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Comprehensive assessment of quality of life and psychosocial rehabilitation of children with CNS tumors

Abstract. Today, psychosocial care is one of the significant steps in the process of treatment and rehabilitation of cancer patients, as well as one of the most actively developing areas of modern medical psychology. The formation of the system of psychosocial support of cancer patients and its implementation into practice is one of the main tasks of the healthcare system of the Republic of Kazakhstan in order to ensure the protection and promotion of public health.

The article presents the results of a comprehensive assessment of the quality of life and psychosocial rehabilitation of children with CNS tumors. In choosing the psycho-corrective techniques, particular attention has been paid to the localization and prevalence of malignancies that affect the semiotics and complications of the disease.

The study of the quality of life of patients before treatment and during the treatment has provided extremely valuable multidimensional information about the individual response to the disease and the conducted therapy. Analysis of the quality of life when planning a program of treatment of cancer patients is important not only because of the need to account for individual patient characteristics but also due to a high correlation of the quality of life with survival rates, particularly in patients with CNS tumors.

Keywords: oncology, psychosocial support, rehabilitation, quality of life.

Relevance. The growth of oncological diseases mainstreams the problem of developing innovative forms of medical and social assistance aimed at optimizing the quality and duration of patients' life.

Cancer patients require not only professional medical care but also a comprehensive approach that covers all aspects of human being, from qualitative diagnostics and individual therapy to accessible psychological assistance. The quality of life is one of the key indicators in studying the final treatment outcome [1]. Quality of life analysis during the planning of cancer patient treatment is important not only due to the necessity to consider individual traits of the patient but also due to the available data on a high correlation of the quality of life with the survival rates, especially in patients with CNS tumors.

CNS tumors account for 14-20% of cancer morbidity of children. Brain tumors (95-97% of cases) are significantly more often than spinal cord tumors.

According to the International Agency for Research on Cancer (IARC), the standardized incidence of CNS tumors in different countries varies from 0.42 to 3.37 cases per 100 thousand children. Boys below 10 get are affected more often. Histologically, neuroepithelial tumors predominate making 66% of cases [2]. The prevalence of CNS diseases is geographically differentiated: from 0.42-0.49₀₀₀ in Africa, 1.99₀₀₀ in China, 2.41₀₀₀ in Japan, 2.93₀₀₀ in the US to 3.10₀₀₀ in Denmark, and 3.37₀₀₀ in Sweden. Germany, Sweden, New Zealand, and Finland have the highest brain tumor incidence in children [3]. The incidence of CNS tumors in Russia is 2.4 per 100 thousand children population, i.e. about 600 new cases are registered annually. In the Republic of Belarus, 2.9 cases are registered per 100 thousand children population [4, 5].

In the Republic of Kazakhstan, according to Kazakh Research Institute of Oncology and Radiology (KazIOR), CNS tumors rank second in cancer morbidity of children after leukemia and account for 18-20% of all cancer pathologies

in children. These tumors have high heterogeneity and vary in morphofunctional characteristics that determine the disease prognosis and the approaches to treatment. The treatment strategy is also influenced by the patient's age, the size and location of the tumor [6].

Cancer not only threatens the life of patients but also has a prolonged impact on the quality of life since in many cases it becomes chronic. The concept of the quality of life as an important quantifiable result is applied in many areas of medicine. It attracts growing attention and in some cases can serve as the main criterion of clinical efficacy. In medicine, more attention is paid to the health-related quality of life which is an overall characteristic of the patient's physical, mental and social functioning based on the patient's perception. The quality of life is considered to be one of the key indicators in the assessment of the final treatment outcome [7]. The emotional well-being of patients is directly connected to their physical condition. The long-lasting treatment causes such psychosocial problems as the deformation of interpersonal relationships, difficulties in learning, keeping up with the school curriculum, difficulties in entering the society, and many others. These manifestations are prolonged in time, so the psychological assistance should not be a one-time action. It requires the creation of an integrated system of social, psychological, medical and psychological rehabilitation [8].

Despite a significant number of publications devoted to clinical, diagnostics, and treatment of malignant tumors in children, there is not enough research and development in our country in the field of psychosocial rehabilitation of patients with CNS tumors. Today, psychosocial assistance is an important stage of treatment and rehabilitation of cancer patients. It is also one of the most actively developing areas of modern medical psychology. The formation and implementation of the system of social and psychological assistance to cancer patients is one of the main tasks of health care system of the Republic of Kazakhstan

aimed to ensure the protection and strengthening of public health.

