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STUDYING THE NEEDS OF FAMILIES RAISING CHILDREN WITH CEREBRAL PALSY

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Abstract

Raising a child with cerebral palsy (CP) is a complex task that requires significant physical, emotional, and financial resources. This article examines the basic needs of families raising children with cerebral palsy, including medical, psychological, social, and financial support. An initial study of the key problems faced by such families has been conducted and recommendations for their solution have been proposed.

Keywords:

Cerebral Palsy, Family Needs, Parents, Social Adaptation, Medical Care, Rehabilitation

Introduction

The diagnosis of cerebral palsy significantly changes the life of not only the child, but also the whole family. Parents become the main guardians and caregivers, which requires a lot of effort and adaptation from them. Studying the needs of families raising children with cerebral palsy helps identify areas for developing effective support programs and improving their quality of life.

Analysis of the Literature on the Research Topic (Literature Review):

The systematized data from the literature serve as the basis for the formation of recommendations, the development of treatment standards, government programs and rehabilitation measures aimed at improving the quality of life of patients with cerebral palsy. The literature also provides an opportunity for specialists and researchers to track the latest advances in the diagnosis, therapy and rehabilitation of children with such a diagnosis, expanding understanding of the pathogenesis, identifying risk factors and stimulating the development of innovative treatment methods. A review of existing sources also makes it possible to identify areas where there is not enough data yet, and this launches the process of new scientific work and clinical trials, which ultimately contributes to improving diagnostic and treatment methods.

Foreign scientific literature demonstrates significant progress in understanding the causes and treatment of cerebral palsy. The main research areas include neuroscience, therapy, as well as psychological and educational aspects.

Modern foreign works pay special attention to the neurobiology and pathogenesis of cerebral palsy. For example, Baxter (2005) [2] describes cerebral palsy as the result of hypoxic-ischemic brain damage to the fetus or newborn. Graham and Devlieger (2016) [3] focus on prenatal and perinatal risk factors such as infections, asphyxia, and prematurity.

Rehabilitation methods abroad are characterized by technological novelty. Bobath therapy and Vojta therapy aimed at normalization of motor functions are considered popular in international practice (Bobath, 1990; Vojta, 2007) [4, 5] These approaches are widely used in Europe and the USA. Clarke and Hunt (2018) [6] analyze the effectiveness of robotic systems and exoskeletons for restoring motor functions − in a number of developed countries, these methods are still being implemented at an experimental level.

Social adaptation and inclusion are also actively explored. Rosenbaum (2007) [7] emphasizes the importance of early psychological and social support for families, inclusive education and training for parents. Novak and Spittle (2020) [8] focus on training programs for families and professional development of specialists working with children with cerebral palsy, which helps to mitigate emotional stress and improve rehabilitation outcomes.

Uzbekistan and Russia traditionally pay great attention to rehabilitation technologies, psychological and pedagogical approaches and issues of social integration of children with cerebral palsy.

Epidemiology and diagnostics. In the studies of L.R. Muminova and S.M. Amirsaidova [9], risk factors, various types of injuries, and methods of early diagnosis of cerebral palsy were considered. Z.N. Mamarazhabova, M.U. Khamidova, D.B. Yakubzhanova, Z.M. Jalolov, and N.Z. Abidova [10] describe in detail various features of disorders, as well as factors that contributing to the development of complications. The works of K. A. Semenova (2000) [13] and L.O. Badalyan (1984) [11] analyze the risk factors for cerebral palsy, including obstetric injuries and diseases in early childhood.

Rehabilitation technologies. K.A. Semenova [13] has developed a patterning technique that involves stimulating motor functions through the creation of correct motor models. Kozyreva O.V. (2003) [10] evaluates the effectiveness of physiotherapy, massage and therapeutic physical therapy (LFK) in the framework of comprehensive rehabilitation in her research.

Social integration and inclusive education. Russian and Uzbek authors emphasize the need for an inclusive approach in the education of children with cerebral palsy. For example, the research of M.R. Bityanova (2012) [15] emphasizes the importance of developing individual educational routes. An important contribution to this topic was made by T.V. Vorontsova and A.A. Arkhipova [10], who studied teaching methods taking into account the peculiarities of cognitive development of children with cerebral palsy.

