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COHESION AND ADAPTABILITY OF A FAMILY WITH A CHILD WITH INTELLECTUAL DISABILITY AND PARENTS' SENSE OF LONELINESS DURING THE SARS-COV-2 CORONAVIRUS PANDEMIC IN POLAND

**Spójność i zdolności adaptacyjne rodziny z dzieckiem niepełnosprawnym
intelektualnie oraz poczucie osamotnienia rodziców w czasie pandemii
koronawirusa SARS-CoV-2 w Polsce**

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Abstract

We are currently experiencing many changes, which are the consequence of the coronavirus SARS-CoV-2 pandemic which occurred around the world. Families with a child with disabilities, self-isolated in family homes, often deprived of contact, help and support, and worried about the situation of their disabled children, their health, specialized rehabilitation, education or therapy, are in a particularly difficult situation. The aim of this article is to diagnose the sense of loneliness of a family with a child with disabilities as a system and its cohesion and adaptability in the time of the SARS-CoV-2 coronavirus pandemic. For the purposes of the research, tools such as the De Jung Gierveld Scale were used to

examine the sense of loneliness and the *FACES III* family questionnaire was used to measure cohesion and adaptability. The research was conducted in a group of 131 people, including parents and children with intellectual disabilities, and revealed a relationship between loneliness and the level of family cohesion and adaptability, as well as a relationship between mothers' loneliness and fathers' loneliness. However, an association of parents' sense of loneliness with the sense of loneliness of children with intellectual disabilities was not confirmed. Diagnosis from the obtained research results can contribute to outlining the direction of preventive, supportive and therapeutic interventions resulting from the SARS-CoV-2 coronavirus pandemic.

Keywords: family systems, cohesion, family adaptability, young people with intellectual disabilities at the time of SARS-CoV-2 coronavirus.

Streszczenie

Obecnie doświadczamy zmian, które są konsekwencją występującego w wielu krajach koronawirusa SARS-CoV-2. W szczególnie trudnej sytuacji znajdują się rodziny, których członkiem jest dziecko niepełnosprawne. Rodziny samoizolowane w domach rodzinnych, często pozbawione kontaktów, pomocy i wsparcia, z troską o sytuację swoich niepełnosprawnych dzieci, ich zdrowie, specjalistyczną rehabilitację, edukację czy terapię. Celem artykułu jest diagnoza poczucia osamotnienia rodziny z dzieckiem niepełnosprawnym jako systemu oraz jej spójności i zdolności adaptacyjnych w dobie pandemii koronawirusa SARS-CoV-2. Na potrzeby badań wykorzystano takie narzędzia jak skala De Jung Gierveld do badania poczucia osamotnienia oraz kwestionariusz rodzinny *FACES III*. Badania zostały przeprowadzone w grupie 131 osób, w tym rodziców i dzieci z niepełnosprawnością intelektualną i wykazały związek między poczuciem osamotnienia a poziomem spójności rodziny i zdolnościami adaptacyjnymi, a także związek między poczuciem osamotnienia matek i poczuciem osamotnienia ojców. Nie potwierdzono natomiast związku poczucia samotności rodziców z poczuciem samotności dzieci z niepełnosprawnością intelektualną. Diagnoza z uzyskanych wyników badań może przyczynić się do nakreślenia kierunku interwencji profilaktycznych, wspierających i terapeutycznych wynikających z pandemii koronawirusa SARS-CoV-2.

Słowa kluczowe: systemy rodzinne, spójność, adaptacyjność rodziny, młodzież z niepełnosprawnością intelektualną w okresie występowania koronawirusa SARS-CoV-2.

Introduction

The time of the SARS-CoV-2 coronavirus pandemic is particularly affecting family systems including a child with a disability. The COVID-19 pandemic continues to be a major global concern. Therefore, many families, and especially families with a child with disabilities, are confronted with a variety of challenges that range from disruptions in family functioning to anxiety arising from concern for the disabled child, his or her education, therapy and health (Chen et al., 2021, 1). The situation of the pandemic is challenging for the whole community; however, family systems including a child with disabilities are in a particularly difficult situation due to many constraints, including the burden of caring for a disabled child, lack of support, or limited access to support (Glac & Zbebska, 2020). Many families with children with disabilities experience numerous difficulties. External support from other members of the family system, and also external support as a result of obstacles or disturbances in life, can be disrupted. The situation is also aggravated by the need to care for the child at home and provide support

