

Trying to assess the quality of life of families of parenterally fed children

(Próba oceny jakości życia rodzin dzieci żywionych pozajelitowo)

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Abstract – Introduction. Parenteral nutrition is a method of nutrition which involves the introduction of nutrients in their simplest form into the bloodstream without the digestive system. In the case of children in Poland, it has been used successfully for over 30 years.

Aim of the study. To assess the quality of life of families of children fed parenterally.

Materials and methods. The group of the examined persons consisted of 56 people, who were parents/guardians of a child fed parenterally. The mean age was 35.13 (± 7.79) in mothers/guardians and 38.41 (± 7.57) in fathers/guardians. The research was carried out by means of a diagnostic survey, using the author's questionnaire.

Results. The parenteral nutrition of 3/4 of the group was conducted at home for several years. It was found that parenteral nutrition of a child significantly affects the functioning of the whole family (94.64%). The health situation in many cases forced one parent to resign from professional work (69.64%), reduced social contacts (48.21%), reduced holiday and holiday trips (80.36%). The leading cause of these changes was the need to adapt to the nutritional cycle of the child (85.71%). In the opinion of 35.71%, parenteral nutrition of a child burdened the family budget to a large extent, while in half of the respondents only slightly (55.36%).

Conclusions. The parental nutrition of a child is a difficult task for parents, requiring from them strength and commitment to daily care activities. The need to adapt to the nutritional cycle disrupts the daily life of the family and often leads to the need for one parent to give up his or her professional career. The situation related to the parenteral nutrition of the child involves a financial burden on the family. Parental nutrition is a challenge for parents of children of all ages, with full and incomplete families, living in the countryside and in the city.

Key words - parenteral nutrition, children, home conditions, surveys.

Streszczenie – Żywienie pozajelitowe jest metodą żywienia, która polega na wprowadzeniu substancji odżywczych w najprostszej postaci do krwiobiegu z pominięciem układu pokarmowego. W

przypadku dzieci w Polsce jest ona stosowana z powodzeniem od ponad 30 lat.

Cel pracy. Ocena jakości życia rodzin dzieci żywionych pozajelitowo.

Materiały i metody. Grupę badanych stanowiło 56 osób, będących rodzicem/opiekunem dziecka żywionego pozajelitowo. Średnia wieku badanych wynosiła: u matek/opiekunek 35,13 ($\pm 7,79$), a u ojców/opiekunów 38,41 ($\pm 7,57$). Badania przeprowadzono drogą sondażu diagnostycznego, metodą ankietowania z wykorzystaniem kwestionariusza autorskiej ankiety.

Wyniki. Żywienie pozajelitowe 3/4 grupy prowadziło w warunkach domowych przez kilka lat. Stwierdzono, że żywienie parenteralne dziecka znacząco wpływa na funkcjonowanie całej rodziny (94,64%). Zaistniała sytuacja zdrowotna w wielu przypadkach wymusiła rezygnację jednego z rodziców z pracy zawodowej (69,64%), ograniczenie kontaktów towarzyskich (48,21%), ograniczenie wyjazdów wakacyjnych i urlopowych (80,36%). Wiodącą przyczyną tych zmian była konieczność dostosowania się do cyklu żywieniowego dziecka (85,71%). W opinii 35,71% żywienie pozajelitowe dziecka w dużym stopniu obciążało budżet rodziny, gdy u połowy badanych tylko nieznacznie (55,36%).

Wnioski. Żywienie pozajelitowe dziecka jest dla rodziców trudnym zadaniem, wymagającym od nich siły i zaangażowania w codzienne czynności pielęgnacyjne. Konieczność dostosowania się do cyklu żywieniowego dezorganizuje życie codzienne rodziny i często prowadzi do konieczności rezygnacji jednego z rodziców z pracy zawodowej. Sytuacja związana z żywieniem pozajelitowym dziecka wiąże się z obciążeniem finansowym rodziny. Żywienie pozajelitowe jest wyzwaniem dla rodziców dzieci w każdym wieku, mających rodziny pełne i niepełne, mieszkające na wsi i w mieście.

Słowa kluczowe – żywienie pozajelitowe, dzieci, warunki domowe, badania ankietowe.

