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## Psychological Features of Parents Raising Children with Cerebral Palsy

Aida F. Minullina\* (a), Kseniya V. Pyrkova (b)

(a), (b) Kazan Federal University, 420008, Kazan (Russia), 18 Kremlyovskaya street, aidamin@rambler.ru

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### Abstract

Cerebral palsy is the main cause of disabilities among diseases of nervous system in childhood. According to the World Health Organization, the number of children born with cerebral palsy is 3-4 cases per 1000. The birth of a child with disabilities causes disorder of the normal course of family's life and often leads to disruption of relationships in the family. The reason is a huge psychological burden that the child's family members have to carry.

The purpose of the research is to study the psychological features of parents raising children with cerebral palsy. Research methods are interviewing, testing (test for anticipatory competence by Mendelevich; Inclination to dependent behavior method by Mendelevich; Beck Depression Inventory; The Quality of Life Assessment inventory (SF-36 Health Status Survey); inventory of the emotional relations in the family by Zakharova; parental attitude inventory by Schaefer and Bell (PARI method). Experimental group included 25 parents of children with cerebral palsy who were undergoing rehabilitation at the center for children and adolescents with disabilities. Control group consisted of 25 parents raising children without neurological and somatic pathologies in one of Kazan educational institutions.

The research results showed that parents raising children with cerebral palsy perform a reduced level of communication and insufficient ability to anticipate life events and situations. Parents of both groups have an increased tendency to addictive behavior, a high focus on psychoactive substances use and an increased risk of developing psychological dependence on psychoactive substances. Parents of children with cerebral palsy have a higher level of depression than parents of the control group. Parents of children with cerebral palsy show decreased activity and deterioration of health in general; their physical activity is limited by the actual state of health compared to the control group. The interests of mothers of children with cerebral palsy are limited only to the interests and concerns of the family and they tend to feel maternal self-sacrifice. The results of the study can be used to enhance parent-child relationships and the adaptation process.

*Keywords:* family, parents, parent-child relationships, cerebral palsy.

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\* Corresponding author. E-mail: aidamin@rambler.ru

## **Introduction**

In 2015, there were 604 000 children with disabilities under the age of 18 in the regions of the Russian Federation. In 2019, this figure reached 670 000 people. Cerebral palsy is the main cause of disabilities among diseases of nervous system in childhood. According to the World Health Organization, the ratio of children born with cerebral palsy is 3-4 cases per 1000.

Birth of a child with disabilities causes disorder of the normal course of family's life and often leads to disruption of relationships in the family. The reason is a huge psychological burden that the child's family members have to carry. Long-term stress causes a highly deforming effect but due to life orientations, it deforms mothers and fathers in different ways. Mother takes all responsibility for the state of the family as well as education and training. Father of a disabled child provides family with the financial support (Bogdanova & Mazurova, 2019; Gerber, 2016).

Gerber (2016) notes that the divorce rate in families, where children with disabilities are brought up, is quite high, and it makes up about 50% of the total number of families. The birth and upbringing of a child with cerebral palsy has a mental impact on parents and the entire family in general.

## **Purpose and objectives of the study**

The purpose of this study was to examine the psychology of parents raising children with cerebral palsy. As a hypothesis, the following assumption is put forward – the psychological features of parents who raise children with cerebral palsy have a specific peculiarity in comparison with parents who raise children without neurological and somatic pathology.

## **Literature review**

The problem of emotional disorders among parents raising children with disabilities was first discussed in the early 20th century. In Russia, the problem of raising children with disabilities is extensively presented in the works of many scientists. Thus, Mayramyan (1976) considers a traumatic situation as the main reason that leads to deterioration of the parent's mental health. It was found that when mothers expect the birth of a healthy child only and do not assume possible disorders and pathologies, their psychotrauma is more obvious. In his research, Mayramyan (1976) revealed a high probability of a divorce in the family, which could not cope with the crisis of giving birth to a child with disabilities. In many families spouses start blaming each other for giving birth to an unhealthy child with severe developmental problems. Some begin to blame themselves, assuming the fact of the child's illness as a disaster for all the family.

Grinina and Rudzinskaya (2016) states that for the development of a child with disabilities, it is necessary to change the attitude of the nearest social circle, in particular, parents.