in remote education (Chen et al., 2021) The anxiety and stress experienced by the parents can have a negative impact on family relationships, the well-being of the parents and the well-being of the child with a disability. Social isolation of parents of children with disabilities significantly affects their mental functioning, increases their fear of COVID-19 infection, or its consequences for the health and functioning of the child with a disability, leading to a reduction in their sense of security (Kim et al., 2021). Parents of children with disabilities experience many negative emotions as early as at the moment of the child's diagnosis, such as shock or exhaustion from caring for the child, his or her behaviour and special needs, which often leads them to experience burnout syndrome. Parents in these situations seek effective coping strategies, social contacts and support. The SARS-CoV-2 coronavirus situation prevents the kinds of contacts and relationships that build a sense of security and support. Parents may therefore have problems controlling negative emotions, such as sadness or helplessness, leading to feelings of powerlessness and loneliness (Ślifirczyk et al., 2016).

In theory, as well as in research, the contemporary dominant paradigm of the family is the systemic approach. In systems theory there are many theoretical models of the family (Przybylska & Wajsprych, 2018, 50). One particularly interesting systemic view of the family emphasizes the importance of relations and ties as well as communication between its individual system elements (Barłóg, 2020, 20). There are many studies on the issue of the family in the Polish literature, especially in psychology (Radochoński, 1987; Margasiński, 2015), but also education (Gruca-Miąsik, 2004, 2005, 2007), Barłóg, 2020a, 2020b). However, it seems justified to present the main assumptions of systems theory in relation to the family system (Gruca-Miąsik, 2004, 113–126; 2005, 119–129; 2007, 300–311; Barłóg, 2020a, 2020b). The system orientation proposes a broader way of looking at the individual. It asks a question as to not only how others affect the person, but also how the behaviour of a given person affects others in a given family group. This is related to the assumption that the individual is an element of numerous systems and subsystems, subject to conditions defined on this account, the omission of which must make cognition imperfect. The basis of this approach is to expose the relations that occur between the parts, and to analyse events in the context, i.e. against the background of the environment, rather than in isolation (Margasiński, 2015, 6).

Assuming that the family is a space of many relations and bonds which are the basis for the development of personality, it is justified to present a family with a child with disabilities in terms of systemic theory. This theory, growing out of biological and physical sciences, also finds justification in reference to interpersonal interdependencies and bonds (Barłóg 2020b). This theory, created in the 1930s, is one of the so-called global theories. As a method it is a way of perceiving and analysing phenomena and processes of man and his space in the surrounding world, which were inaccessible until

recently. The Circumplex Model focuses on three main dimensions of marital and family systems: *cohesion*, *flexibility* and *communication*. The main hypothesis is the assumption that balanced couple and family systems are more functional than unbalanced systems (Olson, 2000). Stressing the importance of relationships between different elements of the family system with regard to circular relationships, in 1979 David H. Olson, Candyce S. Russel and Douglas H. Sprenkle from the University of Minnesota developed the Circumplex Model as a precise scientific theory, which was supplemented and enriched over the years (Olson et al., 1979). The model developed is closely linked to Salvador Minuchin's conception which assumes that a human always functions in a social context that has a significant impact on him or her. In this approach, the whole context of the requirements of individual functioning is a basic element of the social structure, which is the family (Przybylska & Wajsprych, 2018). In David H. Olson's Circumplex Model, the family is characterized by such dimensions as: *cohesion*, *flexibility* and *communication* in family life. Cohesion refers to the emotional bond between the elements of the family system, flexibility is the ability of the family to adapt to changes, while communication is the ability of the members of the family system to communicate positively (Margasiński, 2015). With regard to cohesion, loose families, separated families, families as connected systems and as open systems were distinguished. Intermediate (balanced) levels of family functioning cohesion are expected. On the other hand, in terms of the flexibility of family life, the following families are distinguished: rigid, structured, flexible and chaotic. In the model, the decisive factor is the balance between the ability of the family system to introduce changes and the preservation of the existing balance (Margasiński, 2015). Many studies conducted have sought to answer the question of how family systems including a child with intellectual disabilities function (Villavicencio & López-Larrosa, 2020). Since the COVID-19 pandemic is currently a serious problem for many family systems, it seems interesting to learn about the functioning of individual members of families with children with intellectual disabilities in Poland, about their sense of loneliness, and whether it is related to family cohesion and adaptability in the situation of the SARS-CoV-2 coronavirus pandemic. The sense of loneliness is understood as a subjectively felt emotional state that results from a lack of interpersonal relationships.

