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## Health and Social Aspects of the Life Quality of Children with Chronic Gastroduodenal Pathology in Yakutsk

### ABSTRACT

This work reviews aspects and the research tools and the quality of life of children with chronic gastroduodenal pathology.

Quality of life is one of the new criteria for evaluating the effectiveness of medical care that have been widely used in countries with high levels of medicine. The quality of life is considered as an integral characteristic, which should be guided in evaluating the effectiveness of rehabilitation of sick and disabled people. The accumulated experience of studying the quality of life shows that this method is very promising for all branches of medicine. The study of quality of life in medicine allowed to return at a new stage in the evolution of the most important principle of clinical practice "does not treat the disease, but the patient".

To study the quality of life in children with chronic gastroduodenal pathology it can be used special questionnaires: GSRS, QLDUP, QOLRAD, IBS-QOL, IBDQ; and also - general questionnaire - CHQ-Child Health Questionnaire, PedsQL - general version. The quality of life of children with chronic gastroduodenal pathology may vary depending on age, sex, stage of disease, the presence or absence of complications, the degree of social well-being of the family and psychological factors. Assessment of the quality of life of children with chronic gastroduodenal pathology has significant potential for application not only in clinical trials and clinical practice, but also in the field of public health and health care.

**Keywords:** quality of life, gastroduodenal pathology, medical and social aspects.

### INTRODUCTION

Today, much attention has been paid to the quality of human life in our country. The concept of quality of life assessment in medicine is declared as a priority. The President of the Russian Federation Vladimir Putin declared that "improving the quality of life of Russian citizens should be a priority for the long term." It is an important new scientific and practical direction of interdisciplinary research in pediatrics. The concept of quality of life research in Russia is primarily based on the main components of the definition of health. The World Health Organization (WHO) provides an effective model for integrated assessment of the human condition with the versatile and deep understanding of the impact of the disease on its physical, psychological, emotional and social functioning. Quality of life is seen as a multidimensional, complex structure, including the perception of the individual's physical and psychological condition, their level of independence, their relationships with others, and personal beliefs and their relationship to the significant characteristics of its environment. WHO has established the basic criteria of quality of life and physical (power, energy, fatigue, pain, discomfort, sleep, rest), and psychological (positive feelings, thinking, learning, concentration, self-esteem, appearance, emotions), the level of independence (everyday activity, performance, dependence on drugs and treatment), social life (personal relationships, social value of the subject, sexual activity), the environment (way of life, well-being, safety, accessibility and quality of health and social care, security, environment, training opportunities, the availability of information); spirituality (religion, personal beliefs).

Over the past 5 years, the overall incidence of children of all ages in Russia increased annually by 6.5%. The health of children of teenage age is alarming, 70% of them have chronic pathology, socially constructed and socially significant diseases. The pathology of the digestive system is one of the priority diseases of the internal organs and, as indicated in the literature,



does not tend to decrease. According to Baranova A.A. (2010), in recent decades, the prevalence of digestive diseases among teenagers of 15 to 17 years increased by 1.8 times, amounting to an average of 300 - 400 %.

In the literature there are the works of assessing the quality of children's life with celiac disease, bronchial asthma and frequently ill children of our republic with the help of international questionnaires, but the study of quality of life of children with chronic gastroduodenal pathology wasn't conducted. The knowledge of this index will allow a comprehensive approach to assessing the health of the child, his satisfaction with various aspects of their lives, the degree of adaptation, effectiveness of treatment and rehabilitation measures, and also it will serve as a prognostic factor. However, in order to obtain reliable data on the parameters of quality of life, methodology must be observed. Significant contribution to the development of methodology contributed experts of Multinational Research Center of the Quality of Life in St. Petersburg.

At the end of the twentieth century, the term of "health related quality of life, HRQL" appeared. It allows to define precisely the medical aspects of this concept from the variety of aspects of human life. Health related quality of life describes how the physical, emotional and social well-being of the patient is influenced by the disease or its treatment. The most comprehensive definition that reflects the essence of the concept was given by experts of Multinational Research Center of the Quality of Life in St. Petersburg: health related quality of life is an integral characteristic of the physical, psychological, emotional and social functioning of healthy or sick person, based on his subjective perception.

A significant contribution to the development and introduction of a methodology for assessing the quality of life of children have Feeny D. (Canada), Landgrave J. (USA), Varni J. (USA), Bullinger M. (Germany), Kind P. (UK). There are more than three thousand foreign publications, devoted to the study of the quality of life. This method is currently used in various fields of pediatrics in the USA, Canada, UK, France, Germany, Italy, Japan, as part of programs coordinated by the International Society for the Study of quality of life.

The basis of the study of the quality of life for both children and adults is based on three main features: multi-component, variability in time and part of the respondent (the child or parents) in the assessment.

*Multicomponent feature.* The quality of a child's life reflects the following aspects of his life: physical (physical activity, mobility, experience, independence in everyday life, physical role), psychological (emotional background, psychological problems, cognitive ability), social (relationships with peers, parents, social role, self-esteem). The components of quality of life in children differ from those of adults, reflecting thus the physiological, psychological, intellectual, social, and other age-related features. Studies have shown that the basic meaning for the child has the following aspects of life: games, the level of welfare of the family, friends, self-esteem, lack or presence of pain, sickness, and hunger. Changing the name of these factors entails, as a rule, changes in the level of quality of life. Schooling for children is an important indicator of social and physical activity. As for adults, the same indexes are professional activities, work, behavior in society.

