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## PARENT-CHILD RELATIONS IN FAMILIES THAT BRING UP DOWN SYNDROME CHILDREN

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### Abstract

Down syndrome children need special attention. As long as the illness is often accompanied by mental disorders, there should be an individual approach to child in upbringing and education. This compels parents to adjust their rhythm of life in accordance with child's needs. Difficulties in raising a child with special needs can lead to a deterioration in the attitude of parents towards the child. This comes out in the behavior of parents and leaves an imprint on the psychological state of the child, his character and subsequent life.

**Materials and methods:** 97 Down syndrome children were examined. All patients met the inclusion criteria. The patients' parents gave informed consent to the participation in the study. Down syndrome in children has been genetically verified. Patients were divided into two groups according to the criterion of ability to verbal communication: group 1 (G1) included 77 children capable of verbal communication, group 2 (G2) – 20 children who did not speak. Individualization in the most of both groups respondents was at an average level, which indicated sufficient parents' acceptance of the individual characteristics of the child, sufficient attention to his interests, satisfaction with the time spent together. Cooperation did not show statistically significant differences in G1 and G2. The average score on this

indicator did not differ in both groups ( $6.87 \pm 1.13$  for G1,  $6.75 \pm 1.10$  for G2). Statistically significant difference between G1 and G2 was found in symbiosis ( $4.25 \pm 1.43$  points against  $5.10 \pm 1.55$  points, respectively). Authoritarianism in G1 was  $3.27 \pm 1.26$  points, in G2 –  $4.05 \pm 1.60$  points, which corresponds to the average level of severity and means achieving a balance between giving the child freedom of action and the establishment of restrictions. Disability in G1 and G2 was  $2.43 \pm 1.40$  and  $2.90 \pm 1.77$ , respectively, which corresponds to a low level of its severity: parents of Down syndrome children are generally not inclined to increase the defects of their children, regardless of their language skills.

**Key words:** Down syndrome; parent-child relations; parenting/psychology; verbal communication.

**Relevance.** In childhood personality develops rapidly. Parents fulfill the role of a standard for the formation of the child's behavioral patterns and worldview. The example of interpersonal relationships in the family is followed by the child and then used as a template for building his or her own relationships [1].

Children with chronic diseases need medical supervision and timely treatment. As a result, they remain completely dependent from their parents for longer than healthy children. This means that psychological situation in the family affects them more [2, 3].

Children with Down syndrome need special attention [4]. As long as the illness is often accompanied by mental disorders, there should be an individual approach to child in upbringing and education [5]. This compels parents to adjust their rhythm of life in accordance with child's needs [6, 7].

Difficulties in raising a child with special needs can lead to a deterioration in the attitude of parents towards the child [8]. This comes out in the behavior of parents and leaves an imprint on the psychological state of the child, his character and subsequent life [9].

Almost 50% of parents of children with special needs show a tendency to excessive emotional distancing from their children, and another 15% – to excessive concentration on the child [10]. For parents with Down syndrome children (DSC), no special features of interpersonal relationships have been identified so far, which makes it impossible to provide targeted medical and psychological assistance to such families.

**The purpose:** to determine the characteristics of parents' attitudes towards Down syndrome children (DSC).

**Contingents and methods:** 97 DSC and their parents participated in the study. All patients in the study met the inclusion criteria. The patients' parents gave informed consent to

the study. Down syndrome in children has been genetically verified. Patients were divided into two groups according to the criterion of ability to verbal communication: group 1 (G1) included 77 children capable of verbal communication, group 2 (G2) – 20 children who did not speak.

Features of parents' attitude to children with Down syndrome were defined using PAQ (Parental Attitude Questionnaire, A. Ya. Varg and V. V. Stolin). Reliability of differences between groups was calculated using the Mann-Whitney test. To establish the interaction of indicators of different subscales within each group, the calculation of Spearman's rank correlations was performed. All statistical calculations were performed using the program STATISTICA 10.0.

**Results and discussion.** DSC were divided in two groups. G1 consisted of children who were able to verbal communication. G2 contained patients who were not able to verbal communication. Children`s parents were explored with PAQ. The average values obtained from both groups were compared and statistical analysis was conducted. The following data was found:

- *individualization* in both groups in most respondents is at an average level, which indicates sufficient acceptance by parents of the individual characteristics of the child, sufficient attention to his interests, satisfaction with the time spent together. The number of respondents who showed a high level of individualization differs significantly in the two groups (1.30% in G1 and 10% in G2;  $p < 0.01$ ). This means that there are more parents who show a strong emotional attachment to their children in G2 than in G1. This phenomenon can be explained by the expressed guilt of parents in G2 for their children`s defects in language development and social abilities, as well as by an increased desire to compensate for children's defects with love for them.