In their research, Bogdanova and Mazurova (2019) describe the mental awareness of birth of a child with disabilities. Antonova (2010) studied the self-conception features of parents who raise children with disabilities and discovered that their insufficient adaptation to their social environment is most significant for them. It was also found that these parents are introverts, which in its turn, leads to a low level of reflection. However, it should be mentioned that they need certainty and consistency. Researchers Grinina and Rudzinskaya (2016), based on an extensive analysis of the literature and practical research, studied the problem of parent-child relations in families where a child with disabilities is raised. During the study, it was revealed that parents have an inadequate perception of their child, tension in relationships, rigidity of the parental position, as well as destructiveness.

When studying families, Vysotina (2011) revealed that a stressful situation when a disabled child is born, leads to such emotional changes as increased irritability and fear for the child's future but also to various somatic disorders. Similar results were found in the studies of Markova and Piontkovskaya (2013) who studied families where children with cancer are brought up. It was found that such families suffer tension in relationships and increasing conflicts, which leads to distancing between family members.

Kolpakova (2003) found aspects of emotional and personal features of mothers who raise children with disabilities. These are (1) a state of high mobilization, that is, readiness to cope with any difficulties encountered (61% of cases); (2) reduced activity, i.e. inability and unwillingness to cope with difficulties (31%); (3) anxiety, fear, and suffering that are common to all groups of parents.

Fomina (2014) discovered that in many families where children with complex developmental disorders are brought up, intrafamilial relationships are distorted. There are frequent conflicts, the presence of symbiotic relationships, and excessive attachment of mother to a child. In addition, research shows that parents who raise children with musculoskeletal disorders meet many intractable problems while upbringing the children (Rostkovskaya & Shimanovskaya, 2017).

The birth of a child with locomotorium disorders is a psychotraumatic factor for the whole family. In families where a child is born with disabilities, the functioning of the family changes, as various spheres of life are limited. This factor negatively affects family's health, which, in turn, can lead to neurotization and psychosomatic disorders of family members (Bogdanova & Mazurova, 2019; Gerber, 2016).

Tkacheva (2004, 2005) found that in families where children with cerebral palsy are featured with the prevailing hyperprotection. This type of relationship inhibits the personal development of the child, deprives him of independence, and unrealistic plans for the future are formed. It was also revealed that some families express an emotional rejection of the sick child, which leads to the sense of inferiority and insecurity.

The works of Matyash and Pavlova (2015) showed that parents, when communicating with a teenager with cerebral palsy, use the style of an indulgent reaction. This can manifest itself in satisfying any whims of a sick child without making adequate demands. The indulgent reaction style contributes to the development of egocentrism and increased dependence on parents.

Kocherova (2014) found that parents of disabled children have various emotional disorders, as well as a negative attitude to divorce. Mothers are not satisfied with the child's development; they worry about their child's lag in speech and mental development. They understand that the child needs the help of good specialists.

Researchers Mastjukova (2003) and Tkacheva (2004, 2005) state that parents raising children with musculoskeletal disorders experience psychological difficulties associated with prolonged exposure to a traumatic situation, which is the result of the disabled child birth. Tikhomirova and Isaev (2011) found that psychological assistance is especially needed for mothers, since they bear the main burden for the education and treatment of children with cerebral palsy. As research shows, mothers' experience is much stronger and more acute than fathers'. This may be due to various emotional, physical, and social pressures that mothers of children with disabilities suffer.

Also, in her research, Zinova (2015) defined such personal specific features of parents raising children with cerebral palsy as an increased level of excitability, anxiety, conflict behavior in difficult situations, avoidance of close social contacts (they do not communicate with anyone except their closest relatives); a small circle of interests, as well as an external locus of control.

Shebanets and Khatit (2015), after conducting a study, concluded that a woman raising a child with cerebral palsy experiences large psychoemotional and physical loads that lead to emotional tension and to well-being deterioration. These factors also affect a woman's personality.

Mastjukova (2003) revealed that mothers raising a child with cerebral palsy, as well as other parents raising a child with disabilities, are in a state of parental crisis. After birth and up to the 3 years period, it

tends to increase, as the concerns associated with the child increase as well, and they are anxious about the future of the child. It was found that any mothers of children with illnesses, regardless of the diagnosis, have such personal problems as depression and experiences associated with self-blame for the birth of a sick child. Social isolation as well as depression and neuroses of various origins can also be observed.

It should be noted that one of the main problems is the social adaptation of the family in society after the birth of a "special child" (Mastyukova, 2003; Mastyukova & Moskovkina, 2012; Tkacheva, 2004). Today, there are more than 200 works devoted to this problem abroad. At the top of this list is an American psychoanalyst, Professor of clinical psychology Stone (2019) with his work "Parental attitudes to retardation". When studying such families, scientists pay attention to the consequences of the influence of a sick child on the life of family members. These consequences can be displayed both on the physical and financial side of the family, and on the emotional state of the parents. In the literature, an important place is occupied by the problem of identifying forms and stages of adaptation to family stress by Manuel et al. (2003).

