIGN EXPERIENCE OF THE ACTIVITIES OF PHARMACEUTICAL INFORMATION CENTERS AS THE CONDITION OF IMPROVING THE INFORMATION OF PATIENTS

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Introduction. According to the concept of the World Health Organization (WHO) "Health for All in the 21st Century", aimed at promoting health and disease prevention, it is necessary to raise awareness of the patient in the treatment and prevention of diseases, as well as the modification of the doctor-pharmacist-patient-drug system with priority functions of the pharmacist. At the same time, an important component of pharmaceutical care is the provision of patients with quality pharmaceutical information that allows the effective use of medicines.

Aim. The purpose of our work is to analyze international experience regarding information and reference activities in the pharmaceutical industry.

Materials and methods. Theoretical analysis of literary sources and Internet resources; statistical analysis, generalization, hypothetical, historical and logical methods, analogy.

Results and discussion. As is known, pharmaceutical information is information that characterizes

the pharmaceutical and medical aspects of the circulation of medicines, and includes, first of all, information about the pharmacological, chemical, pharmacoeconomic and other properties of medicines, their production, distribution and release. The main consumers of pharmaceutical information are pharmacists, doctors and other medical workers, patients, health workers and executive and legislative authorities.

According to American sociological research, today more than 63% of Internet users use it to search for information about health. Moreover, studies have shown that about 70% of users acknowledge that the information they receive on the Internet affects their decision regarding adherence to treatment prescribed by the doctor. Pharmaceutical companies also use the Internet to promote their products and increase their consumption, which, in turn, can cause an increase in the incidence of side effects, including those that pose a threat to the life and health of the patient.

In view of the foregoing, in the current context of a significant array of pharmaceutical information, generally of questionable quality, and the lack of necessary knowledge for patients to interpret it, the role of the pharmacist becomes particularly important. In this case, the pharmacist becomes more accessible to the patient as a source of pharmaceutical information than the doctor, and the training of the pharmacist allows him to conduct a competent search, analysis and dissemination of pharmaceutical information. The main structure that allows increasing the access of patients to quality pharmaceutical information, in the world practice are the centers of pharmaceutical information.

In order to increase the availability of pharmaceutical information for the population in many economically developed countries, these centers have been established, in which information is provided on the availability of drugs in the pharmacy network, the mechanisms of action and the possibilities for combining various medications, the possibility of their use in pregnancy, the need for prescription, etc. One of the most famous centers of pharmaceutical information is the World Pharmaceutical Information Center of the University of Samford, USA (World Drug Information Service at the University of Samford). This institution provides health professionals with all information about medicines (dosing, drug interactions, adverse reactions, bioequivalence of the reproduced drugs, pharmacokinetics, pharmacodynamics, use in pregnancy and lactation, drug compatibility, etc.).

It should be noted that there are 89 such centers in the United States as a whole, while in the European countries there are more than 277 of them, 47 of them in the UK, 40 in Italy, 19 in Germany, 16 in France, 8 in the Netherlands, 6 in Spain.

The analysis of information provided in the WHO reports on the health status and development of European countries made it possible to establish that 68% of the centers of pharmaceutical information in the EU countries are based on the territory of large hospitals, 6% in the pharmaceutical faculties and 8% in the medical faculties of higher education institutions.

The vast majority of employees of the centers of pharmaceutical information are pharmacists. Their main activities are answers to questions, issue of bulletins, participation in committees, training and evaluation of drug use. These data are consistent with data from the assessment of the activity of the centers of pharmaceutical information in the United States and other countries.

Today in Ukraine, unfortunately, there are no software tools containing a complex of pharmaceutical information adapted for the perception of the patient. The main domestic specialized sources of information about drugs are: instruction on the use of drugs; State Register of medicines of Ukraine; State Pharmacopoeia of Ukraine; Compendium; Periodicals and Internet resources. In this regard, actual and necessary, in our opinion, is the development of software to optimize the information and reference activities of Ukrainian pharmacies through the installation of terminals in the sales area, as well as the introduction of informational pharmaceutical centers in the practice of domestic health, which will improve the quality and accessibility pharmaceutical information for Ukrainian consumers.

Conclusions. An analysis of foreign experience shows that access to high-quality pharmaceutical information allows rational use of medicines and affects the effectiveness of pharmaceutical assistance, improving information provision for the population and the health system as a whole. In order to improve the quality and availability of pharmaceutical information for the population of Ukraine, taking into account the positive experience of European countries, the current and promising for our country is expanding the range of information services through the establishment of centers for pharmaceutical information on the