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**THE LONG-TERM PSYCHOLOGICAL OUTCOMES OF
CANCER THERAPY CONDUCTED IN CHILDREN**

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Abstract

The influence of antitumor treatment on the physical, mental and social functioning of a person is one of the important factors associated with overcoming the disease. Clinical remission in itself is not a sufficient condition for spontaneous rehabilitation of the person after the disease. This is particularly important in the context of normal or impaired ontogenesis. The social and psychological consequences of the treatment in the long-term period are largely determined by the physical condition of the person, the genetic consequences of the disease, social stigmatization, changes in the family functioning. As a result of the disease, the general motivational field of the child and the parent, their mutual dependence changed, the phasing of many stages of adulthood, including the stage of separation from parents, was violated. An original questionnaire was developed to assess different family restricts. The study involved 80 people – parents of previously ill children and 50 parents from the control group. 64% of parents from the group of patients (remission from 2 to 17 years) restrict them in the field of sports, 46% - in training loads, 40% - in homework. In the control group - the restrictions were at the level of 15-30%. This kind of restrictive behavior can lead to the development close symbiotic relationships, various forms of psychological dependence, and negative behavioral reactions in children.

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Keywords: Long-term outcomes, impaired ontogenesis, restrictive behavior.



1. Introduction

The impact of antitumor treatment on the physical, mental and social functioning of a person is one of the important problems associated with overcoming the disease. Antitumor treatment is burdened with side effects in the treatment process, associated with social stigma, has certain consequences. The study of such consequences at the stage of long-term outcomes is necessary to assess treatment strategy as a whole, the effectiveness of the recovery period.

Of particular importance the study takes in the context of the normal or impaired ontogenesis. As Vygotsky emphasized, it is not the physical defect itself that is important, but the fact that this defect prevents the child from mastering the culture, the social experience of mankind, because culture, in his opinion, is adapted to a normal, typical person (as cited in Leontiev, 1990). Acute or chronic childhood disease can affect the normal ontogenesis to change the entire social situation of human development (Nikolayeva, 1987). Social and psychological functioning in the remote period is largely determined by the physical condition of the person, the genetic consequences of the disease, social stigma associated with the disease, changed relationships in the family (Nesterova, Khrushchev, Vybornykh, & Tkhostov, 2017).

The features of functioning in the sphere of both physical and mental health were revealed in the former patients. So, after the treatment for the most common solid tumors of childhood (nephroblastoma, neuroblastoma, rhabdomyosarcoma), a number of authors noted the lag in the physical development of girls and women, characterized by the predominance of infantile morphotype. In 23.3% of cases in the long-term period were found malformations and inflammatory diseases associated with getting into the zone of direct and scattered irradiation during the treatment of certain organs: Hypo- and aplasia of the mammary glands, pyelonephritis, gastritis, colitis, cystitis, etc. (Nelyubina, 1984).

In many patients, regardless of the methods of anticancer therapy, neurological examination revealed significant changes in the bioelectric activity of the brain, indicating violations of the functional state of the cortical and subcortical (mainly diencephalic) zones. The analysis carried out in patients undergoing in children treated for acute lymphoblastic leukemia (ALL), with integrated chemo-radiation prophylaxis of CNS leukemia showed diffuse and local pathology in 73, 3% of patients. Children with non-complicated premorbid history after 5-14 years after completion of chemo-radiation for the prevention of neuroleukemia in 59.2% of cases were diagnosed with the syndrome of encephalopathy with CSF hypertension 3.6% - encephalopathy syndrome with asthenic condition and only 10.2% of cases in children were not observed neurological disorders (Vilchevskaya et al., 1991).

The presence of transient, and in some cases permanent disorders, such as growth hormone deficiency, altered structure of the vertebrae, cardiac changes, calcification in the brain, etc. makes the problem of the disease noticeable even in the remote stages of catamnesis.