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I. INTRODUCTION

One of the fundamental rights of the child is the right to a happy and joyful childhood. However, it sometimes happens that this period of development is not free from unforeseen and often very sad and difficult circumstances. The life situation of a healthy, loved and desired child and its immediate family can change dramatically if an unexpected obstacle arises. This is a chronic illness of a child - suddenly appearing or accompanying it from the day of its birth - and the need for its long-term treatment and hospitalization. Diseases of this type most often have a huge impact on the functioning of the whole family. To a large extent, they disrupt the normal rhythm of its functioning and adversely affect its material and economic situation. They also have a very significant impact on the mental and physical condition of the family [1-8].

The aim of the study was to assess the influence of parenteral nutrition on the quality of life of families of children affected by chronic disease.

II. MATERIALS AND METHODS

Material

The study covered 56 families of children fed parenterally at home. The research was carried out from November 2019 to March 2020 in the Clinic of Paediatrics, Mental Nutrition and Metabolic Diseases and the Outpatient Nutrition Clinic of the Children's Health Centre in Warsaw-Międzylesie. The basic criterion for selection for the study was to raise the child fed parenterally at home and agree to participate in the study.

Characteristics of the test group:

The age structure of the examined children was as follows: up to 1 year old 10.72%, from 1 to 6 years old 44.64% and from 7 to 15 years old 44.64%.

The period of feeding a child at home was determined by the respondents to be 1.79% for several weeks, 23.21% for several months and 75% for several years.

In the study group, a child was ill from birth in 85.71% of cases, in the first year of life 8.93% of children fell ill, and between 2 and 10 years of age 5.36%.

Number of people trained in central access and infusion pump: mother 66.07%, mother and father 32.14%, more people 1.79%.

The preparation time for parenteral nutrition at home was as follows: about 2 weeks 39.29%, about 3 weeks 32.14% and about one month 28.57%.

Family structure: full 83.93%, incomplete 12.50%, foster 1.79% and adoptive 1.79%.

The mean age of the subjects was 35.13 (± 7.79) in mothers and 38.41 (± 7.57) in fathers.

The age structure of the group was as follows: up to 30 years old mother 26.79%, father 16.07%; 31-35 years old mother 25.00%, father 19.64%; 36-40 years old mother 28.57%, father 26.79%, and over 40 years old mother 19.64% and father 37.50%.

The level of education of the respondents was as follows: mother's primary education 5.36%, professional 10.71%, secondary 42.86%, higher 41.07%.

Father's primary education 7.14%, professional 30.36%, secondary education 33.93%, higher education 28.57%.

In the surveyed group the inhabitants of rural areas accounted for 42.86%, while the inhabitants of towns up to 50,000 inhabitants 35.71%, while the inhabitants of towns over 50,000 inhabitants 21.4%.

In the surveyed group, the sick child had siblings in 57.14% of cases, while in 42.86% it was without siblings.

Professional activity: mothers - 28.57% of the respondents worked, the adequacy of the employed was 71.43%, the father - 92.86% of the respondents worked, not 7.14%.

Methods

In this work, the diagnostic survey method was used. A questionnaire was used as a research technique, while the research tool was a self-research questionnaire. The questionnaire consisted of a label and closed and open questions with multiple choice of answers. The respondents were informed in writing about the purpose of the study. The Bioethics Committee of Collegium Masoviense - Żyrardów University of Health Sciences agreed to conduct the survey.

Statistical elaboration

Statistical analysis was carried out using STATISTICA version 7.0 software by StatSoft Polska. The following methods of quantitative data analysis were used for the analysis of the conducted research:

- the differences between the compared groups were assessed on the basis of the significance test for qualitative (categorizable) variables - chi-quadratic statistics;
- the Pearson correlation coefficient $r(X,Y)$ was also used (a chi-quadrante-based measure of the relationship between categorised variables indicates the strength of the relationship);
- the results meeting the condition $p < 0.05$ were considered statistically significant.

III. RESULTS

The respondents determined whether a parenteral feeding catheter causes limitations in the child's daily functioning. Less physical activity was observed in 51.79% of children, decreased number of contacts with peers in 41.07%, whereas in 30.56% parenteral nutrition does not cause limitations in everyday functioning.

In the opinion of the respondents, there were changes in the functioning of the family due to the child's disease. These included: resignation of one parent from professional work in 69.64% of cases, reduction of social contacts in 48.21% of respondents, reduction of holiday and holiday trips in 80.36% of respondents. In 5.36% of the respondents, the child's illness did not disturb the functioning of the family.