In foreign literature, it is noted that every family where children with disabilities are brought up experiences chronic stress. It is shown that some parents perceive the birth of a sick child as a disaster and blame themselves for what happened. That is the reason why psychological assistance to the family should be aimed at "replacing affective and cognitive filters". The study of foreign literature shows that mothers who raise children with disabilities have certain personal problems (Eker, 2014; Hassall, 2005). The authors indicate the mothers feel guilt due to the birth of a child with pathologies as well as social isolation and depression. Signs that indicate the parental adaptation deterioration are depression, neurotic and psychopathic reactions, as well as changes in parental attitudes to the child (Naglieri, 2011; Romeo et al., 2010; Venkatakrisnashastry & Vranda, 2012).

Heiman (2002) found that the birth of a child with special needs leads to significant changes in the social life of the family. Some experience severe stress as well as feelings of depression, anger, denial, guilt, and confusion. However, such families should not be considered pathological because of their disabled child. In families with a sick child, spouses try to create strong and positive relationships that help them cope with the difficulties that have arisen.

## **Methodology**

The study was carried out with the use of the following methods: 1) interviewing the examinees in order to clarify, supplement, and analyze the information obtained while testing; 2) testing: Inclination to dependent

behavior method by V. D. Mendelevich; Beck Depression Inventory; The Quality of Life Assessment inventory (SF-36 Health Status Survey); inventory of the emotional relations in the family by E. I. Zakharova; parental attitude inventory by E. S. Schaefer and R. Q. Bell (PARI method). 3) mathematical processing of psychological research data: calculating the average, standard deviation, the significance test of the studied indicators with Student's t-test; Pearson's linear correlation coefficient.

The parents of children with cerebral palsy who were undergoing rehabilitation at the center for children and adolescents with disabilities were involved in the study (25 people). The control group consisted of 25 parents raising children without neurological and somatic pathologies in one of Kazan educational institutions.

The study was conducted in three stages, with the content of each stage corresponding to the task: Stage I: identifying the psychological features of parents raising children with cerebral palsy. Stage II: identifying the features of parent-child relationships of parents raising children with cerebral palsy.

Stage III: identifying the relationship between the psychological features of parents raising children with cerebral palsy and the features of their parent-child relationships.

## Results

The following method was used to determine the level of prognostic competence (anticipatory competence) of parents raising children with cerebral palsy and parents raising children without neurological and somatic pathology: test for anticipatory competence by V. D. Mendelevich. The results are presented in Table 1.

Table 1. Anticipatory competence index (test by V. D. Mendelevich)

Examinees	Personal and situational anticipation	Spatial anticipation	Time anticipation	General anticipatory competence
1. Parents of children with ICP	153.40	45.88	40.84	240.12
2. Parents of children without neurological and somatic pathology	166.20	49.44	41.08	256.72
T-test	-1.951	-1.974	-1.491	-0.138

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

Table 1 shows that the standardization group indicators of Personal and situational anticipation are found within the normal range, which assumes their anticipation consistency. Parents who raise children with cerebral palsy, on the contrary, perform Personal and situational anticipation incompetence. This means that these parents have a reduced level of communication and lack the ability to predict life events and situations.

Indicators on the scale of Spatial anticipation consistency in both groups are lower than the average values. That is, these parents are characterized by a lack of ability to anticipate the movements of objects in space and to coordinate their own movements.

Both groups' values of Time anticipation are below average, which may indicate their inability to predict the course of time and accurately distribute it.

To identify the propensity to addictive behavior (namely, alcohol and drug addiction) of parents of both groups, Inclination to dependent behavior method by V. D. Mendelevich was used. The results are presented in Table 2.

Table 2. Inclination to dependent behavior index (test by V. D. Mendelevich)

Examinees	Addiction to drugs	Addiction to alcohol
1. Parents of children with ICP	108.04	99.40
2. Parents of children without neurological and somatic pathology	106.24	97.36
T-test	0.567	0.530

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

The results presented above show that both groups more than average indicators of addiction to drugs, i.e. parents have an increased tendency to addictive behavior, a high focus on the use of psychoactive substances and an increased risk of developing psychological dependence on psychoactive substances. We can assume that they have a risk of developing alcohol dependence under certain social conditions. Since parents raising children with cerebral palsy are under constant stress and they have to solve daily difficulties in concerns of a sick child.

