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Medical Rehabilitation of Children with CNS Tumors Developing State of Minimal Consciousness

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Summary

Objective. To evaluate clinical characteristics and results of individualized medical rehabilitation in children with brain tumors, including those with tracheostomy and/or gastrostomy, upon recovery from a state of minimal consciousness.

Materials and methods. A prospective observational study included 309 patients aged 6 to 17 years who completed treatment for central nervous system (CNS) tumors during 2019–024 yy. at the «Russkoye Pole» medical rehabilitation research center of the Dmitry Rogachev National medical research center for pediatric hematology, oncology, and immunology, Russian Ministry of Health. All patients underwent a comprehensive assessment of treatment effects, including clinical and functional examination, testing of cognitive and emotional functions, and individualized medical rehabilitation. A subgroup of subjects in a state of minimal consciousness with tracheostomy and/or gastrostomy included 9 patients (2.9%). Rehabilitation goals were set based on the domains of the International Classification of Functioning, Disability and Health (ICF), according to an interdisciplinary approach.

Results. Severe neurological deficit as the sequelae of cancer treatment toxicity was documented in 90% of children with CNS tumors. However, all 309 patients achieved the goals of specialized medical programs within 14–21 days. Patients in a state of minimal consciousness most often had impaired breathing, swallowing, eating, communication, and emotional regulation, endangering with life-threatening complications. Adhering to the protocols adapted for management of such patients helped minimize the risk of life-threatening complications. No serious complications were recorded in any patient during the rehabilitation process.

Conclusion. Even in cases of severe functional impairment, including patients requiring tracheostomy and gastrostomy, an individualized medical rehabilitation approach allows for stabilization of patient's condition, upregulation of basic vital functions, and improvement quality of life of patients and their families. Restoring cognitive and sensorimotor functions in children in a state of minimal consciousness requires early initiation of rehabilitation measures by a multidisciplinary team, including a resuscitator, pediatrician, physical therapist, speech therapist, medical psychologist, etc.

Keywords: central nervous system tumors; minimal consciousness; medical rehabilitation; children; tracheostomy; gastrostomy; multidisciplinary approach

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Introduction

Recovery from a minimally conscious state manifests by gradual recovery of cognitive functions to a state that is equivalent to chronic impairment of consciousness [1].

Central nervous system (CNS) tumors are the second most common type of malignant neoplasms in children after leukemia, and the most common type of solid tumors, accounting for up to 20% of all cases of cancer in children. Thanks to advances in mainstream medicine, including the use of combined chemo-radiotherapy (CRT), survival rates have improved significantly in recent decades. Currently, about 70–80% of children with CNS tumors achieve five-year survival [2].

Introduction of modern chemo-radiotherapy protocols has led to significant progress in treatment of CNS tumors. However, the malignant growth site and high toxicity of advanced treatments cause long-term disruption in functioning of virtually all organs and systems of the body. At the same time, the need for tracheostomy and gastrostomy most often arises in patients with damage to the brain stem, to cranial nerves, or in patients with severe bulbar dysfunction, requiring tracheostomy in 7–10% of cases [12]. More than 80% of patients with documented cure of CNS tumors are disabled since childhood, as the arising long-term complications and sequelae of therapy during or after treatment, requiring a multidisciplinary approach at the rehabilitation phase remains one of currently unresolved challenges. Restoring consciousness and cognitive functions lost because of the disease and its treatment requires a significant amount of time [3]. It is also emphasized that recovery of cognitive and sensorimotor functions in children in a state of minimal consciousness requires early initiation of rehabilitation measures involving a multidisciplinary team, including a resuscitator, physical therapist, speech therapist, and medical psychologist [11].

Some patients who have undergone neurosurgical interventions for CNS tumors develop swallowing disorders, weakness of the respiratory muscles, and a need for nutritional and respiratory support, which increases the risk of life-threatening complications. In this regard, tracheostomy and gastrostomy are used in this group of children with CNS tumors to provide respiratory and nutritional support.

