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# ACTUAL ASPECTS OF PROVIDING ANTI-TUBERCULOSIS CARE TO CHILDREN WITH DISABILITIES

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ABSTRACT. Diagnosis and treatment of tuberculosis in childhood are especially difficult. The development and course of the tuberculosis process is significantly influenced by preventive and other available measures to prevent the disease. The most vulnerable are patients with severe comorbidities, such as children with disabilities. We conducted a cohort retrospective-prospective study in primary health care institutions and TB services in the city of St. Petersburg in 2019–2022. The assessment included the incidence of tuberculosis in disabled children, their tolerance to treatment, the frequency and effectiveness of preventive and preventive special anti-tuberculosis measures. It has been noted that among children with disabilities there is a high incidence of adverse events during treatment, parental refusal of preventive therapy, and irregular screening for tuberculosis. The combination of many risk factors for the development of the disease among children with disabilities determines the separation of this group of patients into a separate category, which will help optimize anti-tuberculosis measures in this group of patients.

**KEYWORDS**: children, tuberculosis, disability, risk factors, vaccination

# АКТУАЛЬНЫЕ АСПЕКТЫ ОКАЗАНИЯ ПРОТИВОТУБЕРКУЛЕЗНОЙ ПОМОЩИ ДЕТЯМ С ИНВАЛИДНОСТЬЮ

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ОРИГИНАЛЬНЫЕ СТАТЬИ 37

**РЕЗЮМЕ.** Диагностика и лечение туберкулеза в детском возрасте особенно сложны. На развитие и течение туберкулезного процесса существенно влияют профилактические и иные мероприятия по предупреждению заболевания. Наиболее уязвимы пациенты с выраженной сопутствующей патологией, такие как дети с инвалидностью. Нами проведено когортное ретроспективно-проспективное исследование в учреждениях первичной медико-санитарной помощи и фтизиатрической службы города Санкт-Петербурга в 2019—2022 гг. Оценке подлежали заболеваемость детей-инвалидов туберкулезом, переносимость ими лечения, кратность и эффективность профилактических и превентивных противотуберкулезных мероприятий. Отмечено, что среди детей с инвалидностью высока частота развития нежелательных явлений на фоне лечения, отказов родителей от превентивной терапии, нерегулярность скрининга на туберкулез. Сочетание множества факторов риска развития заболевания среди детей с инвалидностью обусловливает выделение данной группы пациентов в отдельную категорию, что будет способствовать оптимизации противотуберкулезных мероприятий среди таких больных.

**КЛЮЧЕВЫЕ СЛОВА:** дети, туберкулез, инвалидность, факторы риска, вакцинопрофилактика

### INTRODUCTION

Currently, the problem of tuberculosis (TB) continues to be a pressing issue worldwide. According to the World Health Organisation (WHO), by 2021 tuberculosis remains in the list of the 10 most common causes of death from infectious diseases worldwide. For 2021, about 10.6 million people worldwide became ill, among them 1.2 million children, and 1.6 million patients died from tuberculosis [15, 16]. Diagnosing and treating TB in children is particularly difficult, and the disease at this age often goes unrecognised by health care workers [6, 7, 16]. In 2021, Russia was removed from the list of countries with a high burden of tuberculosis, but remains on the list of countries with a significant prevalence of drug-resistant and HIV-associated tuberculosis [15]. According to official data, in 2022, the incidence of tuberculosis among children and adolescents in St. Petersburg was 4.3 and 3.3 per 100,000 population, respectively [10]. The percentage of children among all TB cases in St. Petersburg in 2022 was 3.5%.

The most susceptible to tuberculosis are persons from groups of medical, biological, social, and epidemiological risk [6, 9, 11]. Children with disabilities, as a rule, have a combination of aggravating factors, including lack of vaccination, severe congenital and acquired pathology, social risks (staying in closed institutions, social and economic disadvantage of the family, etc.) [5]. However, special approaches to preventing and detecting TB in children with disabilities have not been developed; official recommendations do not designate this group as a target group for preventive TB interventions; therefore, late diagnosis of

the disease and its severe course can be expected [11, 14].