Method

The aim of the research was to determine the sense of loneliness and its relation to cohesion and adaptability in families, in the opinions of mothers, fathers and children with intellectual disabilities in the time of the SARS-CoV-2 coronavirus pandemic. Therefore, the main problem of the research was narrowed down to the question of how a family with a child with mild intellectual disabilities functions in the context of its cohesion and adaptability, and whether this is related to the feeling of loneliness of its members

in the situation of the SARS-CoV-2 coronavirus pandemic. What are the levels of cohesion and adaptability of the parents of a child with intellectual disabilities? How strong are the feelings of loneliness of its members (parents and child)? What is the relationship between cohesion and adaptability and the feeling of loneliness of parents of a child with intellectual disabilities? Does the sense of loneliness depend on the gender of the parent, the material situation of the family or the education of the parents?

The empirical study was conducted in late 2020 and early 2021, during the SARS-CoV-2 coronavirus pandemic in Poland. The study was conducted after approval from the bioethics committee for face-to-face contact in treatment centers. Both parents and their children were informed of the purpose of the study and agreed to participate. Participants were also informed that participation in the study was voluntary and that they could withdraw at any stage. The young people with intellectual disabilities completed the questionnaires in the company of the researcher, who clarified any areas of doubt and provided the required support if necessary. Finally, 131 people forming families with a child with mild intellectual disabilities were included in the study.

The study was conducted using the *FACES III Scale*, which presents the respondents with 20 questions about family life using a 5-point rating scale to indicate the frequency of occurrence of a given behaviour in the family (1 – almost never, 5 – almost always). Scores for both subscales are calculated separately.

The second tool used was the *Loneliness Scale* by De Jong Gierveld and van Tilburg (Polish adaptation by Grygiel et al., 2013) for measuring loneliness. The scale is used to measure the sense of satisfaction related to interpersonal relations. Each respondent is asked to indicate to what extent the statements express his or her current situation and feelings. The respondent can answer on a 5-point scale.

Fifty-three children, i.e. young people with mild intellectual disability, participated in the study. All of the children had mild intellectual disabilities (100.0%) and some of them additionally had other disorders. There were 16 girls (30.2%), 30 boys (56.6%), while for seven children (13.2%) no information was obtained about their gender. Thirty young people (56.6%) were aged 13–17, six (11.3%) were between 18 and 20 years old, 16 (30.2%) were aged 21–30, and in the case of one person (1.9%) no information was obtained. Twenty-eight respondents accounting for 52.8% of the surveyed sample declared that they lived in the countryside, 17 (32.1%) lived in towns and six (11.3%) in cities. In relation to the education of the young people surveyed, 30 of them had primary education (56.6%), 15 people had vocational education (28.3%) whereas three (5.7%) had completed secondary school. Two respondents (3.8%) described their level of education as 'other', while in three cases (5.7%) no data were recorded. Analysing the type of school attended by the young people surveyed, responses were obtained from 49 people. Four young people (7.5%) attended mainstream schools, one (1.9%) attended an inclusive school and 44 respondents (83%) attended a special school. Four (7.5%) did not give any answer to this question. Fifty young people with intellectual

disability declared the type of disability they had. The respondents could indicate more than one type of disability. The results are summarised in Table 1. All of the children had mild intellectual disabilities (100.0%), and some of them additionally had other disorders.

Table 1

Type of disability of the respondents

	Indicated		Not indicated	
	<i>N</i>	%	<i>N</i>	%
Intellectual disability	29	58	21	42
Physical disability	7	14	43	86
ASD	22	44	28	56
Other	7	14	43	86

Due to the time of the pandemic, the Internet access of the young people with intellectual disabilities under study was analysed. Internet access was declared by 48 young people, with 42 of them (79.2%) describing it as full and 6 (11.3%) as incomplete. Three young people (5.7%) indicated that they had no access to the Internet, while two (3.8%) did not provide any answer to this question.