During the child's stay in hospital, the respondents determined that there was a need to care for the child of the mother or another family member in 92.86% of cases.

Childcare and demanding medical activities took 30 minutes per day according to 26.79% of the respondents, 44.64% of the respondents and more than an hour according to 28.57% of the parents.

The respondents considered their material situation and assessed it mainly as average 51.79%, good 37.50%, very good 5.36%, and poor 5.36%.

The respondents assessed the child's conditions for play and rest as good in 57.14% of cases, as average in 25.00% and as very good in 17.86%.

The need to adapt the flat to the needs of the child, which consisted in changing the furniture, was indicated by 53.57% of the respondents, while renovation - 33.93%, changing the flat to a larger one - 12.50%, while 32.14% of the respondents did not undertake any adaptation measures of the place of residence.

The respondents stated that due to parenteral nutrition of a child, 35.71% of them experienced a very heavy burden on the family budget, while a further 55.36% experienced a slight burden, and 8.93% of them said that the child's illness did not affect the family budget.

In 66.07% of cases, the surveyed parents used the family's help to care for a sick child, however, another 33.93% of respondents managed to care for the sick child by themselves.

In 58.93% of cases, respondents expected financial assistance from state institutions, in 16.07% - legal assistance, while 30.36% of respondents did not expect any form of assistance.

The attitude they adopted towards a child's illness in 64.29% of cases expressed the desire and need to do everything possible for the child to recover. 28.57% of respondents as the main motto had the need to survive and the belief that everything would be alright, while 5.36% of respondents rather doubted their strength and abilities, doubting whether they could manage.

When asked if they had come to terms with a child's illness, 39.29% answered *strongly in the affirmative*, 41.07% were of the opinion that *they rather did*, but 12.50% did *not come to terms* with the situation, and 7.14% stressed that they would *never come to terms* with it.

In the studied group 94.64% of the respondents did not hide information about the child's illness from family, neighbours or friends.

The system of rewarding and punishing was used by 53.57% of respondents for their sick child, the rewarding

itself was used by 25.00% of respondents, while 21.43% did not use such an educational system.

A child in a family home has its duties consisting mainly of cleaning (in the opinion of 16.07% of the respondents), cleaning toys (in the opinion of 12.50% of the respondents), cleaning the room (in the opinion of 5.36% of the respondents), helping at home (in the opinion of 3.57%), feeding the dog (in the opinion of 1.79%), feeding animals (in the opinion of 1.79%), taking care of order (in the opinion of 1.79%). On the other hand, 21.43% of respondents stated that a child has no household duties, when he or she is too small (21.43% of the opinion), is disabled (7.14% of the opinion), is ill (1.79% of the opinion), gets tired quickly (1.79% of the opinion).

According to the parents surveyed, 39.29% of their child maintained contact with their peers, 5.36% of the respondents stated that their child was too young for the reason of lack of contact. The main reason for lack of peer contacts was in 1.79% of cases lack of acceptance by peers, in 1.79% - reduced immunity, in 1.79% - problems with relations, communication, in 1.79% - fear of infection, in 1.79% - lack of colleagues, in 1.79% - fear of infection and in 1.79% - lack of immunity.

In the opinion of 10.71% of the respondents, parenteral nutrition did not cause them any concern, while 87.50% of them believe that there is a risk of sepsis or catheter infection. Fear about the child's life prospects was expressed by 37.50% of the respondents, concern about their own skills 7.14% and concern about the technical condition of equipment 12.50%.

The source of information about a child's illness for the respondents in 96.43% of cases was the attending physician, in 50% of cases the parents of other sick children, for 44.64% the main source of information was nurses and for 41.07% of the Internet.

The degree of satisfaction with the cooperation with the attending physician was considered *satisfactory* by 92.86% of the respondents, but 7.14% were of the opposite opinion.

According to 82.14% of the respondents, when contacting medical personnel, they met with the right treatment, appropriate to their ideas. The opposite opinion was expressed by 17.86% of respondents.

64.29% of the respondents stressed that in the case of problems arising from parenteral nutrition at home, they used the help of local health care institutions, sporadically 19.64% of the respondents, while 16.07% of the respondents did not use such help from the nearest health care institution.

According to 46.43% of the health care institutions surveyed indicate *good knowledge of family problems*, in the opinion of 42.86% it is only insufficient knowledge.

