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HEALTH ORGANIZATION

ON THE ISSUE OF INTRODUCING AN ELECTRONIC DATABASE OF CHILDREN WITH ONCOLOGICAL DISEASES INTO SPECIALIZED MEDICAL ORGANIZATIONS: RESULTS OF A MEDICAL AND SOCIAL RESEARCH

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ABSTRACT

Accounting for children with cancer is characterized by low reliability of statistics. In addition, the available data do not have significant scientific value., Since they represent only an approximate number of patients identified annually and some general information (incidence, prevalence, etc.). Moreover, subsequent analysis of the accumulated information is of particular importance. An electronic database of children with cancer has been developed that meets these requirements and has been introduced into the clinical practice of pilot medical organizations.

Purpose of the study. Our aim was to study the opinions of pediatric oncologists on the issues of registration of children with oncological diseases.

Materials and methods. In order to assess the results of the implementation of the electronic database, a "Questionnaire for a survey of a pediatric oncologist to assess the effectiveness of the implementation of an electronic database" was developed, which contained 15 questions. For objectivity, the questionnaires were filled in anonymously by the respondents.

Results. The medico-social study involved 187 pediatric oncologists. The majority of respondents (71.3 ± 3.3%) noted that currently there is no register of children with cancer in the Russian Federation, 15.4 ± 2.6% noted the regional register, 9.1 ± 2.1% – independent in individual medical organizations, 1.7 ± 0.9% is a single register for the Russian Federation and 2.5 ± 1.1% are not aware of this. Among respondents, 81.9 ± 2.8% noted that the electronic database is an effective tool for recording children with cancer, while as an advantage, 15.1 ± 2.6% noted an increase in the reliability of statistical data, 9.2 ± 2.1% – reduction of time for searching patient information, 4.4 ± 1.5% – optimization of working time, 71.3 ± 3.3% – a combination of the above options.

Conclusion. A medical and social study showed the feasibility of introducing an electronic database of children with cancer into the clinical practice of pediatric oncologists.

Keywords:
pediatric oncology, malignant tumors, health care organization, sociological studies, digital data base, informing.

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ОРГАНИЗАЦИЯ ЗДРАВООХРАНЕНИЯ

К ВОПРОСУ О ВНЕДРЕНИИ ЭЛЕКТРОННОЙ БАЗЫ ДАННЫХ ДЕТЕЙ С ОНКОЛОГИЧЕСКИМИ ЗАБОЛЕВАНИЯМИ В ПРОФИЛЬНЫЕ МЕДИЦИНСКИЕ ОРГАНИЗАЦИИ: РЕЗУЛЬТАТЫ МЕДИКО-СОЦИАЛЬНОГО ИССЛЕДОВАНИЯ

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РЕЗЮМЕ

Учет детей с онкологическими заболеваниями характеризуется низкой достоверностью статистических данных. Кроме того, имеющиеся данные не имеют значимой научной ценности, поскольку представляют собой лишь приблизительное число пациентов, выявляемых ежегодно и некоторые общее сведения (заболеваемость, распространенность и т. д.). При этом особую значимость представляет последующий анализ накопленной информации. Разработана электронная база данных детей с онкологическими заболеваниями, отвечающая данным требованиям, внедрена в клиническую практику пилотных медицинских организаций.
Цель исследования. Изучить мнения врачей детских онкологов по проблемам учета детей с онкологическими заболеваниями.
Материалы и методы. В исследовании приняли участие 187 врачей детских онкологов. Респондентам разослана разработанная авторами «Анкета опроса врача детского онколога для оценки результативности внедрения электронной базы данных», которая содержит 15 вопросов. Анкеты заполнялись респондентами анонимно.
Результаты. В исследовании приняли участие 187 врачей детских онкологов. Большая часть респондентов (71,3 ± 3,3%) отметила, что в настоящее время в Российской Федерации отсутствует регистр детей с онкологическими заболеваниями, 15,4 ± 2,6% известен региональный регистр, 9,1 ± 2,1% – независимый регистр в отдельных медицинских организациях, 1,7 ± 0,9% – единый регистр для Российской Федерации, 2,5 ± 1,1% не знают о существовании регистров. Среди респондентов 81,9 ± 2,8% отметили, что электронная база данных является эффективным инструментом учета детей с онкологическими заболеваниями, при этом в качестве преимуществ 15,1 ± 2,6% указали повышение достоверности статистических данных, 9,2 ± 2,1% – сокращение времени на поиск информации о пациенте, 4,4 ± 1,5% – оптимизацию рабочего времени, 71,3 ± 3,3% – сочетание перечисленных вариантов.
Заключение. Проведенное исследование показало целесообразность внедрения электронной базы данных детей с онкологическими заболеваниями в клиническую практику.