Forty-six mothers participated in the survey. One mother (2.2%) stated her age to be between 26 and 30 years old, while the remaining 45 (97.8%) were between 31 and 50 years old. Forty-four of the interviewed women reported their education, of which five (11.4%) had primary education, eight (18.2%) vocational education, 21 (47.7%) secondary education, three (6.8%) incomplete higher education, and seven (15.9%) complete higher education. In 26 cases mothers described the family structure as two-parent (56.5%), in 19 cases as single-parent (41.3%) and in one case a reconstructed family was indicated (2.2%). Twenty-five mothers (54.3%) indicated that they were currently unemployed, 12 (26.1%) were working full-time, six (13%) were working part-time, two were on a disability pension (4.3%) and one was retired (2.2%). Forty-five mothers assessed their material situation. Only one of them (2.2%) stated that their material situation was very good. Eleven women (24.4%) declared their material situation to be good, 24 of them (53.3%) to be sufficient for basic needs, whereas 9 (20%) that it was insufficient for basic needs. Out of the 44 mothers who responded to the question about the support they received, 21 (47.7%) indicated that it was sufficient and 23 (52.3%) insufficient.

Thirty-two fathers participated in the study. All of them declared that they were aged between 31 and 50 years old. Thirty-one of the fathers interviewed reported their education, of which three (9.7%) had primary education, 14 (45.2%) had vocational education, 9 (29%) secondary education, two (6.5%) incomplete higher education, and

three (9.7%) complete higher education. In 24 cases fathers described the family structure as two-parent (75%), in seven cases as single-parent (21.9%) and in one case a reconstructed family was indicated (3.1%). Three fathers (9.4%) reported that they were currently unemployed, 23 (71.9%) were working full-time, three (9.4%) were working part-time, two were on a disability pension (6.3%) and one was retired (3.1%). Thirty fathers assessed their material situation. Eleven (36.7%) declared a good level of material situation, 15 (50%) sufficient for basic needs and four (13.3%) insufficient for basic needs. Out of 30 men who responded to the question about the support they received, half indicated that it was sufficient.

To verify the research hypotheses, statistical analyses were performed using the IBM SPSS Statistics 25 package. They include frequency analyses, descriptive statistics analysis with the Kolmogorov-Smirnov test, Student's t-tests for dependent samples, Student's t-tests for independent samples, one-way analysis of variance in the within-group scheme, Pearson's r coefficient correlation analyses and Spearman's ρ rank correlation analyses. The classical threshold $\alpha = .05$ was considered the level of significance; however, the test statistic probability scores of $.05 < p < .1$ were interpreted as significant at the statistical tendency level.

Presentation of the results

The level of coherence and adaptability

In the next stage, the distributions of results obtained using the FACES III questionnaire were analyzed. First, the results obtained in the group of mothers were analyzed. Full results, enabling the analyses to be performed, were obtained in a group of 45 women. Twenty mothers obtained scores indicating the level of 'disengaged', and fourteen of them obtained a score of 2 points. Nineteen mothers obtained scores indicating the level of 'separated'. Only six mothers achieved 'connected' scores, and there was not a single mother whose cohesion level could be considered 'enmeshed'. Different scores were obtained on the adaptability scale. The results obtained from only one mother allowed us to classify her level of adaptability as 'rigid'. Six mothers obtained scores that allow us to classify the level of their adaptability as 'structured'. The level of 'flexible' was recorded in 18 mothers, while 'chaotic' in 20 mothers. It is worth noting that only one mother obtained the maximum score on the scale (8 points). Then, the results obtained in the group of fathers were analyzed. Full results, enabling the analyses to be performed, were obtained in a group of 30 men. First, the distribution of the level of cohesion was analysed. Fourteen fathers obtained scores indicating a 'disengaged' level, with ten of them obtaining a score of 2. Nine fathers obtained scores indicating a 'separated' level. Only seven fathers scored at the 'connected' level. There was not a single father in the study group whose level on the cohesion scale could be considered as 'enmeshed'. In contrast, the level of the adaptability scale was different. Only three fathers

scored as 'rigid' on the adaptability scale. A further three fathers scored as 'structured'. 'Flexible' was reported by 10 fathers and 'chaotic' by 14 fathers. It is worth noting, however, that no father achieved the maximum score on this scale. All of the results are presented in Figure 1.

In the next stage, it was decided to check whether the level of cohesion and adaptability is different in the group of women and men who form a family together. Such an analysis was carried out on 27 people. A Student's t-test was performed for dependent samples; however, no differences were noted, even at the level of statistical tendency (Table 2). The level of cohesion and adaptability was not significantly different in the group of mothers and fathers.