The introduction of inclusive education in schools in Uzbekistan is actively supported by government initiatives, including a number of regulatory acts aimed at improving the education system for children with disabilities. Among them is the decree of the President of the Republic of Uzbekistan "On measures to further improve the education system and upbringing of children with special educational needs" [1]. The document approved the Concept of the development of inclusive education in the public education system in 2020-2025.

Psychological assistance to the family. The works of I.V. Dubrovina and A.M. Matyushkin (2018) [14] indicate that the stress level of parents of children with cerebral palsy is high and requires specialized support in the form of trainings, consultations and educational programs. Such measures facilitate the process of socialization of children with cerebral palsy and increase the effectiveness of rehabilitation.

Research Methodology

The study of the needs of families was conducted using questionnaires, interviews with parents, as well as an analysis of existing support programs. The most important aspects that require attention from the state and public organizations to assist families raising children with cerebral palsy have been identified.

Primary Results and their Analysis (Analisys and Results)

Basic needs of families raising children with cerebral palsy

1. Medical care and rehabilitation

Families are in need of affordable and high-quality medical care, including regular consultations with specialists, medication, physiotherapy and specialized equipment.

2. Psychological support

High levels of stress and emotional burnout are frequent companions of families raising children with cerebral palsy. Parents need psychological help, support groups, and the possibility of temporary relief (for example, respite services).

3. Social integration

Parents want their children to be able to socialize and participate in public life. This requires the development of inclusive education, an accessible environment, and adaptation programs.

4. Financial support

Families with children with cerebral palsy face additional costs for treatment, rehabilitation, and special equipment. Government and charitable assistance play a key role in providing the necessary conditions for their children.

5. Information support

Parents need up-to-date information about treatment options, family rights, benefits, educational programs, and available social services.

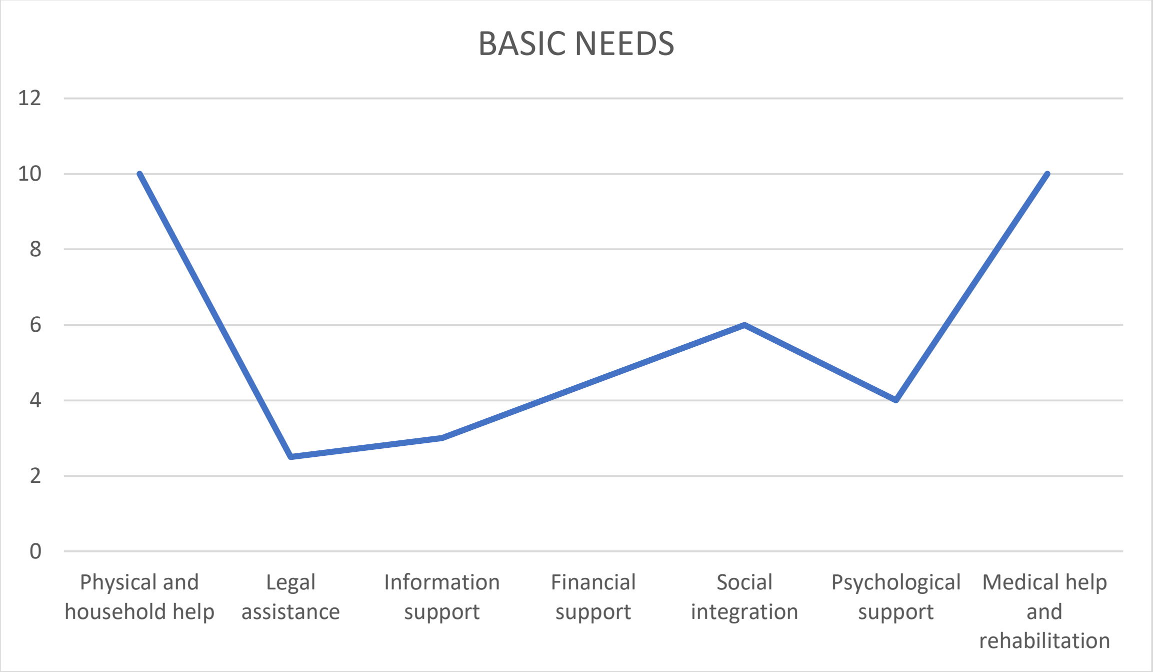
6. Legal assistance

Families often face difficulties in obtaining documents, obtaining benefits, and defending their child's rights. Access to legal advice and legal support plays an important role in protecting the interests of families.