Tracheostomy and gastrostomy significantly improve life support indicators; however, these procedures are associated with a risk of developing stoma infection, obstruction of the cannula or tube, proliferation of granulation tissue, and septic conditions. This is confirmed by a global survey that revealed insufficient staff training and lack of standardized protocols, which exacerbates the risk of complications [4].

Young children and patients with concomitant neurodegenerative, metabolic, and immunosuppressive conditions are particularly vulnerable in this regard. The lack of standardized protocols for managing patients in a minimally conscious state during the rehabilitation phase, as well as a shortage of trained personnel and difficulties in home care, further increase the risk of adverse events.

A recent review of tracheostomy in children published in Respiratory Care points to increased mortality in this particular patient group, and emphasizes the importance of caregiver training in care and emergency response to reduce the number of emergency hospitalizations [5]. In addition, a 2025 systematic review showed a significant reduction in the quality of life of parents who cared for children with stomas: approximately 40% of mothers experienced moderate or severe stress, and the key risk factors were the young age of the child, comorbidities, and lack of social support [4].

According to recent studies, gastrostomy in children receiving home enteral nutrition is associated with a high risk of complications. Among the most common are infections in the stoma area, excessive growth of granulation tissue, leakage of gastric contents, and displacement or extrusion of the gastrostomy tube. The incidence of these complications reaches 73%, with up to 14% of cases categorized as severe and requiring repeated medical interventions, including surgical correction or device replacement [6].

Specialized inpatient rehabilitation, carried out in accordance with Order No. 878n of the Ministry of Health of the Russian Federation dated October 23, 2019, «On Approval of the Procedure for Organizing Medical Rehabilitation of Children», provides comprehensive support for stoma-treated children who have undergone neurosurgical interventions. The organization of care involves the participation of a multidisciplinary rehabilitation team (MDRT). However, the available literature on medical rehabilitation of children who have undergone CNS tumors is quite limited [14].

Materials and Methods

From 2019 to 2024 a prospective observational study was conducted at the «Russkoe Pole» medical and rehabilitation research center of the Dmitry Rogachev National Medical Research Center for pediatric hematology, oncology, and immunology of the Ministry of Health of Russia (NMRC PGOI named after Dmitry Rogachev, MoH of Russia), focused on the long-term complications and consequences of treatment in children with CNS tumors.

Criteria for inclusion of patients in the study

- CNS tumor in remission or long-term stable disease after specific treatment, including chemo-radiotherapy;

- Age 6 to 18 years;
- Informed consent signed by parents or children over 14 years of age.

Exclusion criteria:

- Severe mental disorders, mental retardation, amblyopia, or other disorders that make it difficult to communicate with the child, infectious diseases;
- Refusal of participation by parents or patient;
- Recurrence of the underlying disease.

The required sample size was not calculated, as the aim was to fully evaluate the center's patient cohort.

The study included 309 patients who were in transition from a state of minimal consciousness. The children's ages ranged from 6 to 17 years, *Me = 11.00 [9.00; 15.00]; min = 6, max = 17.*

There were 254 patients in remission, accounting for 82.2%, and 55 patients, or 17.8%, in a state of long-term stable disease; all children completed therapy for CNS neoplasms. The median follow-up time after discontinuation of therapy was 25.00 months [12.00; 65.00]; min = 1, max = 123.

Boys prevailed in the group, accounting for 179 (57.9%) patients; there were 130 girls (42.1%). This distribution is generally characteristic of the epidemiology of CNS tumors. The median age at tumor onset was 7.5 years [5;10]; min — 0.3, max — 16. The majority of patients — 196, or 63.4% — had a tumor located infratentorially.

The study protocol was reviewed and approved by the Ethics committee of the Dmitry Rogachev National Medical Research Center for pediatric hematology, oncology, and immunology of the Ministry of Health of the Russian Federation (No. 8e/13-17 dated October 27, 2019).

The study complies with STROBE recommendations for cohort studies.

The Glasgow Coma Scale (GCS) and the Coma Recovery Scale — Revised (CRS-R) were used to assess the state of minimal consciousness.