Table 2

Differences in the level of cohesion and adaptability of mothers and fathers forming a family together

	Mothers		Fathers		<i>t</i>	<i>p</i>	95% <i>CI</i>		Cohen's <i>d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			<i>LL</i>	<i>UL</i>	
Cohesion	35.41	6.39	34.81	7.37	0.77	.447	-0.99	2.17	0.15
Adaptability	29.74	5.28	28.85	5.80	1.15	.262	-0.71	2.48	0.22

Loneliness level of respondents

The next stage presents the distribution of the results obtained on the loneliness scale, beginning with the group of mothers. The average score in the study group was 29.93 points with a median of 26 points. As can be seen in Figure 7, which presents the results aggregated to groups of five points, the most frequent scores were between 20 and 24 and between 25 and 29 points. Individual mothers were characterised by either extremely high or extremely low levels of loneliness (minimum – 14 points, maximum – 55 points). Next, the results for the group of fathers were analysed. The mean score in the study group was 30.70 points, with a median of 30.5 points. As can be seen in Figure 8, scores between 30 and 34 were the most frequent, and scores between 20–24 and 25–29 were similarly numerous. The results in the fathers' group were characterised by less variation compared to the results in the mothers' group. The lowest score obtained in the fathers' group was 17 points, while the highest was 50 points. In the final stage of this series of analyses, the results obtained in the group of young people with disabilities were taken into account. The average score in the study group was 28.77 points with a median of 28.5 points. As can be seen in Figure 9, scores between

25 and 29 points were recorded most frequently. Only one young person with intellectual disability obtained an extremely high score of 55 points, standing out from the whole sample. The minimum value obtained in the survey was 11 points.

The level of loneliness in a group of 27 people forming families (with both parents/carers and a child) was compared. A one-way analysis of variance was performed in the within-group schema. However, the result was not recorded even at the level of the statistical tendency, $F(1.36; 35.34) = 0.31$; $p = 0.652$. As shown in Figure 10, the level of loneliness of both carers – a woman ($M = 29.37$; $SD = 9.42$), a man ($M = 30.48$; $SD = 7.99$) and a child ($M = 28.96$; $SD = 9.71$) was not significantly different.

Relationship of the level of loneliness of parents and a child – a young person with intellectual disability

Then, it was checked whether there is any relationship between the level of loneliness of parents / carers and a child with intellectual disability. Correlation analyses were performed with the Pearson r coefficient. There was a statistically significant relationship between the level of loneliness of women and men (carers), $r = .77$; $p < .001$. The positive sign of the observed correlation means that with the increase in the level of a woman's perceived loneliness, the level of man's loneliness in the examined family also increased. The strength of the observed relationship was very high, which is well illustrated in Figure 2. In contrast, the relationship between the loneliness level of a disabled child and the loneliness of the mother (carer), $r = .17$; $p = .261$; and the loneliness of the father (carer), $r = .21$; $p = .272$ was found not to be even close to statistical significance. This means that the loneliness level of a child (a young person with intellectual disability) did not depend on the loneliness level of his or her parents/carers.

Relationship between parents' and child's level of loneliness and parents'/carers' level of cohesion and adaptability

The relationships between the level of loneliness of parents/carers and the child with a disability and the parents' level of cohesion and adaptability were then tested. Further correlation analyses with Pearson's r coefficient were performed. As can be seen in Table 3, five statistically significant relationships were noted. The mothers' level of cohesion correlated with the level of both her own loneliness and the level of loneliness of her partner (father/carer of the child with disability). The correlation was negative, i.e. as the level of cohesion of the female respondent increased, her and her partner's level of loneliness decreased. The strength of both relationships was high. Similar results were reported for the correlation of the father's level of cohesion. This time, a strong relationship was found for the level of the father's own loneliness while a moderately strong relationship was found for his partner's own loneliness. A moderately strong

negative relationship was also reported between the father's loneliness and his adaptability. The remaining relationships, particularly the correlations between the child's level of loneliness and the cohesion as well as the adaptability of their carers/parents, were found not to be even close to statistical significance.