To identify the presence and intensity of depression among parents of children with ICP and in parents of children without neurological and somatic pathology, the Beck Depression Scale (Beck, 2014) was used. The results are shown in Table 3.

Table 3. Beck Depression Scale Index

Examinees	Depression Scale
1. Parents of children with ICP	5,84
2. Parents of children without neurological and somatic pathology	3,24
T-test	2.053*

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

Student's T-test statistical analysis revealed a significant fact that parents of children with cerebral palsy have a higher level of depression than parents of children without neurological and somatic pathology. Depressive state of parents of children with ICP is expressed in low mood and sense of guilt. After the birth of a child with cerebral palsy, parents are unable to change anything. Their condition is defined as a psychological and social "dead end", which is combined with high physical and mental stress followed not only with the nervous system breakdown, but also the body exhaustion in general. Also, mothers have decreased mental tone, low self-esteem, which is manifested in the loss of the taste of life, the inability to become self-fulfilled, as well as losing interest in themselves as women.

To determine the quality of life of parents raising children with ICP and parents raising children without neurological and somatic disorders of the musculoskeletal system, The Quality of Life Assessment inventory (SF-36 Health Status Survey) was used. The results are presented in Table 4.

Table 4. The Quality of Life Assessment inventory index. (SF-36 Health Status Survey)

Scores	Parents of children with ICP	Parents of children without neurological and somatic pathology	T-test
1.Physical functioning (PF)	76.60	88.00	-2.370*
2.Physical role functioning (RP)	65.00	71.00	-0.590
3.Bodily pain (BR)	65.64	77.92	-1.772
4.General health (GH)	59.04	71.08	-2.583*
5.Vitality (VT)	52.60	66.20	-2.468*
6. Social role functioning (SF)	65.16	78.32	-2.016*
7.Emotional role functioning (RE)	59.96	71.96	-1.016*
8. Mental health (MH)	55.20	74.92	-3.738***

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

The results presented above show that parents of children with cerebral palsy have lower scores than parents of children without neurological and somatic pathology. The former perform the following: physical activity is limited by their state of health; pain significantly limits the ability of parents to freely engage in daily activities, including work in and outside the home; reduced activity; significant restriction of social contacts. In addition, the psychological health of parents of children with cerebral palsy is much lower than that of parents of children without neurological and somatic pathology. These indicate the parents' anxiety and depressive experiences, as well as their mental health problems.

The following methods were used to identify the features of parent-child relationships in families where children with ICP are raised: inventory of the emotional relations in the family by E. I. Zakharova and a parental attitude inventory by E. S. Schaefer and R. Q. Bell (PARI method). The results are shown in Tables 5 and 6.

Table 5. Inventory of the emotional relations in the family index. (E. I. Zakharova)

Scores	Parents of children with ICP	Parents of children without neurological and somatic pathology	T-test
1. Accepting the child's condition	3.32	3.36	0.530
2. Understanding the causes of condition	3.16	3.52	-0.130
3. Empathy	3.24	3.28	-1.569
4. Sensitivity block	9.64	9.88	-0.194
5. Maternal feelings when interacting with the child	3.72	4.32	-0.456
6. Unconditional acceptance	3.56	3.92	-2.579*
7. Self-attitude as a parent	3.84	3.64	-1.729
8. Prevailing emotional background of interaction	3.48	3.24	0.908
9. Emotional acceptance block	14.40	14.56	1.905
10. Physical contact eagerness	3.60	3.32	-0.292
11. Providing emotional support	3.44	2.88	1.065
12. Focus on the child's state when building an interaction	3.00	2.80	2.395*
13. Ability to influence the child's condition	3.36	3.20	0.718
14. Block of behavioral manifestations of emotional interaction	13.16	12.20	1.786

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

Table 6. Parental attitude inventory index (PARI method). (E. S. Schaefer and R. Q. Bell)