A low level of individualization was not found in any of the groups;

- *cooperation* did not show statistically significant differences in G1 and G2. The average score on this indicator did not differ in both groups ( $6.87 \pm 1.13$  for G1,  $6.75 \pm 1.10$  for G2), but there is a noticeable difference in the distribution between the level of expression of cooperation within groups: in G1 66.23% of parents showed a high level of cooperation, and only 33.77% – the average level of cooperation, while in G2 the number of parents with a high and average level of cooperation was almost the same. The reason may be that parents in G1 find it easier to interact with the child due to the possibility of using verbal communication, while parents with G2 have to limit themselves to non-verbal contact with the child. The parents of any group did not demonstrate the low level of cooperation;

- a statistically significant difference between G1 and G2 was found in *symbiosis* (4.25±1.43 points against 5.10±1.55 points, respectively). This difference was observed due to a significant variation in the number of individuals who showed a high level of symbiosis (18.18% in G1 and 45% in G2; p=0.02). This result indicates that in G2 there is no significant psychological distance in parent-child relationships, the child is completely under the protection of an adult. This difference may be due to the fact that parents of children from G2, who are unable to verbal communication, feel that they are more important in their children's life and establish a stronger connection with them than the parents of children who talk.

In both groups, a small amount of parents was found to show low symbiosis with the child. Consequently, there is a low prevalence of significant psychological distancing of parents from children with Down syndrome;

- *authoritarianism* in G1 was 3.27±1.26 points, in G2 – 4.05±1.60 points, which corresponds to the average level of severity and means achieving a balance between giving the child freedom of action and the establishment of restrictions. This indicator more often reach a high level in parents from G2, due to a heightened sense of responsibility for the child, unable to make language contact. A low level of authoritarianism is more common in parents with G1 – such parents have little control over the child's behavior, because children capable of verbal communication seem more independent to their parents;

- *disability* in G1 and G2 was 2.43±1.40 and 2.90±1.77, respectively, which corresponds to a low level of its severity: parents of children with Down syndrome are generally not inclined to increase the defects of their children, regardless of their language skills . However, it should be noted that 15% of parents from G2 showed high rates of disability, which indicates the perception of the child as a burden that complicates the lives of parents. In G1, high rates of disability were not detected.

The averages for all PAQ subscales for both groups and the statistical difference between the results of G1 and G2 are shown in Table 1.

Table 1

The average PAQ for both groups of DSC

Name of subscale	G 1	G 2	P
Individualization	13,06±2,72	15,55±4,24	<0,01
Cooperation	6,87±1,13	6,75±1,10	0,51
Symbiosis	4,25±1,43	5,10±1,55	0,02
Authoritarianism	3,27±1,26	4,05±1,60	0,09
Disability	2,43±1,40	2,90±1,77	0,32

*Note: the results obtained were considered reliable at p <0.05.*

Data on the number of individuals in both groups and the results of different levels for each subscale are shown in Table 2.

Table 2

Number of the patients in both groups and subscales different levels

	G 1						G 2					
	High		average		low		high		average		low	
	p.	%	p.	%	p.	%	p.	%	p.	%	p.	%
Individualization	1	1,30	76	98,70	-	-	2	10	18	90	-	-
Cooperation	51	66,23	26	33,77	-	-	9	45	11	55	-	-
Symbiosis	14	18,18	52	67,53	11	14,29	9	45	9	45	2	10
Authoritarianism	5	6,49	51	66,23	21	27,27	6	30	11	55	3	15
Disability	-	-	31	40,26	46	59,74	3	15	6	30	11	55

A correlation analysis of indicators that reflect the attitudes of parents to children with Down syndrome within each group was carried out, in order to define the relationships between the various components of the parent-child relationships.

For G1, the data on the correlations between the indicators of PAQ are given in Table 3.