Table 3

Relationship of the level of loneliness of parents and children with the level of cohesion and adaptability of carers

		Loneliness – mother	Loneliness – father	Loneliness – child
Cohesion – woman	Pearson's r	-.457	-.471	-.164
	significance	.002	.013	.281
Adaptability – woman	Pearson's r	-.086	-.063	-.213
	significance	.577	.753	.160
Cohesion – man	Pearson's r	-.450	-.525	-.100
	significance	.019	.003	.600
Adaptability – man	Pearson's r	-.119	-.446	-.178
	significance	.553	.014	.346

The relationship between the education of parents of children with disabilities and the level of loneliness of parents and the child as well as the adaptability, coherence and family scale scores for carers

Next, it was checked whether there are connections between the level of education of carers of children with disabilities and the level of parents' and children's loneliness, as well as adaptability and cohesion. Further Spearman's ρ rank correlation analyses were performed. As can be seen in Table 4, one statistically significant relationship was noted. The educational level of mothers of children with disabilities correlated negatively with the level of loneliness of their partners (fathers). This means that the higher the educational level of mothers of children with disabilities, the lower the level of loneliness of their partners. The strength of the relationship recorded was moderately high. Two relationships at the level of statistical tendency were also recorded. The educational level of mothers correlated negatively with the level of their own loneliness and positively with the level of cohesion of their partners. Thus, as the educational level of the surveyed mothers of children with disabilities increased, their level of loneliness decreased, and the level of cohesion in their partners' assessment increased. The strength of both these relationships was moderately high. The remaining relationships appeared not to be even close to statistical significance.

Table 4

Relationship between the education of carers of children with disabilities and the level of parents' and children's loneliness and carers' adaptability and cohesion.

		Educational level	
		Mother	Father
Loneliness – woman	Spearman's rho	-.300	-.032
	significance	.051	.875
Loneliness – man	Spearman's rho	-.463	-.062
	significance	.015	.745
Loneliness – child	Spearman's rho	.000	.055
	significance	.998	.770
Cohesion – woman	Spearman's rho	.185	-.084
	significance	.229	.678
Adaptability – woman	Spearman's rho	-.053	-.030
	significance	.733	.881
Adaptability – man	Spearman's rho	-.111	-.075
	significance	.583	.694
Cohesion – man	Spearman's rho	.333	-.078
	significance	.090	.683

Family type of a child with a disability and levels of parent and child loneliness, adaptability and cohesion of carers

In the next step, levels of loneliness, cohesion and adaptability were compared according to the type of family of the child with a disability. The results obtained in two-parent and single-parent families were compared. Student's t tests for independent samples were performed. As can be seen in Table 5, one statistically significant result was recorded. The level of cohesion in the group of mothers was higher in the case of two-parent families. The strength of the recorded effect was moderately high, as indicated by the value of Cohen's d coefficient. There was also a result at the level of statistical tendency in the level of loneliness of mothers, which was lower in two-parent families. The strength of this effect was also moderately high. For the other variables, no results were recorded even at the level of statistical tendency.

Table 5

Family type of child with a disability and levels of parent and child loneliness and adaptability and cohesion of carers

	Two-parent family		Single-parent family		<i>t</i>	<i>p</i>	95% CI		<i>Cohen's d</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			<i>LL</i>	<i>UL</i>	
Loneliness – mother	27.52	8.92	32.39	9.24	-1.74	.089	-10.52	0.78	0.54
Loneliness – father	29.23	8.24	35.25	3.50	-1.42	.169	-14.78	2.74	0.77
Loneliness – child	28.88	9.84	29.68	6.79	-0.31	.762	-6.13	4.52	0.09
Cohesion – mother	36.08	6.24	31.32	6.94	2.39	.021	0.74	8.79	0.73
Adaptability – mother	29.72	5.88	27.84	4.13	1.19	.242	-1.32	5.07	0.36
Adaptability – father	29.59	5.89	25.75	5.19	1.22	.235	-2.67	10.35	0.66
Cohesion – father	35.09	7.68	32.50	6.86	0.63	.535	-5.91	11.09	0.34

Figure 1
Percentage share of cohesion and adaptability scale scores among mothers and fathers