The purpose of the study is to improve the quality of life of children with CNS tumors by a system of psychocorrectional measures.

Materials and methods. The study called "Developing and improving psychosocial rehabilitation program aimed to improve the quality of life of children with CNS tumors" was conducted at the Kazakh National Research Institute of Oncology and Radiology (KazIOR). It involved a total of 40 children – patients of the Center for Pediatric Oncology at KazIOR. 28 children aged 8 to 12 years (Age 1) compiled Group 1, 12 children aged 13 to 18 years (Age 2) – Group 2. Their parents also participated in the study.

The study was aimed at developing the programs for the correction of psycho-emotional disorders in children with cancer. The examinations included traditional studies of the psycho-emotional status of the patients taking into account the localization of CNS malignant tumors affecting the clinical picture of the disease and the occurrence of complications during treatment [9]. Special attention was paid to the tumor localization due to its influence on the disease symptoms, the occurrence of complications and the choice of psychocorrection techniques. Various approaches to psycho-correction were identified and compared taking into account the identified localizations. Correctional targets for psychosocial impact using various correctional programs were selected taking into account the anatomical and physiological features of the patients.

Attention was also paid to the neurocognitive aspects and the development of optimal psycho-rehabilitation programs. It required a clear understanding of the etiology of detected disorders including:

- the diagnosis, the course of the disease and the treatment applied;
- the patient's age at the time of illness and at the time of implementation of rehabilitation psychosocial programs.

In developing the programs, the emphasis was on such consequences of the disease as the emotional, behavioral and neuropsychological disorders.

The typological psychological diagnoses were put in the list and encoded in order to evaluate and compare different approaches to psycho-correction in patients with CNS tumors. The proposed typology was applicable to a limited but mostly common age in psychological practice, from 8-12 to 12-15 years [10]. The optimal psycho-rehabilitation programs were developed taking into account the etiology of the identified disorders, the diagnosis, the course of the disease and the applied treatment, as well as the age of the child at the time of illness. The task was to fully represent the most significant indicators of the child's mental status, primarily affecting the nature of his/her adaptation in the social environment.

The system of psychocorrection measures included a differentiated combination of methods of individual, group and socio-centered intervention and was aimed at reducing the symptoms, activation of adequate psychological defenses, and the increasing success of rehabilitation processes.

Art therapy was actively used as part of psychocorrection work with the study patients. It included fairy tale therapy; puppet therapy, sand therapy, playing fairy tale therapy, and etc. Those methods were used to correct the children's behavior and mood.

Art therapy is an area of psychological therapy and correction based on art and creativity. For cancer patients, it is primarily the possibility to sublimate their emotions and to transfer their feelings and experiences to a canvas or a piece of paper. Abstract patterns and naive images allow expressing ones hidden feelings, transfer them intuitively to a piece of paper thus getting read the accumulated emotions and achieving abreaction.

Special techniques that can reduce anxiety and fear were developed. Fairy tale therapy has allowed attracting hidden resources, reuniting with personal creativity. Fabulous contents helped children to remove emotional stress, free oneself from the accumulated emotions, and discover a new view on difficult life situations. Fairy tale therapy was structured by certain psychological problems:

- fairy tales for children who have fears of a medical office and medical procedures;
- fairy tales for children with increased anxiety and irritability;
- fairy tales for hyperactive children;
- fairy tales for aggressive children;
- fairy tales for children suffering from behavioral disorders with physical manifestations: problems with food, problems with sleep, etc. ;
- fairy tales for children who faced the problems of family relations (parental divorce);
- fairy tales for children in case of loss of significant people.

Those methods of working with children helped them cope with feelings and fears and form a positive perception of the surrounding reality and social relations [11].

Quality of life analysis during the planning of cancer patient treatment is important not only due to the necessity to consider individual traits of the patient but also due to the available data on a high correlation of the quality of life with the survival rates, especially in patients with CNS tumors. During the study, the quality of life of children with tumors was assessed using the children's version of the quality of life questionnaire – PedsQL Cancer Module, PedsQL Brain Tumor Module [12] for children aged 8-12 years and 13-18 years, in Kazakh and Russian languages (after their linguistic and cultural adaptation). The children participating in the study have completed the questionnaires before and after the intervention.