Another factor complicating social functioning was a factor in the genetic history of individuals who have undergone anticancer treatment. The question of the reproductive function of one of the parents, as well as the probability of transmission of the risk of the disease to future children, required an assessment of the medical and genetic status. Of particular importance in the context of the study of normal or impaired ontogenesis is the stigmatization of the disease. The diagnosis in many cases was

considered by patients as an existential threat, often caused a special attitude on the part of society to sick children.

Experiences that can give the situation the meaning of the existential crisis in children were associated with the position of the immediate social environment, in particular parents. During treatment in the hospital, the mother was in close proximity to the child. At this time, she found great support from other parents, whose children were also on treatment. A community of parents supporting each other is being formed.

Severe stress or a severe, traumatic event can be accompanied by mental disorders (depression, anxiety disorder). After some time, the psyche of a person who has suffered traumatic stress can adapt, and then the person continues to live a normal life. There is also a third way out of mental disorders associated with severe stress; it is personal growth (Tedeschi & Calhoun, 2004).

The reaction to a traumatic event can be accompanied by a special restrictive behavior, which is set by the nearest social environment (Nesterova, Khrushchev, Vybornykh, Emelin, & Tkhostov, 2018). A set of poorly understood self-limiting beliefs can significantly impoverish a person's life. Some authors consider such a system of self-limiting cognitive behavior as a cognitive cell (Tedeschi & Calhoun, 2004).

The process of personality development after a traumatic event occurs during the cognitive and emotional processing of the event. The main external factor of post-traumatic personal growth is the presence of high-quality social support, the ability to put everything experienced in words, to look at the past from the outside, "from a safe place", to discuss in a circle of people who have suffered the same or similar event. It is important not only the ability to understand emotions, but also their pronunciation, reaction, especially in the group. This study reduces the intensity of experiences and minimizes the characteristic of the acute period of psychological trauma mental processes: constant "chewing" of what happened, unproductive fantasy. Obsessive monotonous thoughts about the event are replaced by deeper thoughts, there is an analysis of facts and experiences, thoughts acquire the character of reflexive reflections. The experience is gradually integrated into the life experience, becoming a part of the personal history (Tedeschi & Calhoun, 2004).

The role of the social environment in the disturbed ontogenesis is especially important, since the resources of the individual are not yet sufficient. The interaction of the child with the social environment is limited, and the main system of relations remains the "child – mother" dyad.

2. Problem Statement

The problem with the study was to investigate somatopsychic disorders in the long-term period after the treatment, especially functioning in the psychological and social spheres. Our assumption it was that numerous physical dysfunctions, the risk of genetic inheritance, especially the stigmatization of the disease, as well as violation the functioning of the family can lead to a distortion of the process of ontogenesis.

3. Research Questions

In this study, we tried to assess how the situation of an existential crisis, what is the situation of cancer, influenced the normal development of the child: violated ontogenesis, prevented its normal formation, left it without any changes, or contributed to post-traumatic growth. Post-traumatic growth was understood as a situation when a former patient after the crisis showed signs of compensation or overcompensation of the existing defect. Thus, it was necessary to assess how well-being, behavior, some psychological characteristics (physical and psychological functioning), social functioning of former patients changed in comparison with normal ontogenesis.

4. Purpose of the Study

The aim of this work was to study the features of psychological and social functioning of persons in the remote period after childhood antitumor treatment. Motivational sphere was studied through the study of the definition of the hierarchical structure of self-esteem. Compare the obtained data with the results in the control group.

5. Research Methods

To solve these problems, an empirical study was conducted, which involved former patients (50 people) who were treated for cancer in childhood and are in long-term remission from 2 to 17 years. The age of the subjects ranged from 16 to 25 years. Research methods: clinical conversation, a specially designed questionnaire, a modified version of the method of studying self-assessment Dembo – Rubinstein.