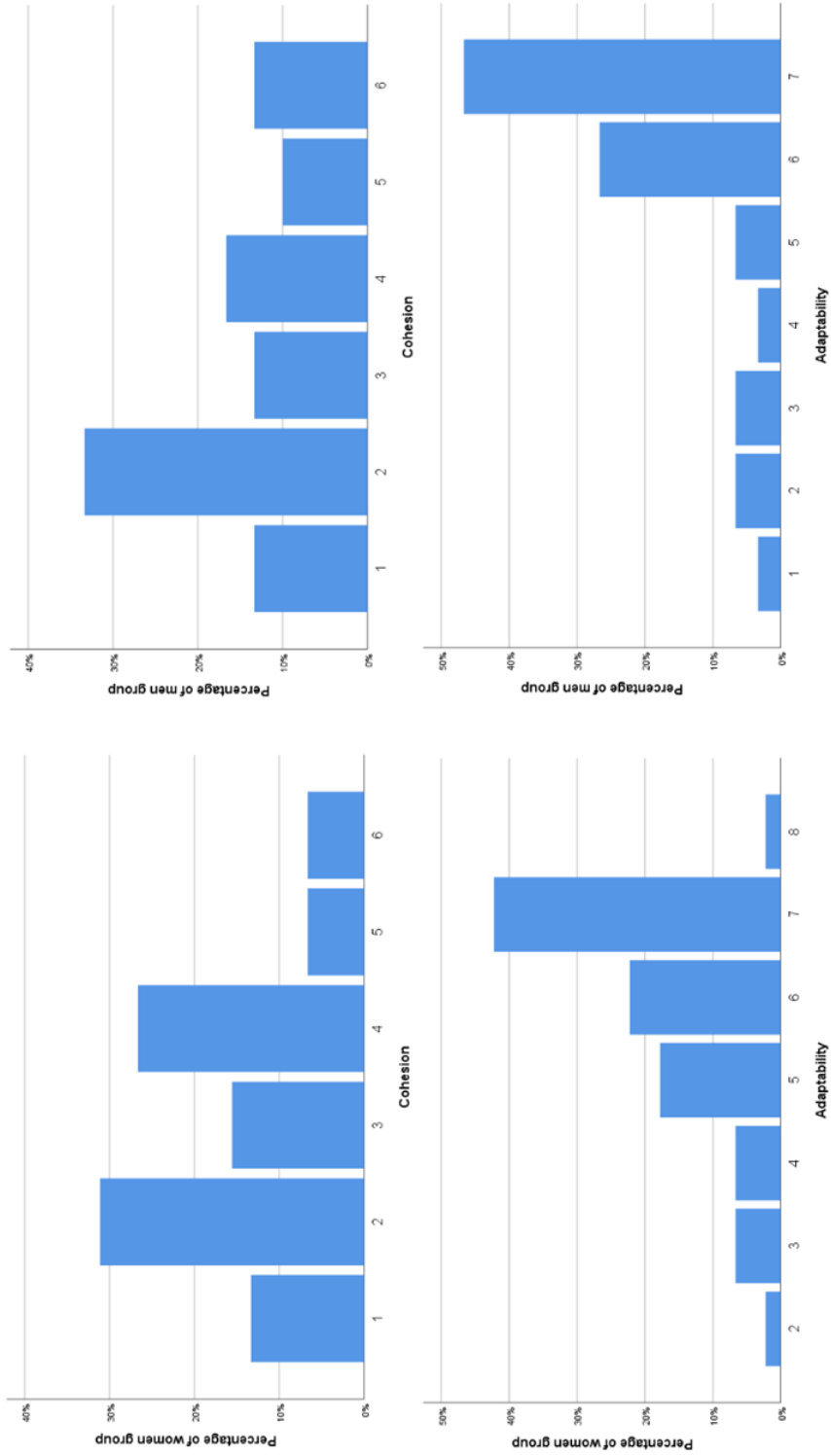
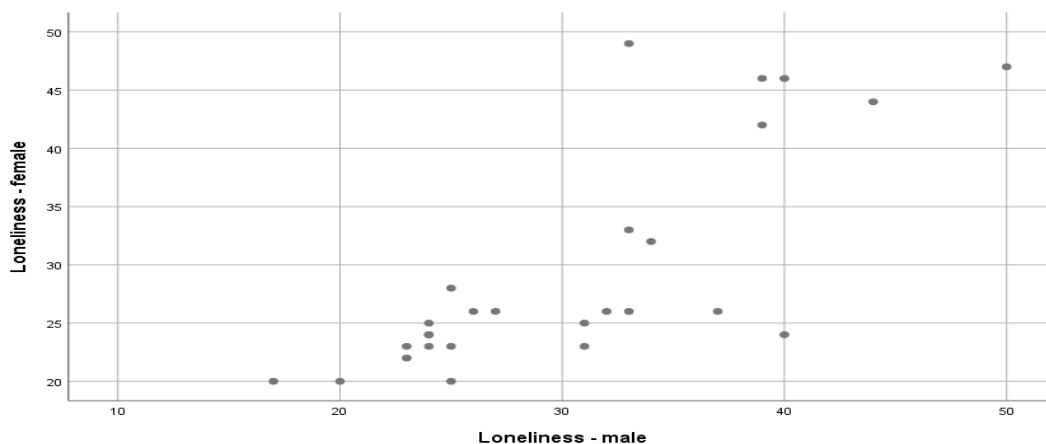