In general, the psychological assistance was adapted taking into account the problems identified during the initial analysis. The purpose of the assistance was to form a positive internal picture of the disease in the child himself and through the formation of adequate (cognitive and emotional) attitudes in the parents.

Psychological assistance to families with chronically ill children was aimed at reducing family stress and preventing distress when the family system is in chaos and is not capable of efficient functioning [13].

In parents, the psychological correction was targeting their psycho-emotional state. The correction was performed both individually and in groups.

Results and discussion. The initial analysis and diagnostics revealed a range of pronounced cognitive and emotional changes in the psyche of the patients with CNS tumors receiving the main course of treatment. They included reactive states like anxiety, fear, the manifestations of depression, negative and aggressive reactions, and etc. The corrective targets that took into account the identified anatomical and physiological features included increased

anxiety, inefficient coping strategies, the inability to openly express own feelings (alexithymia), the presence of fears and phobias, the presence of obsessive thoughts, physiological disorders, and the sleep disturbance.

Before the intervention, the average (median) scores were higher in Group 1 on “cognitive problems”, “pain and

the feeling of pain” and “anxiety”, and in Group 2 – on “the fear of medical procedures.” The “pain and feeling of pain” indicator was significantly lower in Group 2 (Mann – Whitney U-test, $p = 0.038$), i.e. children of that age group suffered less from pain and the feeling of pain. No significant differences were identified for the remaining indicators (Figure 1).

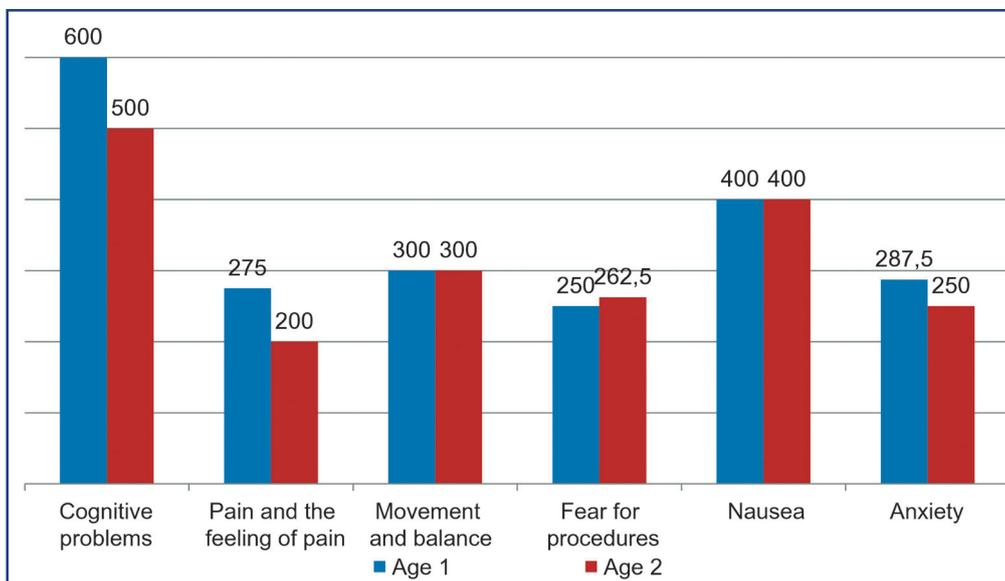


Figure 1 – Mean (median) self-assessed values of the quality of life in children before the intervention. Age 1 – children aged 8 to 12 years, Age 2 – children aged 13 to 18 years

After the intervention, the average (median) scores were higher in Group 1 on “pain and the feeling of pain”, “movement and balance”, “fear of procedures,” and “anxi-

ety”, and on “Cognitive problems” – in Group 2. No statistically significant differences were identified by Mann-Whitney U-test (Figure 2).