Table 3

Correlations between PAQ indicators, G1

PAQ subscale	individualization	cooperation	symbiosis	authoritarianism	disability
Individualization	1				
Cooperation	0,04	1			
Symbiosis	<0,01	<b>0,30</b>	1		
Authoritarianism	<0,01	<b>0,60</b>	<b>0,55</b>	1	
Disability	<b>0,25</b>	<b>0,50</b>	<b>0,40</b>	<b>0,50</b>	1

*Note: correlations were considered strong at  $r \geq 0.7$ , moderate at  $r = 0.3-0.6$ , and weak at  $r < 0.3$ . The results obtained were considered reliable at  $p < 0.05$ . Strong correlations are highlighted in dark gray, moderate correlations in light gray, and weak correlations in white.*

The following correlations between the indicators of PAQ in the parents of patients in G1 were identified and described:

- it has been established that individualization is the only component of parent-child relationships that has a weak connection with other indicators. Cooperation, symbiosis, authoritarianism, disability have medium-strength correlations, and therefore, most components of the parent-child relationships have moderate interaction and common psychogenesis.

Visualization of the relationships between the components of parent-child relationships in G1 is shown in Figure 1. Note: moderate correlations are marked by a thin line, weak –by dotted.

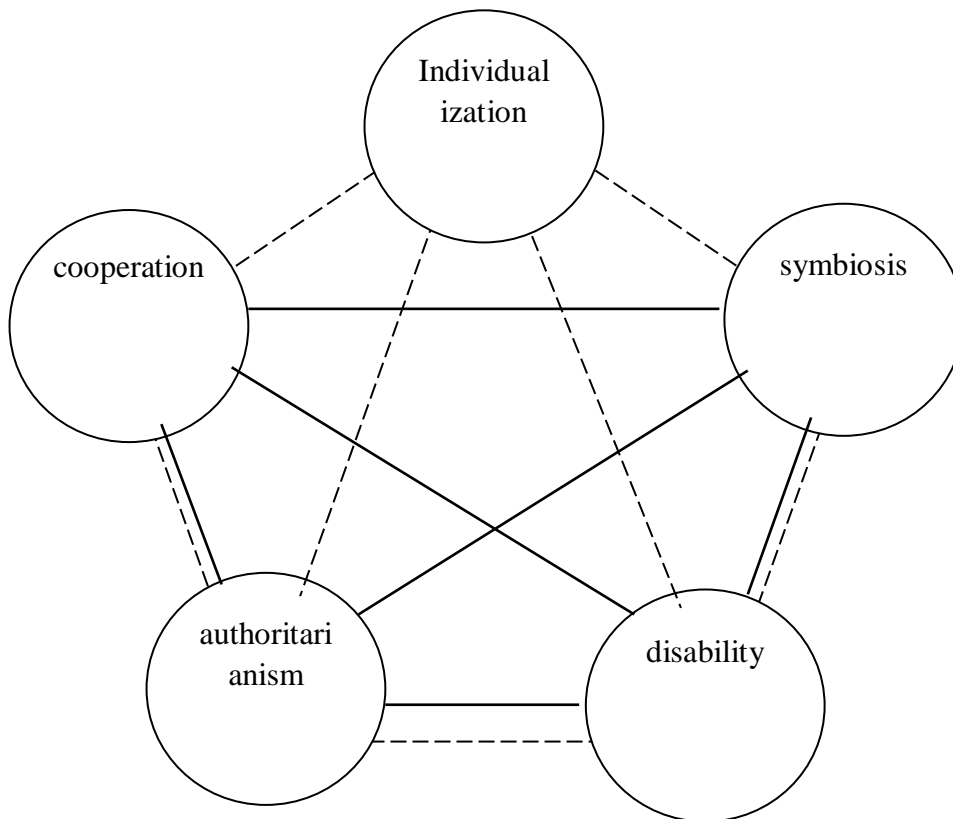


Fig. 1. Visualization of the relationships between the components of parent-child relationships in G1

For G2, the data on the correlations between the indicators of parental attitudes are given in Table 4.