In a clinical conversation, the history of the child, the peculiarities of its development, the family situation at the time of the onset of the disease, as well as after treatment were studied. We also studied the problems of family functioning – material support, cohesion or disintegration of the family, the interaction of the child with peers, the presence of a special relationship to the child and the family on the part of society. Separately studied the question of what the child knows about his diagnosis. Parents could make additional remarks in the questionnaire concerning behavior of the child. With the help of the questionnaire, 80 people were examined.

The hierarchical structure of self-assessment was studied by its factor structure. As a material, a set of scales was used to complement the self-assessment measurement technique of Dembo - Rubinstein (34 scales in total). The choice of scales was based on the equalization of the number of characteristics related to external moments, and, as is commonly believed, independent of the person (beauty, luck), and internal, controlled (activity, restraint, etc.). Upon completion of the first form the subject received the same form and the task to evaluate themselves in a similar way, but how he sees himself in the future, after 5 years.

6. Findings

Almost all parents noted the financial difficulties that accompanied their lives. One of the parents, as a rule, had to give up work in order to take care of a sick child; the other had to take care of the financial situation of the family. This approach could be maintained in the long term after treatment. If the

child was brought up by one of the parents, the whole burden of care fell only on him. During the treatment of the child, as a rule, there was a family cohesion. The whole life of the family obeyed his interests. In the future, families could break up, but not more often than the average in society. In many families the decision on the second child was made.

The relationship with society in these families was determined by the system of restrictions imposed by parents on the child. Through the system of restrictions parents influenced the motivational sphere of the child. It was possible to trace that became the main thing in life of the child and in what he practically did not participate. The main limitation was related to sports games and physical activity – 64%, training loads – 46%, homework 40%. Restriction of communication with other children was 4%, cultural leisure – 3%.

The relationship with society in these families was determined by the system of restrictions imposed by parents on the child. Through the system of restrictions parents influenced the motivational sphere of the child. It was possible to trace that became the main thing in life of the child and in what he practically did not participate. The main limitation was related to sports games and physical activity – 64%, training loads – 46%, homework 40%. Thus, according to the family, communication with other children was for the child useful and desirable, as well as cultural leisure. This would compensate for the "gentle" behavior towards the child about other activities. In the control group, the restriction in communication and cultural leisure was 12%. On the question of whether the behavior of the child has changed after the disease, the affirmative answer was at 70% of parents. Of these, 50% claimed that the behavior changed immediately after treatment. The question of difficulties in communicating with children was pointed out by 30% of respondents. The main features in the behavior that parents noted are weakness and irritability (50%). When explaining the reasons said: "Limited and cherished unnecessarily after the disease." In another questionnaire, which also almost all questions relating to restrictions, was given an affirmative answer, the parents wrote about their child (15 years old): "Is irritability, rage, intolerance to everything and to all, a rejection of the world and healthy people". In the same questionnaire it was said that the child was shocked when he learned about his diagnosis, as before he did not remember what disease he was treated for. Thus, there was a variety of parents' responses in the distribution of negative and positive assessments. This indicated the ambiguity of the influence of the treatment on the formation of behavior in the long term.

During the treatment period, parents of sick children actively formed parent communities, a special environment based on mutual support and assistance. The environment helped to cope emotionally with the difficulties, to work out the typical questions that arise in parents: "Why does this disease occur in children? Maybe it's a punishment for something? «After the end of treatment, the parents did not maintain close contact with each other. At the remote stages of treatment, during the long-term remission, the parents isolated the child from communication with those children with whom he was treated. This was to protect children from possible unpleasant news related to the deterioration of other children. Thus, they deprived themselves of communication with other parents with similar psychological and social problems. Ours the study was a case where the parents changed their place of residence in order that no one knew about what the child was sick.

Sometimes, to avoid stigmatization, parents did not encourage conversations with the child about the diagnosis, reducing the explanation to the fact that it was just a serious disease. When the child entered into marriage, the parents said that, most likely, they would not inform the future spouse (45%) about the fact of the disease.