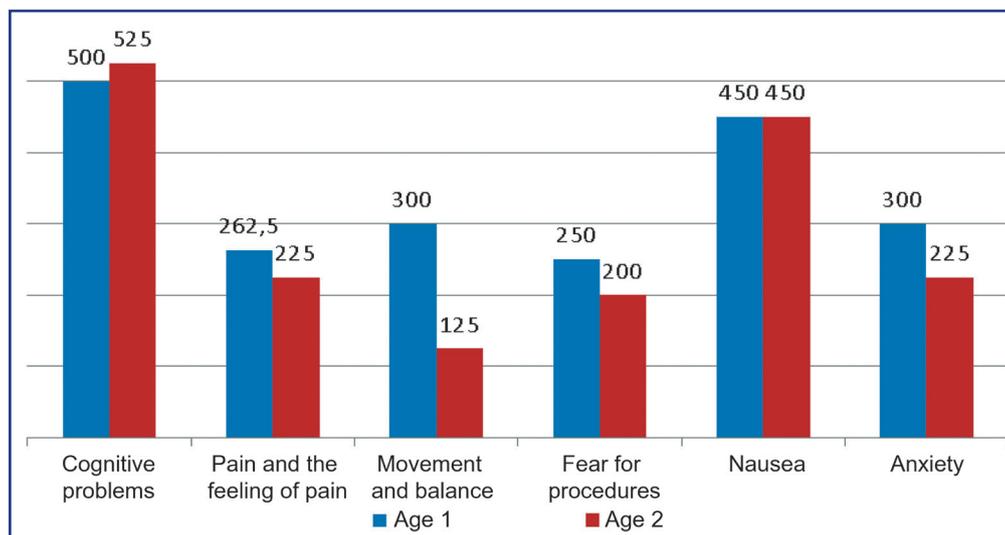


Figure 2 – Mean (median) self-assessed values of the quality of life in children after the intervention. Age 1 – children aged 8 to 12 years, Age 2 – children aged 13 to 18 years

After the psychosocial intervention, the average scores for cognitive problems and the presence of nausea have improved. Statistically, the significant changes were noted only in the assessment of the feeling of nausea (Wilcoxon T-test, $p = 0.026$). For the rest of the indicators, the significant differences were identified on “movement and balance”, “fear of procedures”, “anxiety” (Figure 3).

Then, 40 parents of the involved children were interviewed. Before and after the intervention, the average

(median) scores for parents were higher in Group 1 on “pain and the feeling of pain”, “movement and balance”, “nausea” and “anxiety” indicators, and in Group 2 – on “Cognitive problems.” No statistically significant differences were identified by Mann-Whitney U-test (Figure 4).

Psychological diagnosing of parents has revealed a large share of neurotic and depressive reactions and conditions that required skilled and quite long-term assistance. Mental disorders in parents were most often caused

by the chronic psycho-traumatic situation, overfatigue, often malnutrition and the lack of sleep, the financial, hous-

ing and other domestic problems arisen in connection with the development of the serious illness in their child.

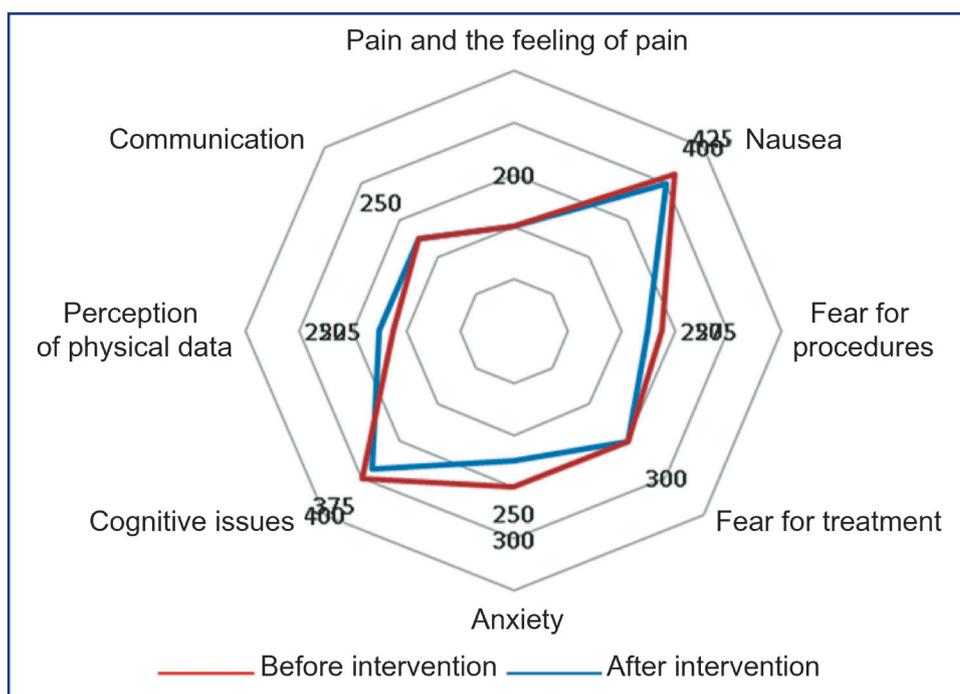


Figure 3 – Mean (median) self-assessed values of the quality of life in children before and after the intervention

