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THE IMPACT OF CLINICAL CHARACTERISTICS OF JUVENILE IDIOPATHIC ARTHRITIS ON FAMILY FUNCTIONING AND PARENTS' DAILY ACTIVITIES

Abstract: *juvenile idiopathic arthritis (JIA) is a chronic inflammatory disease that can affect not only the physical functioning of a child, but also family life and the daily activities of parents.*

The aim of the study is to analyze the relationship of the clinical features of JIA with family functioning, daily activity of parents, their quality of life and the burden of care based on scientific literature.

Materials and methods. A descriptive review of the scientific literature was conducted using PubMed/MEDLINE, scientific journal websites, and open access publication archives. The review includes original research, qualitative research, systematic reviews, and meta-analyses, mostly published in 2021-2026, as well as earlier publications directly related to the topic. The results are summarized using a descriptive approach.

Results. The reviewed studies indicate that pain, fatigue, functional limitations, and higher disease activity may be associated with an increased burden of care. The consequences for parents include reduced productivity, changes in work schedules, financial losses, difficulties in combining child care with daily responsibilities, as well as problems with maintaining physical and psychological well-being. The burden of care is multicomponent and may depend on the socio-economic conditions of the family, as well as the availability of family and professional support. However, differences in research design, sample characteristics, and evaluation methods limit the possibility of direct comparison of the results obtained.

Conclusion. Juvenile idiopathic arthritis can affect various aspects of family functioning and the daily lives of parents. It is important to assess the needs of the family and develop appropriate information, psychological, medical and social support. Further research is needed to determine the extent of the care burden in the Republic of Kazakhstan.

Keywords: *juvenile idiopathic arthritis, family functioning, parents, caregiver burden, parental quality of life, work productivity, daily activities.*

Introduction.

Juvenile idiopathic arthritis (JIA) is a group of chronic inflammatory joint diseases that begin in childhood. The clinical course of the disease is characterized by variability in symptoms and may be accompanied by pain, morning stiffness, fatigue, limited mobility, and a decrease in the child's functional capabilities. JIA requires timely diagnosis, individualized treatment, and long-term medical monitoring [1].

In the Republic of Kazakhstan, the legal framework for providing medical care and protecting public health is defined by the Code of the Republic of Kazakhstan «On the Health of the Population and the Healthcare System» [2]. The protection of children's rights and legitimate interests is governed by the Law of the Republic of Kazakhstan «On the Rights of the Child in the Republic of Kazakhstan» [3]. At the same time, the legal regulation of medical care does not in itself reflect all the consequences of a chronic disease for the daily life of the family.

The impact of a chronic disease affects not only the child's physical condition but also the family's functioning. Parents participate in organizing treatment, following medical recommendations, visiting medical facilities, and providing assistance to the child in carrying out everyday activities. A qualitative systematic review of the experiences of children with JIA and their families revealed difficulties related to managing the disease, financial burden, and the need to adapt to changed living conditions [4]. The study by Currie and co-authors also showed that disease symptoms, treatment, and medical consultations can affect family activities, travel, and parents' professional activities [5].

Of particular importance is the relationship between the clinical features of JIA and family functioning. The severity of pain, fatigue, and functional limitations can determine the child's need for assistance. In a study of 855 children with recently diagnosed JIA, relationships were identified between pain, fatigue, and physical limitations [6]. At the same time, psychosocial factors may also be associated with pain perception and the child's adaptation, although the results of studies on individual factors are heterogeneous [7].

The study by Grazziotin et al. examined factors related to the quality of life of caregivers of children with juvenile idiopathic arthritis. The authors considered both the quality of life associated with child care and the caregivers' own health. The results obtained emphasize that the burden on parents is determined not only by the clinical manifestations of the disease in the child, but also by the circumstances related to care and daily family life [8].

Modern studies are increasingly examining parents' quality of life, the burden of care, and the impact of the disease on work capacity. However, data in these areas differ in terms of design and assessment methods. In this regard, it is important to summarize the available information on the relationship between the clinical characteristics of JIA and the daily activities of parents, quality of life, and family functioning.

The aim of the review is to analyze the relationship between the clinical features of juvenile idiopathic arthritis and family functioning and the daily activities of parents based on the scientific literature.

Materials and methods.

This work is a narrative review of the scientific literature devoted to the clinical features of JIA and their possible relationship with family functioning and the daily activities of parents.