Table 4

Correlation between parental attitudes, G2

PAQ subscale	individualization	cooperation	symbiosis	authoritarianism	disability
Individualization	1				
Cooperation	0,12	1			
Symbiosis	0,18	<b>0,84</b>	1		
Authoritarianism	<b>0,50</b>	<b>0,56</b>	<b>0,72</b>	1	
Disability	0,11	<b>0,80</b>	<b>0,70</b>	<b>0,61</b>	1

*Note: correlations were considered strong at  $r \geq 0.7$ , moderate at  $r = 0.3-0.6$ , and weak at  $r < 0.3$ . The results obtained were considered reliable at  $p < 0.05$ . Strong correlations are highlighted in dark gray, moderate correlations in light gray, and weak correlations in white.*

Features of correlations between the components of PAQ in G2:

- individualization has a weak correlation with such indicators as cooperation, symbiosis and disability, and the connection of medium strength with authoritarianism, which indicates its low impact on other components of the PAQ;
- authoritarianism was characterized by strong correlations with symbiosis and medium-strength correlations with all other components of the PAQ;
- formation of a complex “cooperation-symbiosis-disability” with strong correlations within, was noted, which indicates a significant interaction between these components.

Visualization of the relationships between the components of parent-child relationships in G2 is shown in Figure 2. Note: strong correlations are indicated by a bold line, moderate – by a thin line, weak – by a dotted line.

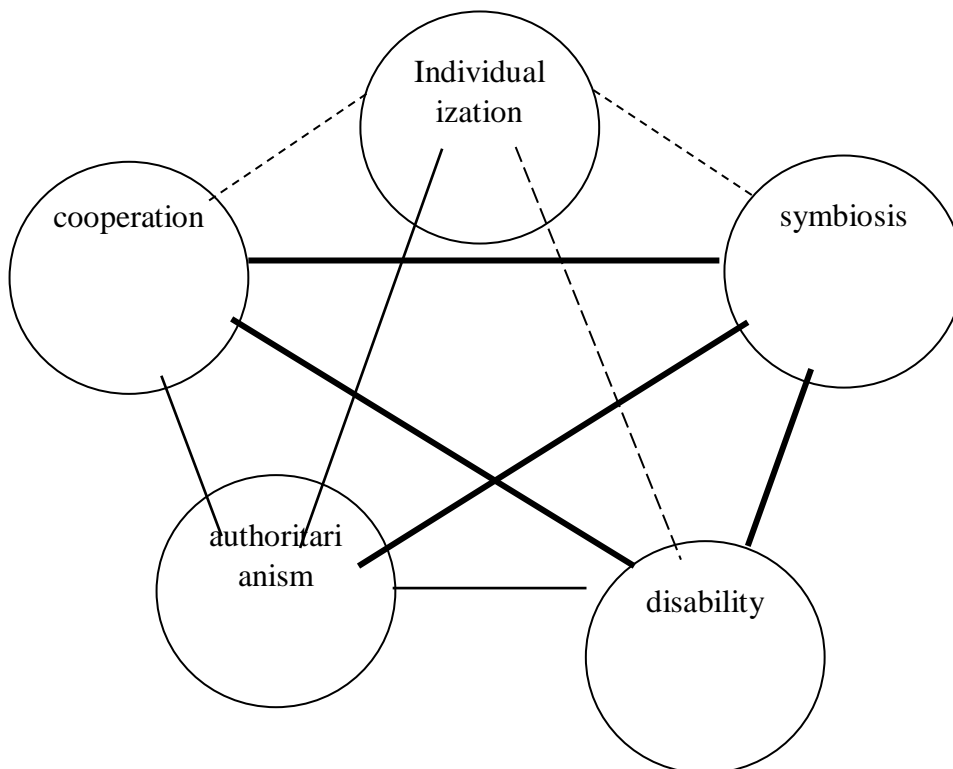


Fig. 2. Visualization of the relationships between the components of parent-child relationships in G2

**Conclusions.** Individualization in both groups in most respondents is at an average level, which indicates sufficient acceptance by parents of the individual characteristics of the child, sufficient attention to his interests, satisfaction with the time spent together.

Cooperation did not show statistically significant differences in G1 and G2. The average score on this indicator did not differ in both groups ( $6.87 \pm 1.13$  for G1,  $6.75 \pm 1.10$  for G2).

Statistically significant difference between G1 and G2 was found in symbiosis ( $4.25 \pm 1.43$  points against  $5.10 \pm 1.55$  points, respectively).

Authoritarianism in G1 was  $3.27 \pm 1.26$  points, in G2 –  $4.05 \pm 1.60$  points, which corresponds to the average level of severity and means achieving a balance between giving the child freedom of action and the establishment of restrictions.

Disability in G1 and G2 was  $2.43 \pm 1.40$  and  $2.90 \pm 1.77$ , respectively, which corresponds to a low level of its severity: parents of children with Down syndrome are generally not inclined to increase the defects of their children, regardless of their language skills.

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