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Psychological-pedagogical aspects of treating children with mucoviscidosis

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The article is dedicated to optimization of psychological help rendering to children with mucoviscidosis. The authors emphasize the need in multidisciplinary approach to rehabilitation of such children and present results of a study of psychological peculiarities of children of 7–18 years of age with mucoviscidosis and formulate the main areas of psychological-pedagogical help in the process of rehabilitation. The children were divided into 2 groups according to physical and psychological condition: group 1 — stable condition, mild disease course and relatively good psychological condition (47.1%); group 2 — progressive aggravation of health, frequent exacerbations, low mood background and personality distortion (52.9%). The authors disclose content of psychological work with families and methods of optimizing social conditions at inpatient hospitals.

Key words: *mucoviscidosis, personality development, chronic disease, adolescents, primary school students, complex medical-social help.*

On the modern stage of pediatrics development, great progress was achieved by creation and introduction of innovative diagnostic methods, pharmacological therapy and expansion of a network of specialized complex medical social care centers for children with mucoviscidosis; one of the indicators thereof is significant increase in life duration of such children. That is why it is of the highest priority to develop new methods, technologies and means to reduce rate and severity degree of secondary social disease consequences (children's life activity restriction) [1, 2].

It is common knowledge, that, like any other severe hereditary disease, mucoviscidosis negatively affects the process of child's mental development, distorts social situation and lifestyle [3-6]. That is why, according to several trials, most (88%) pediatric patients develop psychoorganic syndrome along with a somatic pathology as they grow up; gradual social adaptation decline is observed in such children as well [7-9]. Complex approach to treatment of all diseases has been widely used in world practice in recent decades. Increasing attention has been given to the degree of the patient's mental status impact on course and outcome of the disease. Scientists agree that coordinated approach of a range of specialists (pulmonologist, pediatrician, nutritionist, gastroenterologist, neurologist and psychologist) is necessary in order to improve efficacy of rehabilitation (selection of forms and courses of rehabilitation therapy) [2-4, 10]. That is why modern rehabilitation measures for children with mucoviscidosis include psychological-pedagogical methods of working both with the children and their social environment. Combination of two approaches (therapeutic and psychological) provides complex medical-social-psychological support of such children and their families.

PATIENTS AND METHODS

In order to determine the primary spheres of medical-pedagogical care, we studied mental peculiarities of 17 7-18-year-old children with mucoviscidosis, who were undergoing treatment at the Scientific Center of Children's Health (Federal State Budgetary Institution). The standard examination of the patient's mental status involved clinical conversation and a set of projective techniques suited to age, physical capabilities and mental peculiarities of the child: "Draw a man", "Self-assessment ladder", "Color test of relations" by A.M. Etkind, test "Three wishes" for elementary school students, "Draw a person", Dembo-Rubinstein self-assessment analysis technique, "Incomplete sentences" for adolescents. Child's mental examination procedure involved 1-2 meetings with a child and his/her close relatives, conversation with a doctor and individual consultation for parents.

RESULTS AND DISCUSSION

The child's mental condition is most significantly affected by well-being level and disease course severity. The children were divided into two groups for convenience on the basis of physical and mental condition.

The first group was comprised of children and adolescents (47.1%) with stage I disease – initial manifestations of pathological bronchopulmonary system alterations (8 patients – 6 elementary school students and 2 adolescents). High emotional lability, communication difficulties, domination of non-constructive coping strategies (tendency to escape from problems) and tendency to reject the disease are revealed in patients of this group. Most children (elementary school students) are characterized by negative emotional condition in response to the severe life situation and situational treatment-associated difficulties (restriction of freedom of movement and communication with peers, fear of infecting other people, fear of painful procedures etc.). Lack of physical discomfort, complications and painful sensations often lead children consider vital need in observing medical prescriptions and treatment regimen external, adult-imposed; this results in low compliance, condition aggravation and development of disease complications. Another important factor impeding observation of medical prescriptions is non-constructive position of parents concerning their child's health and development (25%) – underestimation of preventive measures and low medical activity. Tendency to reject health differences and peculiarities of children with mucoviscidosis in comparison with their peers by many parents results in systematic setting of excessively high pedagogical and psychological requirements in view of the child's real capabilities; this affects the child's weakened nervous system negatively and causes overstress. Unworked severe emotional pain often arouses maternal desire to protect the child from psycho-traumatic information connected with unfavorable prognosis by creating a more optimistic vision of the future. This creates stressful environment in the family and prevents formation of trustful and sincere relationship between the parents and the child.

The second group was comprised of children (52.9%) with stage II disease characterized by significant pathological bronchopulmonary system alterations (9 patients – 2 elementary school students and 7 adolescents). Due to prolonged marked physical weakness and development of complications, we revealed such mental peculiarities in this group of children as low mood, strong health-concerning apprehension, conflict attitude to body ego, low self-assessment, marked self-accusation, emotional self-regulation difficulties and sensitive attitude to the future. All adolescents were extremely distressed about their disease. They had negative feelings connected with realization of life prospects and the need in reconciling with severe lifestyle and profession restrictions. The stress is the worst in those children, who had been convinced that recovery was possible and there were no health differences between them and the other children. They try not to notice the disease: they chase after school achievements, ignore their own wishes, interests and health peculiarities and do not notice how negatively it affects their mental and physical development and results in deep stress about social failures.