Data were described using measures of central tendency and variability: median and range (min–max) for quantitative variables, and frequency and percentage for categorical variables. All analyses were performed using StataBE 18 (StataCorp, USA).

Results

A methodology for comprehensive assessment of the severity of long-term complications and consequences following the use of various cancer treatment modalities, including different chemotherapeutic agents and dosing regimens, and radiotherapy has been developed. During diagnostic elaboration involving examinations by relevant specialists, laboratory and functional tests, not only the fact and severity of reported clinical manifestations of damage to the nervous, endocrine, cardiovascular, digestive, and other organ systems were established, but also missed, though predictable, long-term consequences were identified, and the severity of monitored complications was clarified.

Screening of neurocognitive functions using a basic test package, including verbal and nonverbal tests, attention span tests, thinking speed, processing, executive functions, as well as components of emotional and behavioral assessment (Cambridge Assessment Neuropsychological Test Battery, Achenbach questionnaire, subtests from the cognitive tests battery (CTB), and Kaufman Assessment Battery for Children) showed a decline in these functions in all 309 children.

A quantitative assessment of the severity of long-term consequences on the CTCAE v 5.0 scale (National Cancer Institute Common Terminology Criteria Adverse Events) in a group of 309 children is presented in the figure.

As demonstrated by the diagrams, in more than 90% of children, the consequences of cancer treatment toxicity were represented by severe neurological deficits; more than 75% of children had endocrine system disorders; 17% of pediatric patients experienced visual complications caused by cancer treatment toxicity, and more than 18% of children had musculoskeletal disorders.

The rehabilitation program lasted 14–21 days and included the use of physical rehabilitation equipment, massage, physiotherapy, as well as individual neuropsychological rehabilitation programs for children and their parents. The package of specialized rehabilitation interventions included correction of postural function, articulation and breathing exercises, speech therapy massage, immediate correction of vision with glasses, medication to correct digestive function, voice and speech correction, gradual transition to independent feeding (as part of nutritional support), training in walking up the stairs and walking independently.

In all 309 cases, the set goals were achieved.

It is evident that due to the severity of organ damage in minimally conscious patients following treatment of CNS tumors, there's a strong background for development of a critical condition during intensive rehabilitation procedures.

Nine (2.9%, 5 girl and 4 boys) out of 309 patients were subjected to tracheostomies (7 cases) and/or gastrostomies (5 cases), including 3 patients requiring both stomas, due to development of a life-threatening condition in the acute or subacute period.

Patients' level of consciousness was assessed upon admission and monitored during hospital stay. The baseline assessment included the Glasgow Coma Scale (GCS) and the Coma Recovery Scale — Revised (CRS-R). Median GCS score on admission was 9 (min 8, max 11), and median CRS-R score was 10 (min 8, max 12), meeting diagnostic criteria for the minimally conscious state (MCS). Therefore,