IV. DISCUSSION

Parenteral nutrition is a generally available and recognised method of nutritional treatment for adults and children where gastrointestinal feeding is not possible, insufficient or contraindicated. Intravenous administration of ingredients allows the supply of nutrients without the intestines and portal circulation. Properly composed parenteral nutrition provides all necessary nutrients - protein, energy, electrolytes, vitamins, trace elements and water [9-12].

The idea of parenteral supply of medicinal substances was born as early as the 17th century, but it was introduced into clinical practice in the middle of the 20th century and was considered the fourth medical milestone after antisepsis, antibiotic therapy and anaesthesia. In the case of children, parenteral nutrition is mainly associated with intestinal failure, which is usually temporary. In prematurely born newborn babies, these include immaturity of the gastrointestinal tract, necrotizing inflammation of the intestines, in all children - complications of chemotherapy, acute pancreatitis, states of catabolism associated with trauma, surgery or burn. The most common cause of chronic parenteral nutrition in children is short bowel syndrome of different origin. Others include diseases with disorders of intestinal motility such as Hirschprung's disease, total aganglionosis or pseudo obstruction syndrome [10,13].

In our own research, the age of children fed on parenteral nutrition was as follows: up to 1 year of age (10.72%), 1-6 years (44.64%), 7-15 years (44.64%).

In most cases, the child's health problems occurred from birth (85.71%), some of them during the first year of life (8.93%) or later (5.36%).

The parenteral nutrition in the home conditions of 3/4 of the group has been carried out for several years. Parents/guardians were most often trained in handling the central access and infusion pump: only mother (66.07%), mother and father (32.14%).

However, the preparation time for parenteral nutrition at home was as follows: about 2 weeks (39.29%), about 3 weeks (32.14%), about one month (28.57%).

In Poland, parenteral nutrition in pediatric patients has been carried out for over 30 years. Apart from the state of health, the condition is an appropriate social situation and responsible parents. Close cooperation of par-

ents/guardians with the staff of the centre is an inseparable element of effective treatment at home. During the child's stay in the hospital, the parents were trained in the use and care of the central catheter, connection and disconnection of the feeding bag, operation of the infusion pump, and the method of mixture storage.

There is no doubt that home parenteral nutrition provides a child with maximum comfort of life and the best possible functioning in society [10,13-15].

The results of our study showed that caregivers noticed limitations of a child in its everyday functioning due to the parenteral nutrition catheter (69.44% of indications). The main indications were reduced physical activity (51.79%) and decreased number of contacts with peers (41.07%), all the more so due to frequent hospital stays (3-4 times a year 32.14%, 2-3 times a year 28.57%).

Jankowska stresses that home parenteral nutrition in paediatric therapy gives many children with intestinal failure a chance to survive and function normally in society. However, these children require special care and control, as well as close cooperation between specialists in the nutrition team and parents of caregivers [10].

Zatorska-Zola has stated that chronic disease is one of the most undesirable situations in the life and development of a child. It is a serious burden on the young organism, often something incomprehensible and difficult to accept for a young patient. It is also a strong experience for the child's parents. It requires a great deal of effort from them to deal with the disease and to be able to cope with it. The author emphasised that many parents and children live for years in fear of complications. The patients and their caregivers struggle with frustration, discouragement and anger at the disease [16].

Gerc, on the other hand, points out that developmental psychology emphasises the enormous potential of a child, but in relation to children suffering from illness or disability, it seems to be treated not as an asset worth using at work, but only as a manifestation of therapeutic and compensatory opportunities [17].

The family is a system, that is, a set of elements in dynamic interaction, in which each element is determined by the others. The quality of functioning of the whole family as a community of individuals is influenced by all its members, because human relations have never been one-sided and the behaviour of one person has an impact on the whole family system. Therefore, the experience of a life-threatening illness has always challenged the balance of the whole system [18].

Our own research confirmed that parenteral nutrition of a child significantly influenced the functioning of the whole

family (94.64%). The health situation in many cases forced one parent to resign from professional work (69.64%), reduced social contacts (48.21%), reduced holiday and holiday trips (80.36%). The main reason for these changes was the need to adapt to the nutritional cycle of the child (85.71%). The applied feeding method was also associated with frequent separation due to hospitalisation or visits to the outpatient clinic (62.50%). All the more so because, in the opinion of 92.86% of the respondents, there was a need to care for the child of the mother or another family member during hospitalization. At home, the time spent on necessary medical activities was evaluated differently: 30 minutes (26.79%), one hour (44.64%), more than one hour (28.57%).