*The variability in time.* Quality of life time varies depending on his state of health due to various external and internal factors. On the basis of data on the quality of life implementation of long-term monitoring and conducting therapy correction are possible.

Participation in the *assessment of life quality* is carried out by both the child and his parents. An interesting fact is a presence of disagreement between children and parents in assessing the quality of life of children, the so-called proxy-problem, and cross-informant variance is a phenomenon described in detail in the literature. The question of who should evaluate the quality of a child's life is still open. Children are able to adequately represent his personal opinion in regard to their own health after 5 years. Therefore, up to 5 years child's quality of life is assessed by parents and after 5 years old both parents and the children take part



in assessment. The subjective perception of a person plays an important role, because such an assessment is very sensitive and informative. The level of quality of life of the patient, along with the traditional medical opinion can create a complete and objective picture of the disease. Depending on the patient's pathology it can be solved various problems during treatment. The quality of life of the patient can be either a major or additional aim.

Assessment of the quality of life in medicine should be conducted differentially, taking into account the so-called theory of motivation by Maslow A.H., 1970. According to this theory there are vital human needs of different levels, from basic physiological (breathing, eating, relief from pain, sleep) to the needs of high-level (self-esteem, self-actualization). In this case, the more serious the illness, the greater the basic human physiological needs, while the needs of high-level affected a little.

Among the research tools of quality of life, questionnaires filled out by patients are commonly accepted and distributed. Single, universal tool for measuring the quality of life does not exist. At present there are about 400 questionnaires, each researcher selects the most appropriate, based on the goals and objectives of their work. It is important to consider the psychometric properties of the questionnaire, with the help of which they study of quality of life. They are:

- reliability - the ability to give consistent and accurate measurements;
- validity - the ability to reliably measure precisely the characteristic that it laid;
- sensitivity - the ability to produce significant changes in quality of life scores in accordance with changes in the respondent.

Quality of life is one of the new criteria for evaluating the effectiveness of medical care that have been widely used in countries with high levels of medicine. The quality of life is considered as an integral characteristic, which should be guided in evaluating the effectiveness of rehabilitation of sick and disabled people. The accumulated experience of studying the quality of life shows that this method is very promising for all branches of medicine. The study of quality of life in medicine allowed to return at a new stage in the evolution of the most important principle of clinical practice "does not treat the disease, but the patient."

To assess the quality of life of children it was developed a series of questionnaires. Currently, the most commonly used, which have high psychometric qualities and meet the international standards for quality of life assessment tools are the following: Pediatric quality of life questionnaire-PedsQL, Varni JW, 1998. Shild health questionnaire-CHO, Landgraf J.E. et al., 1999. German generic quality of life instrument for children-KINDL, Bullinger M. et al., 1998. In addition, there are other common questionnaires for quality of life of children TACQOL, CHIP-AE, CHIP-CE, QUALIN, FSIIR etc. As noted above, there are specific questionnaires designed for a nosological form. They are narrow, but more sensitive to minimal changes in clinical state of health of children of these groups. From the presented survey questionnaires we can see that a single, universal tool for measuring, both general and specific quality of life of children does not exist, each researcher selects the most appropriate, based on the goals and objectives of their work.

Fields of application the method of assessing the quality of life of children is quite broad. These include: - population studies and monitoring of children's health in identifying risk groups; - evaluation of the combined effect of the disease on the child's life; - monitoring the patient's condition and prognosis of the disease definition; - evaluation of the effectiveness of new drugs, treatment, rehabilitation and prevention programs; - standardization of treatment methods; - evaluation of the effectiveness of programs and reforms in health care; - health economics.

From the position of social health it is particularly important that the study of quality of life is universal and highly informative tool for determining the effectiveness of the health care system, providing complete an objective assessment on the level of the main consumer-patient. It



is possible to assess patient satisfaction, as a recipient of health care services, quality of care from the perspective of both social and physical and mental functioning of the patient.

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The study of quality of life is a simple, reliable and effective tool to assess the patient's condition before treatment, during treatment, a period of rehabilitation. Quality of life allows the monitoring of the disease and improves treatment outcomes. A well-designed methodology helps to ensure a reliable data on the parameters of quality of life of the patient. The results of studies of quality of life, received international and domestic experts, demonstrate great potential of the method in research and clinical practice.

Own experience of the research quality of life of children and teenagers with chronic gastroduodenal pathology with the help of the international PedsQL questionnaire showed that it is possible to identify the factors that influence its component parts and to examine the causes of handicaps and disabilities. The advantage of PedsQL questionnaire are speed filling – only 5 minutes and the accuracy of measuring the components of quality of life, reliability and comparability of the data. It is important that this option is possible to trace the dynamics of the assessment carried out rehabilitation.

This method opens up new possibilities for improving health and social care for children with chronic gastroduodenal pathology. Together with the standard clinical examination techniques it enables a comprehensive assessment of Child Health. It allows carrying out corrective actions on the part of health and social services. This method is recommended for pediatricians and gastroenterologists who deal with this category of patients. In addition, the international general questionnaire PedsQL-module can be used to evaluate the quality of life of healthy children and patients with various other conditions.

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