Ключевые слова:
детская онкология, злокачественные новообразования, организация медицинской помощи, медико-социальное исследование, электронная база данных, информатизация.

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JUSTIFICATION

The development of healthcare is impossible without the introduction of information technologies [1–3]. At the same time, it is important not only to create resource databases aimed at collecting and storing data, but also the subsequent automated analysis of the accumulated information in order to assess the quality of medical care provided, optimize patient routing, as well as continuity in the treatment process [4]. Modern information technologies also include a system for supporting medical decision-making, that is, digitized clinical recommendations [5].

Accounting for children with cancer is characterized by a number of significant drawbacks – low reliability, the inability to use the accumulated information to control and improve the treatment process, as well as in scientific activities [4].

Given the above, developed an electronic database of children with cancer, which since 1 September 2017 introduced into clinical practice of pediatric oncology Arkhangelsk Regional Kid's Clinical Hospital P.G.Vyzhletsov and the laboratory of complex methods of treatment of oncological diseases in children of the Russian Scientific Center of Radiology [4].

Purpose of the study: study the opinions of pediatric oncologists on the problems of accounting for children with cancer.

MATERIALS AND METHODS

A medical and social study was conducted, which included pediatric oncologists who have worked in the departments of pediatric oncology of the subjects of the Russian Federation in 2018–2019 and filled out the "Questionnaire of the survey of pediatric oncologists to assess the effectiveness of the introduction of an electronic database" developed by the authors. The questionnaire contained 15 questions, and respondents were asked to choose one or more answer options or enter their own version. For objectivity, the questionnaires were filled out anonymously by the respondents [1].

The questionnaire included the following questions:

1. Currently, in the Russian Federation, the system of accounting for children with cancer (register) is:
   1. Unified (for the Russian Federation)
   2. Regional (for individual entities)
   3. Independent in individual medical organizations
   4. There is no case
   5. I don't know
2. Do you know about the use of an electronic database of children with cancer in pilot medical organizations:
   1. Yes, I heard about it from colleagues
   2. Yes, I received information from scientific articles
   3. Yes, I received the information from the report at the scientific conference
   4. Yes, I received information from users
   5. Yes, I use it myself
   6. No
3. Do you use an electronic database of children with cancer:
   1. Yes
   2. No
   3. I find it difficult to answer
4. Do you know the main functions of the electronic database:
   1. Yes, there are
   2. No, I don't
   3. I find it difficult to answer
5. If so, please indicate what functions the electronic database has:
   1. Patient records
   2. Treatment planning
   3. Medical decision support system
   4. Plan the routing of patients
   5. Formation of electronic sheets of temporary disability
   6. None of the above
   7. Other answer
6. If not, are you ready to use the electronic database of children with cancer in clinical practice:
   1. Yes, I am ready
   2. No, I am not ready
   3. I find it difficult to answer
7. If not, why not:
   1. An effective accounting tool already exists
   2. Requires significant time costs

   3. There is no necessary material base
   4. I find it difficult to answer
   5. The use is meaningless
   6. Other
8. In your opinion, the use of an electronic database is necessary in the activities of:
   1. Every doctor who provides specialized medical care to children with cancer
   2. Management staff of medical organizations
   3. Executive authorities in the field of health protection of citizens of the subjects of the Russian Federation
   4. Ministry of Health of the Russian Federation
   5. No need to use it
   6. I don't know
   7. Other
9. Is the electronic database of children with cancer an effective tool for recording children with cancer:
   1. Yes
   2. No
   3. I don't know
10. If not, why not:
    1. An effective accounting tool already exists
    2. Requires significant time costs
    3. There is no necessary material base
    4. I don't know
    5. Other
11. If so, what are the advantages of an electronic database of children with cancer:
    1. Improving the reliability of statistical data
    2. Reduce the time to search for information about the patient
    3. Optimizing the use of working time
    4. Other
12. What can prevent you from using an electronic database of children with cancer in your daily clinical practice:
    1. Lack of time
    2. Lack of necessary qualifications to use the software
    3. Lack of a personal computer in the workplace
    4. Not included in the job description
    5. Other
13. Compared to the existing system of accounting for children with cancer, the electronic database is more efficient:
    1. Yes
    2. No
    3. Not familiar with the existing accounting system
    4. I find it difficult to answer
    5. Other
14. What are the most important functions of the electronic database of children with cancer for you:
    1. Reducing the time for maintaining medical records
    2. Ability to monitor the implementation of treatment protocols
    3. The possibility of using a medical decision support system
    4. Automation of routing of patients
    5. Improving the efficiency of using the department's bed capacity
    6. Formation of annual reports on the state of medical care for children with cancer
    7. Other
15. What additional functions do you think are necessary for the effective use of the electronic database?