It has been found that parenteral nutrition of the child is a difficult task for parents, requiring their strength and commitment to daily care activities. The need to adapt to the nutritional cycle has disrupted the daily life of the family and has often led to the need for one parent to give up his or her job. The situation of siblings is an increasingly common topic in terms of a child's illness in the family. Boruszak and Gryglicka pointed out that in the past, parents used to put disabled or chronically ill children under the care of specialist institutions and they had no contact with their parents or siblings. Fortunately, attitudes towards sick children have changed and they have been incorporated into family and social life. However, this undoubtedly entailed a heavy burden on the family and especially on healthy siblings. It had to face many challenges intellectually, including the emotional pain associated with their brother or sister's illness, fear, despair of parents, separation from parents and sick siblings due to their hospitalization [18].

On the basis of a meta-analysis of the publication, Żuchowicz has shown that it is precisely children who, in many spheres of life, feel the effects of siblings' disease most acutely. Initially, it was believed that the emotional or behavioural problems observed in this group were considered rather in the context of reactions to stress, but the persistence of specific changes in the lives of people who experienced chronic sibling disease in childhood is increasingly stressed. Żuchowicz pointed out that almost all subjects confirmed the presence of strong anxiety, presented a lowered mood and experienced remorse. Their emotional bond with their siblings was strong, full of compassion. Siblings of a chronically ill child were burdened with additional duties, while the parents' attention was reduced. Relationships with peers were often limited, which was most often associated with a lack of understanding and loneliness. The disease often shaped the character of the hero,

responsible for his brother or sister, his parents, independent, coping with all difficulties, reaching the top. Continuous tension and effort resulted in the feeling of physical fatigue. It is impossible not to quote the statement presented by Żuchowicz, who belongs to an 18-year-old sister of a brother suffering from cancer: It seems to me that my life will begin when he is gone [19].

In their own research, the respondents assessed their material situation mainly as average (51.79%) and less frequently as good (37.50%). In the opinion of 35.71%, parenteral nutrition of a child burdened the family budget to a large extent, while in half of the respondents only slightly (55.36%). The need to adapt the flat to the needs of the child was stressed most often by changing the furniture (53.57%) or necessary renovation procedures (33.93%). The decision to take advantage of family support measures was made by 66.07%.

The most frequent use was made of foundations' assistance (50.00%) and social assistance (26.79%). Financial support was the most expected form of assistance from state institutions (58.93%). In less numerous cases, legal services were also indicated (16.07%). Only one fifth of the respondents indicated that they did not need any assistance from the state. These results are comparable in relation to other chronic diseases.

According to Zatorska-Zola, parents of children with diabetes confirm the high financial burden on the family, expecting financial assistance, followed by psychological and, to a lesser extent, legal assistance. The child's disease has a very significant impact on the daily functioning of the family [16].

In our own research, it was proved that the situation related to parenteral nutrition of a child was associated with a financial burden on the family. Parents of children of all ages, with full and incomplete families, living in the countryside and in the city, were challenged with parenteral nutrition.

Żuchowicz also stressed the financial difficulties of families with a chronically ill child, the effects of which are directly felt by other siblings. The author points out that the experience of a chronic disease had an impact on the high level of awareness of the financial situation of their families and the adjustment of their needs to the financial possibilities of their parents. In the families of all the respondents, it was the mother who gave up her professional career to take care of the sick child. The respondents pointed to the fact that only one of the parents worked as the cause of the worsening of their financial situation. Financial troubles were also a mental burden related to insufficient possibilities of treatment of sick siblings [19].

Bialic points out that there is a need for special support for parents, especially during the first months of treatment of the child (both in hospital and at home). The lack of support may cause parents to lose hope for a cure and not to fight the disease (due to helplessness in their new situation) [20].

Princess and Sankowski pointed out that parenteral nutrition is an invasive method, which causes many undesirable symptoms. The greatest difficulty is to personalize the energy and nutritional needs of the patient. It is necessary to supply all the nutrients together with the supplementation of nutritional deficiencies. Incorrect estimation leads to overfeeding or malnutrition, which is a very common problem [9].

Laskowska stressed that the proper planning and conduct of parenteral nutrition in children is a challenge, as its aim is not only to ensure proper nutritional status, but also to enable proper somatic growth and development of the central nervous system. The demand for individual nutrients in paediatric patients is individual. It depends on age, gender, coexisting diseases, initial nutritional status [10].