Scores	Parents of children with ICP	Parents of children without neurological and somatic pathology	T-test
1. Interests are limited to family matters only	14.20	11.24	4.344***
2. Mother's sense of self-sacrifice	14.16	12.44	2.287*
3. Family conflicts	12.92	11.88	1.313
4. Hyperauthority of parents	15.20	13.72	2.316*
5. Dissatisfaction with the role of hostess	12.52	10.40	2.824**
6. Indifference of the husband, not being involved in the family matters	12.76	11.92	1.432
7. Dominance of mother	12.76	11.92	1.001
8. Mother's dependence	15.48	15.68	-0.343
9. Verbalization, prompting verbal response	14.96	16.20	-2.175
10. Partnership relation	12.80	14.40	-2.212
11. Child's activity development	14.64	13.84	0.935
12. Equalizing relations between parents and children	15.20	14.92	0.397
13. Irritability	11.84	10.60	1.593
14. Excessive strictness with the child	11.80	11.08	0.807
15. Avoiding contact with a child	11.24	11.16	0.106
16. Excessive care, establishing dependent relations	12.52	12.28	0.334
17. Resistance overcoming, will suppression	13.20	13.12	0.117
18. Security establishment, fear to offend	14.20	13.84	0.495
19. Exclusion of non-family influences	13.12	11.60	1.983
20. Aggressiveness suppression	12.56	12.52	0.057
21. Sexuality suppression	11.80	10.16	1.934
22. Excessive intervention in the child's personal space	11.00	11.76	1.632
23. Intention to speed up the child's development	11.84	11.80	0.053

Note: \* -with  $p=0,05$ ; -with  $p=0,01$ ; -with  $p=0,001$

These figures show that parents raising children with cerebral palsy accept their children under any circumstances and under any conditions, and try to focus on the state of their child. They make sure that there are no excessive requirements in the intellectual and physical sphere of life that would negatively affect the child's condition.

The interests of mothers of children with ICP are limited only to the interests and concerns of the family; they are featured with a sense of self-sacrifice in the role of the mother. However, they strive for authority in the family, try to dominate the children, but at the same time they are afraid to offend them.

To identify possible relationships between the personality of parents raising children with ICP and the features of their parent-child relationships, a correlation analysis method (Pearson's linear correlation coefficient) was used. That allowed us to obtain the following results: 1) the older the parent is, the more verbal influence he has on the child; he/she usually insists on fulfilling the requirements, using yells and complaints in order to make the child obey; 2) parents who adequately assess the child's condition do not lose valuable time and develop the child in every possible way, both physically and intellectually; 3) in the case of unconditional acceptance of the entire situation of raising a special child, mothers begin to feel uncomfortable and unhappy in their family, while in different life situations they try to minimize contact with their child; 4) if a parent has a negative attitude to their parental function, their physical and emotional state deteriorates. There are restrictions in the daily duties, due to the deterioration of the emotional and physical condition. Then, a woman, who has no emotional contact with the child, is dissatisfied with the mother and homemaker's role. Thus, it would manifest itself in the unconscious avoidance of close interaction with the child that will certainly have an impact on balanced upbringing and development of the child. A woman in a state of harmony and emotional stability will strive to create emotional intimacy and close emotional relationships with her child, which will certainly have a beneficial effect on the child's mental and physical development. Parents, in situations of providing emotional support to their child, are willing to listen and understand him/her, but at the same time they seek authority by dominating. In a family with predominantly authoritarian parenting style, if a child has difficulties, emotional support and care will be provided with all the importance of his feelings and experiences. However the support and understanding from friends and relatives will be limited by the parents, to exclude adverse factors that may affect his/her psychosomatic state.

## **Discussions**

The results allowed us to make the following conclusions. First, parents raising children with cerebral palsy have a reduced level of communication, and their ability to predict life events and situations is not sufficiently expressed. Second, parents of both groups have the increased tendency to addictive behavior,

the high focus on the use of psychoactive substances and the increased risk of developing psychological dependence on psychoactive substances. Third, parents of children with ICP have a higher level of depression than parents of children without musculoskeletal disorders. Fourth, parents of children with cerebral palsy have a decrease in life activity and general health, their physical activity is limited by the state of health, compared with the standardization group. Fifth, the interests of mothers of children with cerebral palsy are limited only to the interests and concerns of the family; they tend to feel self-sacrifice in the role of the mother. Sixth, parents who adequately assess the child's condition strive not to lose time and develop the child in every possible way, both physically and intellectually.

Thus, the hypothesis that the psychological features of parents who raise children with cerebral palsy have a specific peculiarity in comparison with parents who raise children without pathology of the musculoskeletal system was confirmed in the course of the study.

## **Conclusion**

The quantitative results obtained in the course of the study and their qualitative interpretation allowed us to hereinafter determine the content of the joint correctional work of psychologist, teacher and parents aimed at the successful adaptation of children with ICP to life. The obtained data can be used in the counseling practice of a psychologist in order to optimize the parent-child relationship and the adaptation process.

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