In the Russian Federation, the primary child-hood disability rate in 2021 was 24.3 per 10,000 of the population of the corresponding age [4]. This indicator reflects the most important social aspects: accessibility of medical care, quality of its provision, effectiveness of chronic disease prevention, etc. [3, 12]. According to the Federal Register of Disabled People, by January 2023, the number of children with disabilities in St. Petersburg was 23,256 people, of whom 9,026 (39%) were girls and 14,230 (61%) were boys. Children with disabilities account for 4.4% of the total number of disabled children, with a large proportion of children with disabilities aged 8–14 years — 11,588 people [13].

According to the structure of primary and recurrent childhood disability by main classes of diseases, three leading groups are distinguished [4]:

- mental disorders and behavioural disorders;
- diseases of the nervous system;
- congenital anomalies (malformations), deformations and chromosomal disorders.

### **AIM**

To develop a set of measures to optimise TB care for children with disabilities at the level of primary health care and specialised TB services.

## **MATERIALS AND METHODS**

A cohort (2019–2022), retrospective prospective study was conducted and included 619 children with disabilities (Fig. 1), of which: Group 1

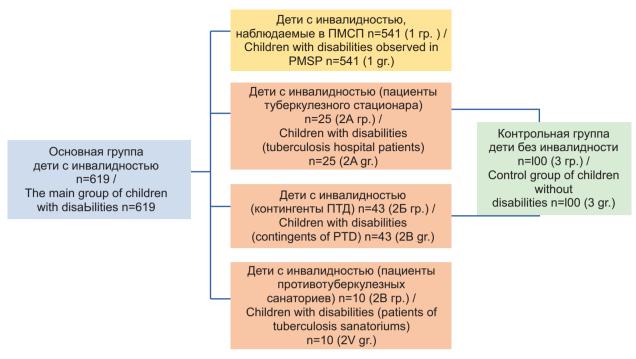


Fig. 1. Structure of the examined children by groups

Рис. 1. Состав обследованных детей по группам

(541) were children with disabilities observed in primary health care (PHC) facilities; Group 2 (78) were children with disabilities observed in specialised phthisiatric care facilities. Among the children of the 2nd group are distinguished: 2A subgroup — 25 children, patients of a tuberculosis hospital, including 10 patients with active forms of tuberculosis, 2B subgroup — 43 children, patients of an anti-tuberculosis dispensary (ATD), 2B subgroup — patients of tuberculosis sanatoria — 10 people. Inclusion criteria: age from 0 to 17 years; presence of established disability on any nosology; exclusion criteria: no disability; children with disabilities among those receiving palliative care. As a control group, group 3 was created by the case-control method — 100 children without disability, with tuberculosis and infected with Mycobacterium tuberculosis (MBT), corresponding in age, sex, nature of tuberculosis infection and treatment to children from group 2.

The research methods in the group of children with disabilities observed in PHC institutions (children's polyclinics) consisted of analysing medical records: child development histories (form No. 112/u), preventive vaccination cards (form No. 63/u), and vaccination certificates.

Research methods in groups of disabled and non-disabled children observed in TB dis-

pensaries, inpatient clinics and sanatoria included analyses of children's case histories (Form No. 003/u), TB dispensary observation cards (Form No. 025/u).

Children with disabilities have been additionally studied:

- Causes of disability (including psychoneurological, somatic, infectious diseases), structure of pathology, ranking by frequency.
- Availability and timing of BCG vaccination, nature of contraindications.
- Availability, regularity, informativeness of mass immunodiagnostic tests (Mantoux test, test with recombinant tuberculosis allergen). Rationale for the use of in vitro tests.
- The frequency of latent tuberculosis infection (LTI) and tuberculosis has been determined among children with disabilities.
- Risk factors for tuberculosis in children with disabilities were assessed: social, medical and epidemiological.

The significance of differences between groups was assessed using Student's t-test. Differences between relative values were determined using the Pearson  $\chi^2$  criterion in the STATISTICA 6.1 programme. The 95% confidence level (p <0.05) was considered to be generally accepted.