Analysis of the social situation children with mucoviscidosis find themselves in demonstrated its inhibition of satisfying basic mental and age needs. Unlike their healthy peers, children and

adolescents with severe chronic pathologies often have restrictions of personal communication with peers (as home education is indicated for most of them). Forced conditions of social deprivation complicate formation of communicative skills and reflection; this results in the development of secondary mental disorders – social adaptation decline and self-actualization development peculiarities. The need in systematic care rendered by adults and their emotional support forms strong, often pathological, child's attachment to parents; this impedes timely reorganization of interpersonal relation between the child and adult family members, often causes strain in relations with the closest relatives and friends and delays formation of the child's personality. Social circle narrowing, habit and ability to form interpersonal interaction only with the closest relatives and friends leads to the development of egocentric communicative position, high concentration on the child's fears and misgivings. This creates significant obstacles for maintaining friendly relationships with peers, high emotional stress and apprehension if communication with other children is imminent.

In the period of active sexual identity formation adolescents experience painful feelings due to not only appearance changes (as they induce painful feelings in all children of this age), but also specific physical differences from peers and objective disease manifestation (deformation of chest and maniphalanxes, chronic cough with abundant sputum, physical development delay etc.).

Prognosis uncertainty and high level of future-associated anxiety hinders setting of life goals, reduces the level of aspiration and increases passiveness of activity (e.g., withdrawal into fantasy).

Everything aforementioned indicates that the following is to be taken into primary consideration when organizing psychological-pedagogical care for children with mucoviscidosis: duration, severity and course pattern of the disease along with the child's mental characteristics, age-associated and individual mental needs.

It ought to be mentioned that a complex psychological-pedagogical examination involving diagnostics of cognitive sphere (resource teacher), speech (speech therapist) and personality (psychologist) development is required to reveal real causes of mental difficulties of school-aged children [10]. Individual psychological-pedagogical rehabilitation plans are developed and methodological help to parents is rendered on the basis of the mental and pedagogical difficulties revealed by the specialists.

The primary concerns of psychological-pedagogical care rendering to the first group children are emotional stress reduction, basic self-regulation skills teaching (teaching of autogenic training basics, relaxation and active imagination skills to children); self-actualization development activation (self-respect, confidence and reflection improvement); formation of constructive coping strategies, personal enrichment and help with overcoming educational difficulties. The most efficient form of work is group therapy. Group exercises help to improve children's behavioral repertoire, positive self-image, communicative competence (development of cooperative skills within a group of peers and emotional support of group members, observation of group norms etc.) and mental activity, induce positive emotions and feeling of acceptance. Through communication and joint leisure activity, children learn not only to give and receive emotional support, but also to find means of self-support, improve the ability to set and achieve goals, plan their future, determine life values and prospects, exercise their own choice and realize their emotional states and needs.

It is reasonable to conduct psychological work with children and adolescents with severe diseases in the form of trainings for both children and their parents. This form of communication allows not only expanding the family's social experience, but also reducing emotional stress in the relations between the child and adults, improving mutual understanding between communication partners and teaching constructive means of interaction to the participants. It ought to be understood that such trainings constitute one of the most important stages of the family psychotherapy indispensable for all families with severely ill children. Positive family atmosphere and the potential to realize all the age-associated and individual needs in the

situation of strict observation of medical regimen considerably improve the child's mental approach and life quality.

Early vocational guidance is especially important in order to improve mental state of adolescents with mucoviscidosis. It helps to work through and built personal life perspective, which is necessary to cope with stressful situations. Specialists reveal and analyze the person's strong and weak points, interests and social situation peculiarities. Possible professional options are selected together with the adolescent taking into consideration his/her individual capabilities, personal preferences and health condition. Content and areas of a vocational guidance counselor's work depend on the medical examination results and are in no way binding. After comparing medical and psychological-pedagogical examination results, the pediatrician discusses whether the selected profession is right for the adolescent with the adolescent and his/her parents together [1].

The second group children and adolescents need systematic individual mental support. Creation of comfortable environment in the family and hospital room, involvement in feasible creative and cognitive activity (e.g., drawing, modeling, construction, object and story games), harmonious emotional and efficient interaction both with adults and peers help to reduce the child's emotional stress, satisfy need in cognition and social activity and, thus, improve his/her physical and mental condition.

Psychological support of an ill child's mother is an important aspect of care rendering. In the situation of daily struggle for health condition improvement and extremely high responsibility for observation of the prescribed treatment, values of "pleasures of communicating with the child, observation of his/her development and social growth" shift towards the value of "the child's recovery or survival". The severely ill child's health improvement becomes a criterion of happiness both for parents and children themselves. In the situation of a progressing disease with possible complication, such an attitude makes children neurotic and exhausts their adaptive reserves. Family psychologists conduct individual trainings in order to structure and stabilize emotional condition of the closest relatives and friends, orientate families towards high social values, creativity, mutual assistance and a friendly relationship; this helps to improve the child's motivational-need sphere and his/her intrapersonal resources.

Thus, in order to prevent social conflict between an ill child's personality and his/her life conditions it is necessary to employ psychological-pedagogical care as one of the methods of recovering the patient's mental and physical health and optimizing social situation of his/her development.

It is necessary to take into account physical state, nature and severity of disease course along with the child's age-conditioned and individual needs when elaborating content of psychological-pedagogical care for all stages of treatment.

Only implementation of the complex approach to disease treatment may create conditions for harmonious child's personality formation and the child's intellectual potential realization and improve life quality of the child's family.

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