A lot of research work concerns the complications described as mechanical. Among the early complications, the most common are those associated with incorrect catheter insertion, such as poor placement of access or its displacement, air congestion or abscess. The later complications include obstructions related to improper use of the catheter. A significant group of complications, so significant for the participants of our study, were septic complications, which include catheter infections, blood and skin infections. The less numerous group includes 56 metabolic complications, such as hypoglycaemia, insulin sensitivity [21-29].

Laskowska also mentioned electrolyte disorders, bone metabolic disease and parenteral nutrition-related cholestasis from frequent metabolic complications in children.

Despite the existing risks, parenteral nutrition is still the "gold standard" for patients with a poor gastrointestinal tract or intestinal disorders [10].

The results of own research indicated that parents/guardians, despite the difficulties experienced with their child's illness, expressed the willingness and need to do their utmost to restore their health (64.29%). A significant group of respondents also presented an attitude of survival and belief that everything will be fine (28.57%). In most cases the situation was accepted (80.36%) and it was not a secret from family, neighbours, friends (94.64%). The respondents applied an educational system consisting of rewarding and punishing children (53.57%), when every fourth person applied only awards (25%). The respondents assigned children responsibilities according to

their age and abilities, such as toy or room cleaning, home help, care of animals. However, one in five respondents considered their children to be too young. Disability was also indicated (7.14%). Only 39.29% of the group confirmed the child's constant contact with their peers. The main reason for these limitations was fear of catheter infection and risk of sepsis (87.50%). Due to self-care of nutritional access, doubts were also expressed about their own skills (7.14%) and anxiety about the technical condition of the equipment (12.50%).

Małgorzewicz stressed that the training process is one of the most important elements preceding domestic nutrition. Its quality determines the success of treatment, the number of complications and the quality of patient's life [30].

The parents we examined were also worried about their child's life prospects (37.50%).

The authors understand this situation, and Gerc stresses that the disease and suffering associated with it often causes the child's living conditions, opportunities, self-image and future to change. The author mentioned above pointed out that a serious somatic disease or a disability acquired during adolescence is particularly problematic in terms of emotions. Gerc also confirmed that a child's 'serious' illness often causes the relationship between his parents and their friends to loosen up, who assume that touching upon the developmental problems of healthy children and telling about personal experiences concerning their proper development can be perceived as embarrassing, untouchable or even heartless [17].

In their own research only 10.71% of parents/guardians indicated that their child's current health situation does not cause them any concern.

Home-made nutrition cannot function without a food advice centre team. Apart from a doctor and a nurse, the nutritional laboratory of a hospital pharmacy plays a fundamental role in running these patients. Proper preparation of mixtures (especially parenteral ones), storage, but also delivery of preparations to the patient's home requires a great involvement of pharmacy staff [30].

According to the respondents, the source of information related to the child's disease was mainly a message from the attending doctor (96.43%). Also important was the contact with parents of other sick children (50%), as well as information obtained from the nurse (44.64%) and available on the Internet (41.07%). The respondents were satisfied with the cooperation with the attending doctor (92.86%) and in most cases they did not experience any difficulties in relations with the medical personnel (82.14%).

The opinion of respondents on the knowledge of family problems by district health care institutions was divided: good (46.43%) and bad (42.86%).

The parents of a chronically ill child experience many problems in their treatment, care and education. At the same time, they have to meet the different needs of other family members. All of this makes them often lonely in their functioning, so they need external support. The parental nutrition of a child is a difficult task for parents, requiring their strength and commitment to daily care activities. The need to adapt to the nutritional cycle disrupts the daily life of the family and often leads to the resignation of one of the parents from their professional activities. This is not without significance for the family's overall financial situation. Parental nutrition is a challenge for parents of children of all ages with full and incomplete families, living in rural and urban areas. Only joint action can influence the quality of support and the quality of life of a family with a child who is chronically ill.

V. CONCLUSIONS

- The parental nutrition of a child is a difficult task for parents, requiring their strength and commitment to daily care activities.
- The need to adapt to the nutritional cycle disrupts the daily life of the family and often leads to the need for one parent to give up his or her job.
- The parenteral nutrition situation of a child involves a financial burden on the family.
- parenteral nutrition is a challenge for parents of children of all ages, with full and incomplete families, living in the countryside and in the city.

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