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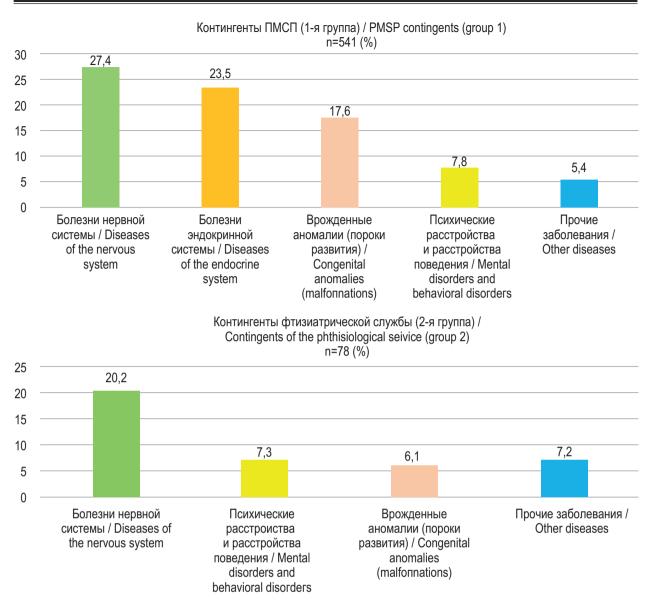


Fig. 2. Causes of disability among children, TB services and primary health care populations

Рис. 2. Причины инвалидности среди детей, контингентов фтизиатрической службы и ПМСП

#### **RESULTS**

In the structure of disability by main classes of diseases among children who were patients of the phthisiatric service (group 2), the first place was occupied by diseases of the nervous system — 20.2%, which is consistent with the structure of disability among contingents of only children's polyclinics (group 1) — 27.4%. Mental disorders and behavioural disorders (7.3%), congenital anomalies and malformations (6.1% vs 17.6% in group 1 (p <0.05), and other diseases (diseases of the circulatory system, digestive organs, genitourinary system, etc.) (7.2%) were less common among group 2 children. It

should be noted that among those observed in PHC facilities (group 1), the proportion of children with endocrine system diseases accounted for 23.5% of all disabled children and ranked second among the main causes of disability, whereas such children were virtually absent among group 2 patients (p <0.05) (Fig. 2).

The following clinical forms of tuberculosis disease (10 patients) were observed among disabled children from the 2A subgroup of patients: intrathoracic lymph node tuberculosis (ITNT) — 5, primary tuberculosis complex (PTC) — 4, infiltrative pulmonary tuberculosis (IPT) — 1. Bacterial excretion was absent in all children. The following causes of disability

were noted in this group of TB patients: Noonan syndrome — 1; cerebral palsy — 2; congenital malformations — 2; autism — 1; mental retardation with speech disorders — 1; III degree sensorineural hearing loss — 1; organic lesions of the central nervous system (CNS) — 2.

Six children out of 10 had established household tuberculosis contact (kin, family): 3 had contact with a patient with multidrug-resistant tuberculosis (MDR-TB), and 3 had tuberculosis contact with patients with preserved drug susceptibility of Mycobacterium tuberculosis (MBT).

It was found that among children who received basic treatment for tuberculosis (10 patients), 3 children were treated with IV chemotherapy regimen (IV CTR — chemotherapy regimen for treatment of multidrug-resistant tuberculosis) and 7 with III CTR (drug-sensitive tuberculosis). It was observed that good treatment tolerability among patients with disability (2A subgroup) was in 30% of cases and among patients without disability (group 3) in 80% (p < 0.05). Adverse events (AEs) on the background of treatment were noted in patients of 2A subgroup in 70%, and in children without disability (group 3) — in 20% (p < 0.05). Adverse reactions to antituberculosis drugs (ATDs) from the gastrointestinal tract (GIT) prevailed among AEs in both groups (groups 2A, 3): 47.1% of cases in children of subgroup 2A and 52.4% in children of group 3. Allergic reactions were almost equally reported (10.8% vs 13.4%, respectively); however, subgroup 2A children had worse tolerance to ATDs, including the development of central nervous system (CNS) (26.5%) and hyperuricaemia (37.5%), which was not observed in the control group (p < 0.05).

Also among group 2 patients, 22 patients had latent tuberculosis infection (LTI), 36 were infected with allergen negative tuberculosis recombinant (ATR) MBT, among which 6 patients were from established tuberculosis contact (5—tuberculosis contact with patients with drug sensitive TB), 1—tuberculosis contact with drug resistant TB. Among children of both groups (group 2, 3), 27 patients required preventive treatment, among whom 18 with disability (2A, 2B subgroups) (66.7%) and 6 from control group (22.2%) refused treatment (p <0.05) (p <0.05). Among group 2 patients (2A, 2B subgroups), 9 (33.3%) received preventive therapy and 21 (77.8%) in the control group. Gastrointestinal

AEs prevailed in group 2 patients — 70.9% vs. 14.3% in the control group (p <0.05). Allergic reactions to ATDs were observed in both groups in almost equal proportion; CNS AEs were also observed in Group 2 patients — 3.6%, which was not observed in the control group.