In the study of the factor structure of actual self-assessment, the largest factor (14% contribution to the total variance) in the group of subjects (women) was the factor of "health-ability to work". The second most important factor (11.2% of the contribution to the overall variance) was the "difficulties in controlling emotional stability". In the control group (women) the most significant factor (13.2% of the contribution to the total variance) was the factor of "material well-being", the second most important factor (12.7% of the contribution to the total variance) was the factor of "internal well-being associated with adaptability".

In the prospective self-assessment in the group of subjects, the largest factor (14.3% of the contribution to the overall variance) in women was the factor of "material and emotional well-being". The second most important factor (11.4% of the contribution to the overall variance) is the "health-well-being" factor. In the control group in the prospective self-assessment of women, the leading factor (11.8% contribution to the overall variance) was the factor of "health - well-being". The second factor (11.7% of the contribution to the total variance) is the factor of "loss of vital activity".

In the actual self-assessment in the group of subjects (men) the leading factor (14.9% contribution to the overall variance) was the factor of "activity-ability to work". The second factor (10.8% of the contribution to the overall variance) in men's actual self-esteem was the "ability – will" factor. In the current self-assessment in the control group of men, the leading factor (13.9% of the contribution to the overall variance) was the factor of "independence-independence". The second leading factor (13.3% of the contribution to the overall variance) in the control group of men was the factor of "poor health". In the prospective self-assessment in the group of subjects (men) the leading factor (14.8% contribution to the total variance) was the factor of "independence-independence", the second factor (10.9% contribution to the total variance) – "confidence – adaptability".

In the prospective self-assessment in the control group of men, the leading factor (14.9% contribution to the total variance) was the factor of "activity-health", the second factor (12.4% contribution to the total variance) – "aggressiveness-irritability".

7. Conclusion

The family, which has a child, previously treated for antitumor disease, had significant difficulties in its functioning. The disease suffered in childhood had long-term consequences and affected the quality of life of the family. As a result of the disease, the general motivational field of the child and the parent, their mutual dependence changed, the phasing of many stages of adulthood, including the stage of separation from parents, was violated. Interdependence was realized through a system of restrictive behavior, when the child was excluded from participation in some areas of activity characteristic of normal ontogenesis.

Self-esteem, as one of the most generalized formations, combining cognitive, motivational and emotional component of personal organization, reflected a diverse restructuring in the personal structure

of the individual. The perception of themselves in the present and the future differed in the test group and the control group. First, these changes concerned the content of the leading factors of self-assessment, leaving the structure of self-assessment undisturbed. This suggests that the change in the motivational sphere was not pathological. The content of the leading factors of self-assessment differed in the group of men and women. The most significant factor in the actual self-assessment in the group of women was the factor of health, and in the control group the factor of material well-being. In prospective self-assessment in the group of subjects the leading factor was the material and emotional well-being, in the control group – the health factor. In the group of male subjects in the current self-assessment is dominated by the factor of activity-ability to work, and in the control group – independence-independence. In the prospective self-assessment in the group of tested men the leading factor was independence-independence, in the control group of activity-health. Thus, self-esteem in the two groups was like a "mirror". Mirroring of the leading factors of self-assessment was also noted in the group of men. In formulating a vision of the future, former patients projected the best expectations into it. The very fact of such a future was the highest value for them.

Healthy subjects are more confident in the ability to control their health. In the group of male subjects, two factors related to self-realization were present in the actual self-assessment. However, in the group of male subjects less confident in the ability to control their health.

There are two main areas of restriction on the part of parents and relatives in relation to former patients: sports, exercise and educational and domestic activities. Close symbiotic relationships during the disease and its treatment persist after clinical remission, which leads to various forms of psychological dependence. High frequency of restrictions can cause negative behavioral reactions in children.

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