When preparing the review, original studies, qualitative studies, systematic reviews, and meta-analyses were taken into account. The main focus was on publications examining the clinical activity of the disease, pain, fatigue, functional limitations, the quality of life of parents, the burden of care, and work capacity. Additionally, studies examining the economic consequences of JIA and the effectiveness of family support programs were considered.

PubMed/MEDLINE, websites of scientific journals, and open full-text archives were used as scientific resources. The search used the following English-language terms: juvenile idiopathic arthritis, caregiver burden, family functioning, parental

quality of life, work productivity, activity impairment, pain, fatigue, and functional disability.

The main focus was on publications from 2021 to 2026. Earlier studies were included if they were directly relevant to the topic. The national context was considered taking into account the regulatory documents of the Republic of Kazakhstan in the field of health protection and the organization of medical care.

Publications that met the review's objectives and contained information about the methods and results of the study were selected for analysis. Information was extracted about the study design, sample characteristics, clinical indicators, and results related to parents and family functioning.

The results were summarized using descriptive and comparative methods. Studies were grouped according to the following areas: clinical features of JIA, the child's functional limitations, the parents' ability to work and daily activities, quality of life and the burden of care, the economic consequences of the disease, psychological adaptation and family support.

Since a comprehensive systematic search with documentation of all stages of selection and quality assessment of each study was not conducted, the work is considered a narrative review. A quantitative meta-analysis was not performed.

Results.

Clinical features of JIA and the child's functional limitations.

The clinical course of JIA can vary significantly in terms of inflammation activity, symptom severity, and the degree of functional limitations. Pain and fatigue are of particular importance, as they can limit the child's physical activity and make it difficult to perform daily activities.

In a study by Choong and colleagues, which included 855 children with newly diagnosed JIA, the severity of pain and fatigue was associated with physical limitations. Fatigue partially mediated the relationship between the impact of pain and physical disability [6]. These results suggest that clinical symptoms may increase a

child's need for assistance, but the direct burden on parents was not the primary outcome in this study.

The study by Attuparambath and colleagues examined the functional status of children with JIA, their quality of life, and the burden of care [9]. Studies like this are important for analyzing the potential link between a child's limitations and the burden on caregivers. At the same time, the presence of a relationship between a child's functional status and the burden of care does not mean that all parents' difficulties are solely due to the clinical characteristics of the disease.

One of the most concrete indicators of family burden is the impact of the disease on parents' professional activities.

In the international study by Marshall and co-authors, published in 2026, 754 parents of children with JIA from Canada and the Netherlands participated. During the 12-month observation period, overall work impairment was estimated at 12%, while impairment of daily activities was 16%. About 10% of parents reported a change in their work schedule due to caring for the child. The average annual loss of earnings due to absence from work was estimated at 3,510 euros [10].

More pronounced limitations were observed in parents of children with high and moderate disease activity. The impact of JIA on employment was most noticeable at the beginning of the observation period and decreased over time. The authors suggested that this dynamic may be related to changes in the child's clinical condition and the family's adaptation to the disease [10].

Additional information is presented in the study by Marshall and co-authors, which focuses on the quality of life of caregivers. The study included 439 parents. More than 40% reported difficulties related to physical and psychological health and balancing caregiving with daily responsibilities. Approximately 12% of participants indicated a lack of any support [11].

Thus, work-related limitations and quality of life represent complementary, but not interchangeable, indicators of family burden.

The study by Gowda and co-authors, conducted in India, focused on the care burden in families with children with JIA. The authors examined emotional and

economic difficulties, as well as factors related to the severity of the burden on caregivers. The results obtained highlight the importance of the disease activity and the socio-economic status of the family [12].

A systematic review of the economic consequences of JIA included 18 studies with data on 6,540 patients. The authors identified significant differences in the estimates of direct and indirect costs. At the same time, indirect costs, including productivity losses and other consequences for families, were less comprehensively represented in the literature than direct medical costs [13].

An earlier study by Rasu and co-authors also showed that parents of children with newly diagnosed JIA reported more lost working time compared to parents in the control group. The most pronounced impact was observed in the period after the diagnosis was made [14].

In a study of families with children with systemic JIA, Shenoi and co-authors examined the consequences of the disease for patients and caregivers, including quality of life and economic burden [15]. These data complement the results of studies devoted to all clinical variants of JIA, although their applicability is limited by the specific features of the systemic disease and the characteristics of the sample.