The study was conducted in the period from 01.03.2019 on 30.04.2019 in pediatric Oncology departments of medical organizations of the federal districts of the Russian Federation: Central (Central Federal District), Northwestern (Northwestern Federal District), Southern (Southern Federal District), North Caucasus (North Caucasus Federal District), Volga (Volga Federal District), Ural (Ural Federal District), Siberian (Siberian Federal District) and Far Eastern (Far Eastern Federal District) [1].

The objects of the study were the questionnaires completed by the respondents.

Ethical expertise

The study was approved at a meeting of the Local Ethics Committee FGAOU VO at the Sechenov First Moscow State Medical University (Sechenov University) No. 05–19 of 11.04.2019.

Statistical analysis

Principles for calculating the sample size

The volume of sample populations for the study was calculated according to the formula of A. M. Merkov (1962) with a known number of observations in the general population [6]:

$$n = \frac{(p \times q \times t^2 \times N)}{(N \times \Delta^2 + p \times q \times t^2)},$$

where *n* is the minimum sample size, *t* is the confidence coefficient (*t*=2 when *p*=0.05); *p* – frequency of the trait in the aggregate indicator of the probability of the phenomenon under study (in this situation is unknown, therefore, is taken as the maximum possible value 50%); *q*=100; *p* – a measure of alternative, alternative p-index; Δ – limit error indicator (5%) [7]; *N* – the number of the General population [1].

Calculations to determine the representativeness of a sample of the minimum number of pediatric oncologists:

n=300 – the number of pediatric oncologists in the Russian Federation in 2018 (data from the Federal State Statistics Service, provided by the Department of Medical Statistics of the Department of Monitoring, Analysis and strategic development of healthcare of the Ministry of Health of the Russian Federation) [1].

$$n = \frac{50 \times 50 \times 2^2 \times 300}{300 \times 5^2 + 50 \times 50 \times 2^2} = 171{,}42$$

That's why, the minimum number of pediatric oncologists to ensure the representativeness of the study is 172 people. Taking into account the stratification of the number of doctors of pediatric oncologists in 2018 in the Federal districts of the Russian Federation CFD – 37.6%, NWFD – 12%, SFD – 11,7%, NCFD – 3%, PFD – 10,7%, UFD – 9.7% of the NFD and 10.3%, FEFD – 5% [1].

Statistical processing of the material was carried out on a personal computer using the programs Office Excel 2013 (Microsoft, USA) and SPSS 22.0 (IBM, USA) [1].

RESULTS OF THE STUDY

187 pediatric oncologists took part in the sociological study. The stratification by the number of pediatric oncologists in 2018 in the federal districts of the Russian Federation is shown on the figure 1.

Women predominated – 51.3 ± 3.7%. The age distribution of respondents is shown in the figure 2. The average age was 43.1 ± 3.4 years [1].

Employees of medical organizations of federal subordination made up 31.9 ± 3.4%. Senior positions (heads of departments) were held by 10.1 ± 2.2% of respondents, positions of researchers – 33.7 ± 3.5%, ward doctors – 56.2 ± 3.6% [1].

The total medical experience up to 5 years was 7.1 ± 1.9% of respondents, from 6 to 10 years – 29.4 ± 3.3%, from 11 to 15 years – 43.5 ± 3.6%, from

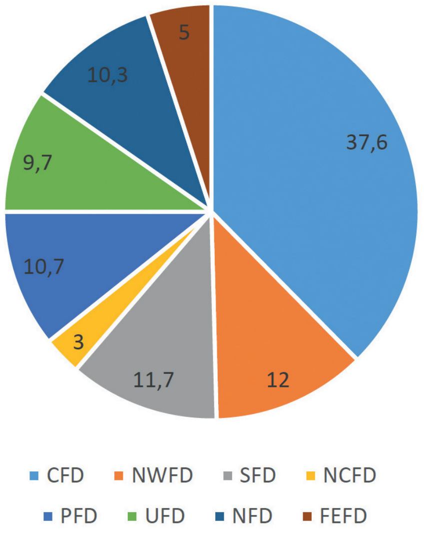

Fig. 1. Distribution of respondents by territory of residence in the federal districts of the Russian Federation, %.