The risk factors for tuberculosis development were analysed in the 1st group of patients (541 children with disabilities who were observed only by the polyclinic). It was noted that 39.7% of children had medical and biological risk factors (such as prematurity, home birth, immunosuppressive therapy, concomitant pathology in parents and child, etc.), 19.3% had unfavourable social factors (single-parent families, home births, immunosuppressive therapy, concomitant pathology in parents and child, etc.), 14.1% had epidemiological factors (tuberculosis contact), and 12.4% of patients with disabilities were migrants.

Specific vaccine prophylaxis plays an important role in the prevention of tuberculosis in children. However, not all newborns can be vaccinated in a timely manner due to medical disqualifications, such as intrauterine infection, severe lesions of the nervous system with pronounced neurological symptoms, generalised skin lesions, primary immunodeficiency states, HIV infection, etc. [1, 8]. In this regard, the combination of severe pathology, which in some cases leads to disability of the child [2], and lack of vaccination increases the risk of tuberculosis development in children from these categories. Among children with disabilities (in children's polyclinic), 328 (60.6%) were vaccinated with BCG-M before the 7th day of life, 159 (29.4%) were vaccinated before 1 year of age, and 54 children (9.1%) remained unvaccinated.

When assessing the regularity of screening for tuberculosis infection by means of Mantoux skin tests with 2 TU and with recombinant tuberculosis allergen (ATR, Dia-Skintest) among children with disabilities from polyclinic contingents, it was noted that in 59.5% of cases immunodiagnosis was performed irregularly, in 1.4% it was not performed, and in 38.1% of patients the regularity of screening was observed. The main reasons for irregular immunodiagnostics were refusals — 32.8%, medical cancellations accounted for 22.3%, and difficulties in attracting patients to screening (such as low mobility and lack of necessary means for transporting pa-

ОРИГИНАЛЬНЫЕ СТАТЬИ 41

tients) were the reasons for omitting immunodiagnostics in 5.8% of children.

Children's tuberculosis sanatoria play an important role in the treatment and rehabilitation of patients with tuberculosis infection [9]. In the period 2020–2021, 10 children from 3 to 17 years of age with disabilities due to comorbidities were treated in tuberculosis sanatoria in St. Petersburg (2B subgroup). The causes of disability were as follows: infantile cerebral palsy, diplegia — 3; hearing loss III st. — 2; consequences of burns, contractures — 2; congenital synostosis — 1; cognitive disorders, mental retardation — 2.

In all cases the treatment was successful: it promoted socialisation, adaptation, and improved the quality of life of the patients.

### **CONCLUSION**

Children with disabilities represent a risk group for TB due to a combination of risk factors, including lack of vaccination (9.1%), irregular immunodiagnosis (38.1%), and refusal of preventive treatment (66.7%). Treatment of disabled children with TB is difficult due to poor tolerance of TB drugs. Children with disabilities should have access to prevention and early detection of tuberculosis infection in children's polyclinics and dispensaries, including: transport, assistance in travelling around the institution, home care (examination by a specialist, taking tests), inpatient care at home, and supervised therapy using telemedicine. Hospitalisation of a child in an inpatient facility must include the possibility of a relative staying with him or her or additional care staff. Rehabilitation of children with disabilities in the presence of tuberculosis contact, tuberculosis infection, active tuberculosis in the phase of continuing chemotherapy is advisable to be carried out in children's tuberculosis sanatoria. TB dispensaries should have medical and social assistance rooms: children with disabilities and their parents need individual health education and psychological support.

#### ADDITIONAL INFORMATION

**Author contribution.** Thereby, all authors made a substantial contribution to the conception of the study, acquisition, analysis, interpretation of data for the work, drafting and re-

vising the article, final approval of the version to be published and agree to be accountable for all aspects of the study.

**Competing interests.** The authors declare that they have no competing interests.

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**Consent for publication.** Written consent was obtained from the patient for publication of relevant medical information within the manuscript.

# ДОПОЛНИТЕЛЬНАЯ ИНФОРМАЦИЯ

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**Конфликт интересов.** Авторы декларируют отсутствие явных и потенциальных конфликтов интересов, связанных с публикацией настоящей статьи.

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ОРИГИНАЛЬНЫЕ СТАТЬИ 43

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