Taken together, the results indicate that the burden of care includes not only the direct costs of treatment but also changes in professional employment, the redistribution of family responsibilities, and the restriction of parents' usual activities.

The psychological adaptation of parents is an important component of family functioning. The need to manage a child's chronic disease may be accompanied by stress, uncertainty, and the need for constant decision-making.

In a randomized study by Mulligan and co-authors, the WebParC web programme, designed to support parents of children with newly diagnosed JIA, was evaluated. The study involved 220 parents from 203 families. The results showed a reduction in the frequency and severity of some disease-related stressful situations in the intervention group [16].

The systematic review by Kupiec and co-authors, which focused on interventions to support caregivers in paediatric rheumatology, included 15 studies.

The authors noted that the number of evaluated programs remains limited, and the methods and performance indicators differ. This makes it difficult to identify the most effective ways to support families [17].

Woolnough and colleagues' study examined children's and caregivers' perceptions of the importance of physical functioning and quality of life in JIA [18]. Such data underscore the importance of taking into account the views of both the child and the parents when planning medical and rehabilitation care.

A systematic review of the social functioning of adolescents with JIA also identified barriers to participation in social life, stigmatization, and the importance of support resources [19]. Although the main focus was on the adolescents themselves, these factors are important for understanding the social context in which families organize care and adapt to a chronic illness.

For Kazakhstan, studying the family burden associated with juvenile idiopathic arthritis is relevant in the context of organizing medical care for children and ensuring their rights. The rules for providing primary health care define the organizational foundations for delivering the relevant medical services [20].

At the same time, the international studies reviewed in this review do not allow for a direct assessment of the prevalence of difficulties among Kazakhstani families. To achieve this, national studies are needed that take into account the availability of specialized rheumatological care, socio-economic conditions, and the specifics of care organization.

Discussion.

The results of the reviewed publications show that JIA may be associated with limitations in professional activities, reduced daily activity, and deterioration in certain aspects of parents' quality of life. At the same time, the family burden is formed as a result of the interaction of clinical, psychological, and socio-economic factors.

The most specific data were obtained in a study of parents' work capacity, where higher JIA activity was associated with more pronounced limitations in work and daily activity [10]. This underscores the importance of the child's clinical condition

as one of the factors related to the amount of care required. However, it cannot be claimed that the severity of the disease is the sole cause of work-related and family difficulties.

Studies on the quality of life of caregivers show that economic consequences do not fully account for the family burden. Parents may experience difficulties in maintaining their own physical and psychological well-being, even if they receive assistance [11, 12]. Furthermore, differences in socio-economic conditions and healthcare systems make it difficult to directly compare the results obtained in different countries [13, 15].

Data on the effectiveness of the web-based support program show that parental stress may be one of the potentially modifiable aspects of family burden [16]. At the same time, the limited number of evaluated interventions does not allow us to conclude that a particular program will be effective for all families [17].

For the Republic of Kazakhstan, a promising direction is to study clinical and family factors within a single research model. This would make it possible to determine which disease characteristics are associated with the most pronounced parental limitations and which types of support meet their needs.

This review has a number of limitations. Firstly, the publications under consideration differ in design, sample characteristics, and assessment tools, which makes it difficult to directly compare the results.

Secondly, a significant portion of the data was obtained outside Kazakhstan. Differences in healthcare, employment, and social support systems limit the possibility of transferring international results to Kazakhstani families.

Thirdly, the relationship between the activity of the JIA and family burden does not prove a direct cause-and-effect relationship. Other factors may influence parents' well-being, including employment, availability of support, financial situation, and their own health.

Fourthly, the review is narrative and does not include a formal systematic selection of all available publications or a meta-analysis. Therefore, its conclusions

should be viewed as a summary of the presented studies, rather than as a comprehensive assessment of the entire evidence base.

Conclusion.

Juvenile idiopathic arthritis can affect family functioning and the daily activities of parents. The most specific consequences described in the studies reviewed are related to limitations in work capacity, changes in work schedules, economic losses, and difficulties in balancing caregiving with daily responsibilities.

The caregiving burden is multidimensional and includes economic, organizational, and psychosocial aspects. Higher disease activity is associated with a greater burden on parents, but family functioning is determined by a combination of clinical and social factors.

The data obtained underscore the importance of taking parents' needs into account when organizing support for children with JIA. For the Republic of Kazakhstan, research is needed to assess the family burden in the national context and to determine the needs for medical, informational, psychological, and social support.

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