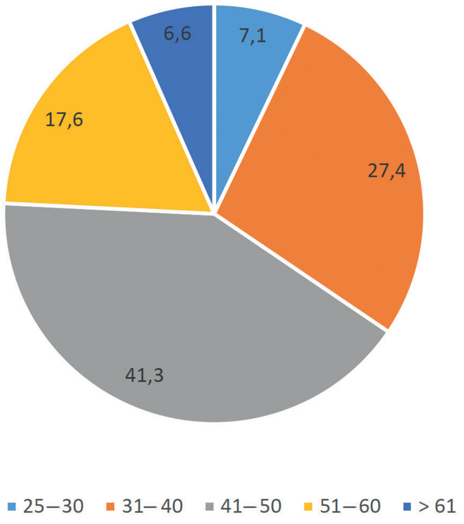

Fig 2. Distribution of respondents by age, years, %.

16 to 20 years – 11.4 ± 2.3%, from 21 to 30 years – 7.3 ± 1.9%, over 30 years – 1.3 ± 0.8% [1].

Among the respondents, 71.3 ± 3.3% noted that there is no register of children with cancer in the Russian Federation, a regional register is known to 15.4 ± 2.6%, 9.1 ± 2.1% are aware of an independent register in individual medical organizations, 1.7 ± 0.9% are aware of a single register for the Russian Federation, and 2.5 ± 1.1% are unaware of the existence of registers [1].

17.3 ± 2.8% of respondents heard about the use of an electronic database of children with cancer in pilot medical organizations from colleagues, received information from scientific articles – 15.7 ± 2.7%, from a report at a scientific conference – 11.3 ± 2.3%, from users – 9.3 ± 2.1%, use themselves – 1.7 ± 0.9%, do not know – 11.9 ± 2.4%. The combination of options was indicated by 32.8 ± 3.4% [1].

The main functions of the electronic database are known to 27 ± 3.2% of respondents, and 11.7 ± 2.4% found it difficult to answer [1].

71.9 ± 3.3% of respondents indicated patient registration, treatment planning, a system for supporting medical decision-making, and a patient routing plan as the functions known to them. Only 11.3 ± 2.3% noted the formation of electronic sheets of temporary disability. At the same time, this function is not available in the electronic database. None of the above was noted by 16.8 ± 2.7% of respondents [1].

Among those respondents who do not use an electronic database, ready to use in clinical practice was 97.4 ± 1.2%. Among the main reasons for those who are not ready, provided that this is a time-consuming (15.3 ± 2.6%), lack the necessary material base (9.7 ± 2.2%) and effective accounting tool already exists (8.1 ± 2.0%). The combination of these options was noted by 66.9 ± 3.4% of respondents [1].

The majority of respondents (81.9 ± 2.8%) indicated that the use of an electronic database is necessary in the activities of every doctor who provides specialized medical care to children with cancer, the administration of medical organizations, executive authorities in the field of health protection of citizens of the subjects of the Russian Federation, the Ministry of Health of the Russian Federation. At the same time, 4.7 ± 1.5% of respondents believe that there is no need to use it [1].

The fact that the electronic database is an effective tool for accounting for children with cancer was indicated by 81.9 ± 2.8% of respondents, while 15.1 ± 2.6% noted an increase in the reliability of statistical data, 9.2 ± 2.1% – a reduction in the time spent searching for information about the patient and 4.4 ± 1.5% – optimization of working time. The combination of options was indicated by 71.3 ± 3.3% of respondents [1].

Respondents from among those who do not consider the electronic database to be an effective accounting system (13.6 ± 2.5%) indicated as a reason that an effective accounting tool already exists