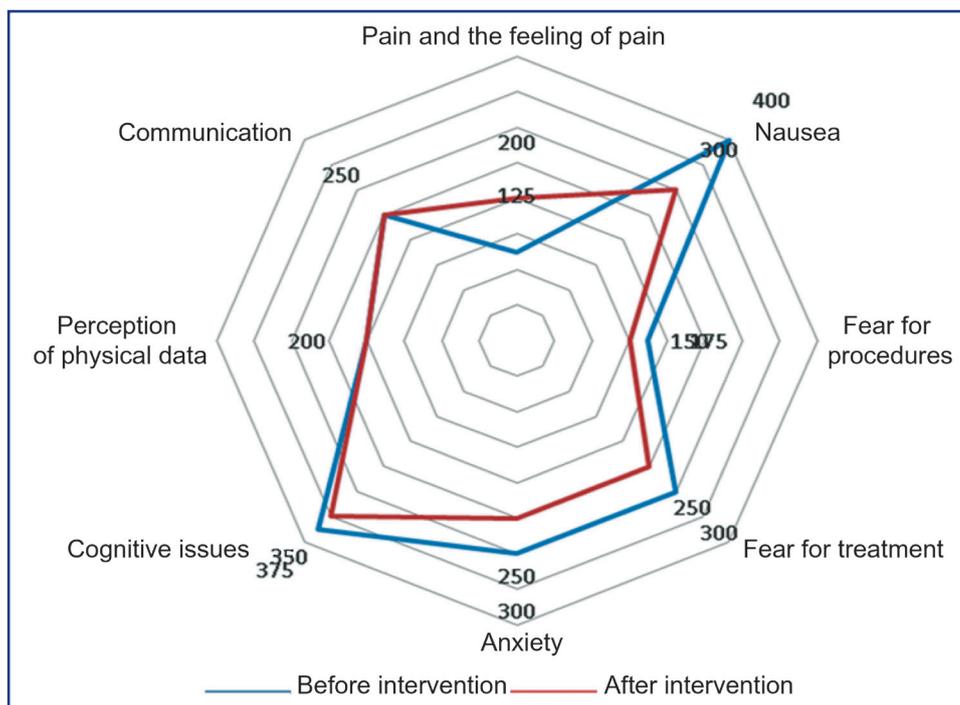


Figure 4 – Average (median) values of the quality of life of children assessed by their parents before and after the intervention

Long treatment was causing not only psychological but also social problems: the deformation of interpersonal relations, the difficulties in accepting the disease, the difficulties in learning and entering the society. Social support for children and parents was an important step in providing psychosocial assistance. The study emphasized the importance of improving the model of providing social assis-

tance. The recommendations and informational materials were developed to improve the level of social protection of cancer patients.

The social assistance to parents included information and advisory support on the following issues: the route of registering disability – 61.0%; get disability allowance and benefits – 78.0%; individual rehabilitation program –

85.0%; reimbursement of transport costs – 59.0%; home education of children – 42.0%; other issues (social services, employment) – 48.0%.

Conclusion. The conducted study has shown the severity of symptoms of mental disorders associated with a long and severe course of somatic illness and has allowed investigating the mechanisms of impact of socio-psychological assistance on the efficacy of treatment when a team of psychosocial specialists supports the oncologists in treating a child.

The quality of life indicators in children with malignant CNS tumors identified using the PEDSQL 4.0 GENERIC CORE SCALES, PedsQL Cancer Module, PedsQL Brain Tumor Module questionnaires have helped in developing the rehabilitation programs for those patients.

The introduction of psychosocial assistance into the rehabilitation treatment process has helped to increase the success of rehabilitation and the quality of life indicators in children with CNS tumors.

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