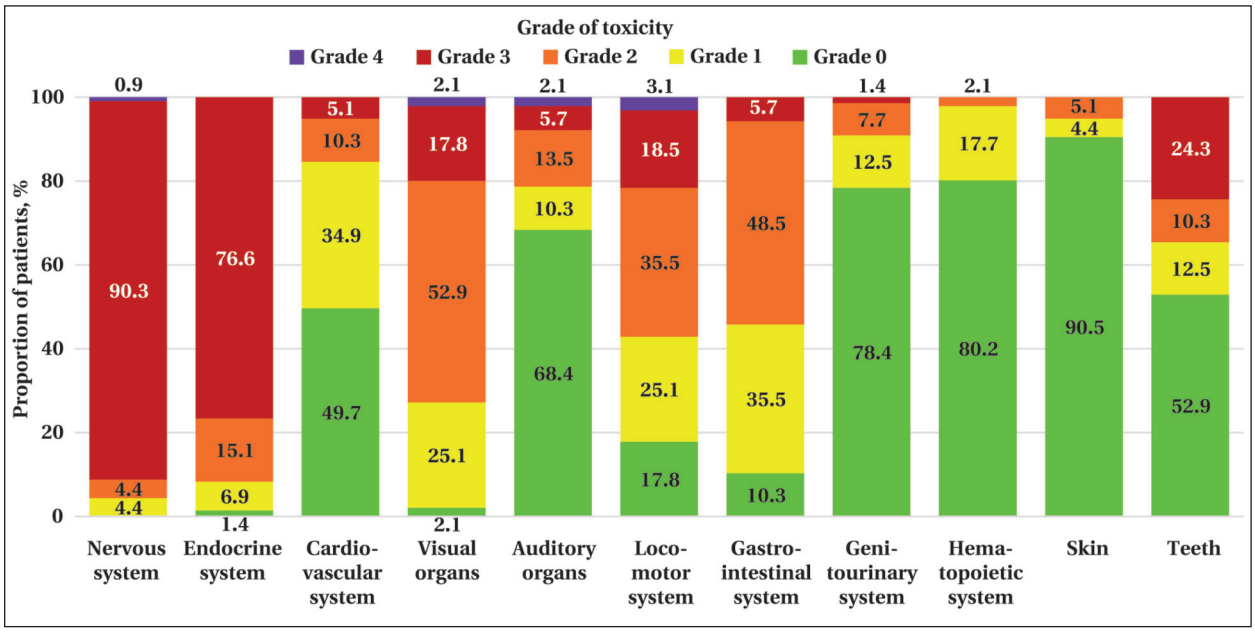

Fig. Toxicity of treatment in patients with CNS tumors according to the NCI-CTCAE v.5.0 scale

all patients in the study group were categorized as having severely altered consciousness and requiring specialized medical rehabilitation measures.

Prior to inclusion into medical rehabilitation program, all patients with tracheostomies had multiple episodes of aspiration in the acute or subacute period that required emergency airway management. Safe enteral feeding was a reliable solution in patients with high risk of aspiration.

Rehabilitation diagnoses, goals, and objectives according to the International Classification of Functioning (ICF) Disability and Health in patients with stomas after treatment of CNS tumors are summarized in Tables 1–3.

Given the severity of illness, challenges with breathing, feeding, and communication, patient's state of minimal consciousness, and vital need for multidisciplinary care, the goals of medical rehabilitation were established using the International Classification of Functioning (ICF) Disability and Health. All patients with gastrostomies and tracheostomies had scores of 4–5 on the Rehabilitation Routing Scale (RRS), which indicated a continuous need for specialized comprehensive rehabilitation. One child had severe sequelae after subtotal removal of a tumor in the posterior cranial fossa and following treatment, including bulbar and ataxic syndromes, bilateral lagophthalmos due to facial nerve palsy, partial optic nerve atrophy (PONA), dysarthria, dysphagia, and dysphonia.

After a 14–21-day course of rehabilitation, the indicators improved: the median GCS increased to 13 scores (min 11, max 14), and the CRS-R increased to 15 scores (min 12, max 17). Two patients improved up to recovery from minimally conscious state.

Improvements in patients' quality of life were achieved through gradual recuperation of the following impaired functions: b770 gait pattern, b320 articulation, b440 breathing, b310 voice and speech, b510 swallowing, b530 weight maintenance, b152 emotional.

Medical rehabilitation in patients with stomas was aimed at minimizing the risks of life-threatening situations. The program envisaged achieving safe, stable movement pattern taking into account the patient's needs, recovery of voice (with the use of alternative or assistive methods of voice and speech communication), recovery or development of oral feeding skills (taking into account the current feeding method), training of communicative (speech-producing) breathing skills, stabilization of patient's emotional state, reduction of anxiety and emotional lability.

Rehabilitation diagnoses, goals, and objectives of medical rehabilitation were formulated for each patient, taking into account the body's structure and functions, as well as the individual characteristics of the patient's activity.

Tables 1–3 present assessments of the progress in terms of achieving the stated goals during hospital stay (at admission and at discharge) in the main rehabilitation domains.