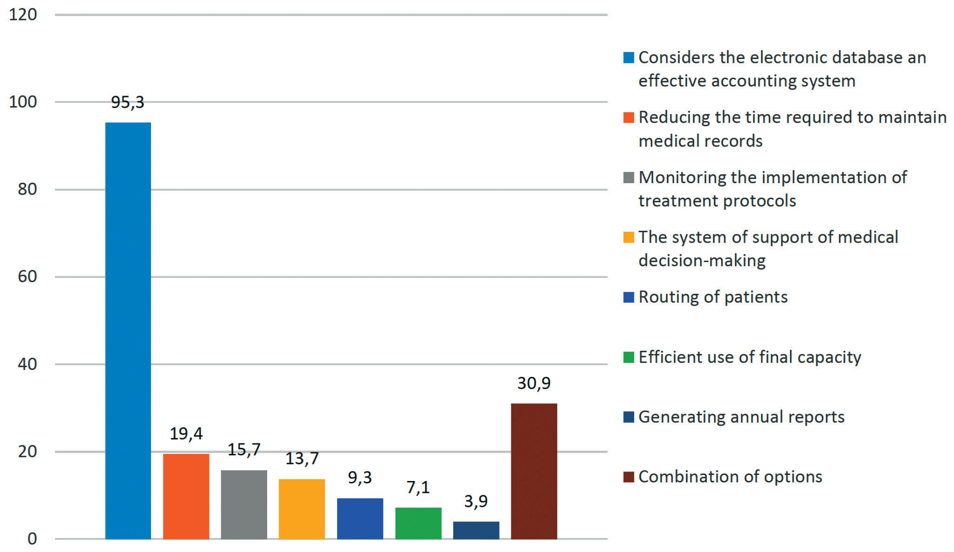

Fig. 3. Opinion of pediatric oncologists on the functions of the electronic database of children with cancer, %.

(11.7 ± 2.4%), that it requires significant time costs (9.3 ± 2.1%) and that the necessary material base is not available (7.1 ± 1.9%) [1].

Among the reasons that may make it difficult to use an electronic database, the majority of respondents (17.9 ± 2.8%) indicated a lack of time, 7.1 ± 1.9% – lack of necessary training for using software, 7.1 ± 1.9% – lack of a personal computer in the workplace, 32.2 ± 3.4% indicated that this is not included in the job descriptions. The combination of these options was noted by 35.7 ± 3.5% of respondents [1].

The majority of respondents (95.3 ± 1.5%) noted that, in comparison with the existing system of accounting for children with cancer, the electronic database is more efficient, 2.5 ± 1.1% of respondents are not familiar with the existing system of accounting, 2.2 ± 1.0% found it difficult to answer [1].

Reducing the time for maintaining medical records as the most important function of the electronic database was noted by 19.4 ± 2.9% of respondents, the ability to monitor the implementation of treatment protocols – 15.7 ± 2.7%, the ability to use the system to support medical decision-making – 13.7 ± 2.5%, automation of patient routing – 9.3%, improving the efficiency of using the bed capacity of the department – 7.1 ± 1.9%, the formation of annual reports on the state of medical care for children with cancer – 3.9 ± 1.4%. The combination of these options was noted by 30.9 ± 3.4% of respondents (fig. 3) [1].

DISCUSSION

In modern conditions, informatization is of decisive importance [4]. The developed electronic database of children with cancer has a number of significant advantages: the collection, processing and accumulation of reliable statistical data, optimal patient routing, a system for supporting medical decision-making, and maximum convenience for parents (legal representatives) of patients [4].

One of the main conditions for improving the survival rate of children with cancer is compliance with treatment protocols [8, 9]. An innovative development is a system for supporting medical decision-making (digitized clinical recommendations), which allows you to choose treatment tactics depending on a specific clinical situation. In the literature, we have not been able to find descriptions of another similar system. It is quite possible that similar solutions will be presented on the market in the medium term, but at present the authors do not have any information about them [1].

It is important that medical professionals understand the importance of informatization: more than 80% of pediatric oncologists noted that the electronic database is an effective system for recording patients. According to the authors, only reliable statistical data are the basis for planning the development of the industry, including for national programs, which have recently received a lot of attention from representatives of the executive and legislative branches of government, as well as the media. But in an era when anyone can pay for a purchase in a store using a smartphone, no one has the exact number of children with cancer, not only in the Russian Federation, but also in individual subjects. At the same time, the number of such patients detected annually is less than 4 thousand people [1].

It should be noted that improving the reliability of statistical data is possible only with the introduction of an electronic database in the clinical practice of all departments of pediatric oncology in the subjects of the Russian Federation and medical organizations of federal subordination.

CONCLUSIONS

Medical and social research has shown the feasibility of introducing an electronic database of children with cancer in clinical practice.

The proposed digital contour provides conditions for creating a unified electronic cartographic framework and provides access to large amounts of data, their analysis and the use of the results obtained in making management decisions on the organization of medical care for children with cancer in the subjects of the Russian Federation and at the federal level.

Authors contribution:

Rykov M.Yu. – research concept and design, data collection and analysis, material processing, text writing.

Manerova O.A. – text writing, scientific editing.

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