7. Physical and household care

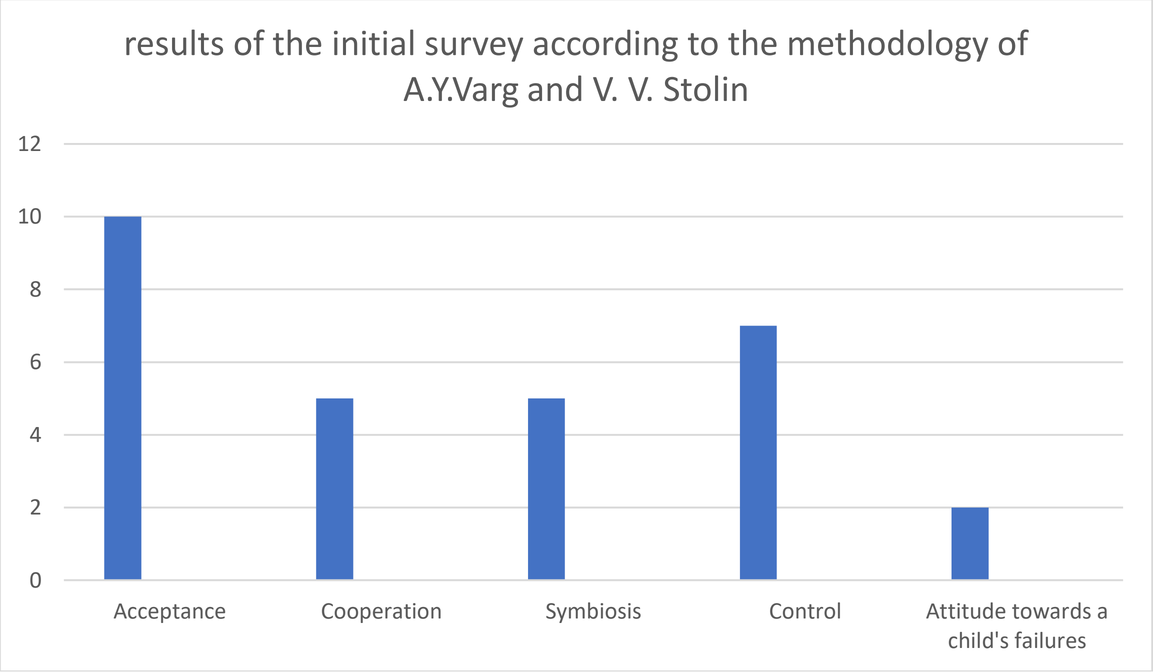
Caring for a child with cerebral palsy requires significant physical effort, especially in families with seriously ill children. Support from social services, caregivers, and access to specialized care services can significantly ease the burden on parents.

Parents rated basic needs on a scale from 0 to 10 in their daily lives.



As we can see, first of all, the main needs turned out to be physical, household, medical care, legal and psychological support turned out to be secondary.

The following features of the questionnaire should also be noted



The questionnaire includes 5 scales.

Here it can be noted that an adult, spending enough time with a child, still experiences contradictory feelings. More often they are negative, it is difficult for a parent or a significant adult to accept the diagnosis, to recognize his individuality, the parent may feel irritated by helplessness, at the same time pity and sadness may be felt. In terms of cooperation, we can note the average value, it means that an adult encourages the child's independence, supports the initiative depending on the situation.

The Symbiosis scale shows a high score, indicating that the adult does not maintain psychological distance, consistently tries to be close to the child, promptly meets their needs, and takes care of them.

The Control scale also shows a high score, suggesting that the adult often behaves authoritatively and is highly demanding.

On the Child's Attitude Toward Failure scale, a low score can be observed. This may reflect optimism and the belief the adult has in the child.

Conclusion

The study showed that families raising children with cerebral palsy need comprehensive support, including medical, psychological, legal and financial assistance. To improve their quality of life, it is necessary to coordinate the actions of government agencies, medical institutions and public organizations. You can also see a contradictory attitude related to emotional burnout and fatigue associated with the diagnosis of a child. The development of support programs, the availability of qualified specialists and the creation of an inclusive environment conducive to the full development of the child and the well-being of the whole family play an important role in providing assistance.

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