Following specialized medical rehabilitation, including comprehensive respiratory support in

Table 1. Recovery of functions in the study cohort.

ICF domain «body functions» codes and categories	Rehabilitation goals and objectives	Assessment		MDRT participant	IMRP
		O1 upon admission	O2 upon discharge		
b770 Gait pattern functions	Restoration of a safe, stable gait pattern within the ward/home, taking into account the patient's needs	2	1	Physical therapy doctor	Correction of postural function
b320 Articulation functions	Providing background for recovery of articulation motor skills, for nonverbal and speech interaction using available communication channels	3	2	Speech therapist	Articulation exercises
b440 Respiration functions	Optimization of respiratory functions, including patients with tracheostomy; adjustment of breathing allowing speech	3	3	Physical therapy doctor, speech therapist	Breathing exercises
b310 Voice and speech functions	Providing background for recovery or establishment of voice function, using alternative or augmentative means of voice and speech communication	3	2	Speech therapist	Assessment and correction
b510 Swallowing functions	Establishing safe and functional swallowing with minimal risk of aspiration, recovery or development of oral feeding skills	2	1	Speech therapist	Speech therapy massage, correction of dysphagia
b210 Seeing		8	3	PRM doctor, ophthalmologist	Assessment and corrective eyewear/surgery
b515 Digestive functions		2	1	PRM doctor	Pharmacological correction
b530 Weight maintenance functions	Ensuring safe and adequate food intake taking into account the current feeding method and patient's swallowing function	2	1	PRM doctor, nutritionist	Nutritional support, medication adjustment Gradual transition to independent eating
b152 Emotional functions	Stabilization of patient's emotional state, reduction of anxiety and emotional lability	2	1	Psychologist	Correction of emotional state

Note. For Tables 1–3: IMRP — individual medical rehabilitation program; PRM — physical and rehabilitation medicine.

Table 2. Recovery of activities and participation (action) in the study cohort.

ICF codes and categories Domain «activities and participation»	Rehabilitation goals and objectives	Assessment		MDRT participant	IMRP
		O1 upon admission	O2 upon discharge		
d451 Overcoming obstacles (going up and down stairs)	After 7 days, the patient will be able to safely climb and descend 5 flights of stairs independently, without assistance and with minimal fatigue.	22	11	Physical therapy doctor	Staircase walking exercise
d450 Walking long distance	The patient is able walk set distance (e.g., from 100 to 300 meters) independently without outside assistance and with minimal fatigue in the rehabilitation course (usually 14–21 days)	22	11	Physical therapy doctor, PRM doctor	Training to walk independently
d550 Eating	Patient after 14 days can independently and safely take regular consistency food without Assistance, within adequate time	22	11	PRM doctor, dietitian, speech therapist	Nutritional support, correction of dysphagia, gradual transition to independent nutrition
d330 Speech	During the 14 days course the patient will be able to make sounds, express basic emotional reactions and use alternative means of communication (gestures, facial expressions, communication cards) for conveying basic needs without using spoken language	33	23	Speech therapist	Enable voice and speech reactions in everyday situations
d240 Handling stress and other psychological demands	During the14 days course patient will reduce manifestations of anxiety and emotional instability, learn and apply minimum 2 self-regulation techniques with psychological support for reducing stress	22	11	Psychologist	Support, search and activation of resources, removal of tension

Table 3. Adaptation of environmental factors and examination of brain structures in the study cohort.

ICF codes and categories Domain «environmental factors» and «body structures»	Rehabilitation goals and objectives	Assessment		MDRT participant	IMRP
		O1 upon admission	O2 upon discharge		
e310 Immediate family	Within 14 days, ensure that the family is actively involved in the patient's care and rehabilitation, and enhance the knowledge and skills of family members in caring for tracheostomies and gastrostomies	+2	+3	PRM, psychologist, nurse	Informing, training in stoma care, and motivated counseling
e110 Products or substances for personal consumption	Ensure adequate and balanced nutritional and medication support	+2	+3	PRM doctor, consultants	Selection and correction of enteral formulas and medication therapy
s110 Structure of brain		3	3	PRM doctor, oncologist	Confirmation of remission/stable disease

most challenging cases, the following goals were achieved:

1) regained skills to climb independently and safely (under supervision) 5 flights of stairs; 2) ability to walk independently for least 100 meters with minimal fatigue; 3) ability to express basic emotional reactions using alternative means of communication (gestures, facial expressions, communication cards); 4) ability to convey simple needs without using voice speech; 5) ability to use voice and speech in everyday situations; 6) ability to eat independently. In all 9 cases, there was a reduction in anxiety and emotional instability.

There were no clinically significant complications in patients with tracheostomy and gastrostomy tubes during rehabilitation, thereby confirming the effectiveness of a multidisciplinary approach to medical rehabilitation based on high standards of patient care.

The systematization of rehabilitation goals according to the ICF main components clearly demonstrates a real multidisciplinary approach to management of stoma patients after neurosurgery at the stage of recovery from a state of minimal consciousness. Disrupted vital functions, such as breathing, swallowing, and speech control, are most clinically consequential, which is particularly noticeable in the domains of bodily functions and their corresponding domains of activity and participation.

Discussion

The rehabilitation of children after surgery for central nervous system tumors is associated with a number of challenges related to both, the underlying disease and the consequences of surgical and oncological treatment. Most demanding among all complications were cases of minimally conscious states associated with tracheostomy and/or gastrostomy. In this study, the proportion of such patients was only 2.9% confirming the exceptionality of such conditions. However, management of such patients requires significant resources and mandatory interdisciplinary coordination.

These data is consistent with the results of other studies, reporting the need for tracheostomy and gastrostomy in an average of 2–5% of children undergoing neuro-oncological treatment, especially when brain stem structures or cranial nerves are involved [7].

The results obtained in this study suggest that the organization of rehabilitation care for patients with CNS tumors does not differ in structure from that for surgical and palliative patients. However, there was a high demand for field-specific professionals, including an intensive care physician, ENT doctor, gastroenterologist, dietitian, and speech therapist, due to the complex nature of the disorders and the need for challenging management. The participation of an intensive care physician ensures adequate medical care for children in a state of minimal consciousness, taking into account the risk of possible life-threatening complications.

The need for regular sanitation and frequent (up to 2–3 times a week) replacement of tracheostomy tubes was due to potential proliferation of granulation tissue with the risk of obstruction and infectious complications, which is also mentioned in publications on the care of children in intensive care units [8]. In combination with swallowing disorders and feeding via a gastrostomy tube, this category of patients requires continuous monitoring of vital functions and a high level of medical competence on the part of the staff.

Recent studies emphasize the importance of objective monitoring of functional status, including autonomic nervous system activity, as one of the criteria for evaluating the effectiveness of therapy and rehabilitation in patients with severe brain damage [9]. This approach allows tracking the dynamics of vegetative regulation, which is especially important in patients with limited consciousness and lack of active feedback.

In addition to medical aspects, the emotional state of parents has a significant impact on the success of the rehabilitation process. Most family members of patients reported anxiety related to the duration of illness, the impairment of basic vital functions in the child, and uncertainty of the prognosis. Similar concerns are described in other studies, emphasizing the need for systematic psychological support for parents of children with severe functional impairments [10, 12]. The study conducted in the United States also reported on parents' concern about the fact that children with tracheostomies suffer not only from physical discomfort, but also from social isolation and inability to participate in normal school and play life [13].

In this regard, a clinical psychologist was involved in the rehabilitation activities to help parents regain emotional balance and build up relevant competence.

Conclusion

Uncommonness of the combination of CNS tumors with minimally conscious state in pediatric patients necessitates development of specialized multidisciplinary organizational and methodological solutions that take into account the phased tasks of cognitive function recovery to provide medical rehabilitation for this category of patients. The results obtained show that even in cases of severe functional impairments it is possible to achieve stabilization of the condition, partial recovery of lost functions, and improvement in the quality of life of both the child and the parents.

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