Figure 2

The relationship between the level of loneliness of women and men (parents, carers of children with intellectual disabilities)



Discussion

The research conducted on this topic confirms the many negative impacts of the SARS-CoV-2 coronavirus pandemic (Rumas et al., 2021) on family functioning (Pan et al., 2021) and especially on parents and children with intellectual disability (Willner et al., 2020). The very fact of having a child with intellectual disabilities, especially in the difficult period of adolescence, further compounds this situation (Sekulowicz, 2013). The high level of adaptability of both parents of children with intellectual disabilities in the time of the pandemic confirms that these families have already developed certain strategies of readiness for new challenges and have the ability to use their own resources and adapt to even extremely negative events. This may mean that families with a child with intellectual disabilities, despite the difficulty of access to necessary support, are able to overcome difficulties in making new changes.

In contrast, the level of cohesion of the surveyed mothers and fathers of children with intellectual disabilities is quite different. The majority of parents in the study group have low, or to a lesser extent, moderate levels of this characteristic. This may mean that the parents surveyed feel burdened by their responsibilities for the care of their child, especially in the pandemic situation. The reason could also be adolescent behavioural problems (Mitchell et al., 2016). Differences in levels of cohesion and adaptability may be due to the fact that parents in the pandemic situation are more burdened with the responsibilities of caring for a child with a disability, which may cause them to experience severe anxiety, physical exhaustion or loneliness (Aksamit, 2018, 157–169). Parents expect to be supported in the difficult time during the SARS-CoV-2 coronavirus

pandemic (Willner et al. 2000). Other studies support the thesis of healthy and balanced family functioning (Tsibidaki, 2020) and bonding in families with a child with disability, while at the same time accentuating parents' difficulties in adapting to new challenges that the family face (Villarreal-Zegarra & Paz-Jesus, 2017). Mothers and fathers forming couples are unequivocal in their declared adaptability and cohesion, i.e. they evaluate the functioning of their own family in a similar way. The research confirms a moderate level of feeling of loneliness in the group of parents of children with intellectual disabilities. Individual mothers were characterised by extremely high or low levels of loneliness. Fathers' feelings of loneliness were less differentiated. This may be explained by the fact that up to half of the surveyed fathers explicitly stated that they did not receive any support. Similar results were found when examining family systems including a child with ASD. The higher the level of loneliness experienced by the mothers, the lower the level of balanced coherence and balanced flexibility. In the fathers' group, no statistically significant relationship was found; only as the fathers' sense of loneliness increased, an increase in the sense that their family was enmeshed was confirmed (Barłóg, 2020a).

For comparison, it is worth citing research on cohesion and adaptability, which was also conducted in families of people with multiple sclerosis. Family systems including people with multiple sclerosis were characterised by excessive cohesion. These families generally expressed satisfaction with family life and communicated effectively. As the researchers state, the situation of children of MS patients seems to be particularly difficult. Although high cohesion is adaptive (strong ties give patients a sense of security, support and help), it may pose a threat to the development of children's autonomy. It is possible that parentification (inhibiting children's development) occurs in families, and the process of descendants' independence and separation from the family of origin is disrupted (Treder-Rochna & Jodzio, 2018).

Importantly, the research presented here shows a strong correlation between parents' perceived cohesion, adaptability and parental loneliness in families with a child with intellectual disabilities. If mothers felt more lonely in their family, the level of loneliness of their husbands, the fathers of children with intellectual disabilities, was also higher. However, the level of loneliness of their children was almost completely independent of the level of loneliness of the parents (mother and father).

In the case of a family with a child with disabilities, parents in particular play a key role in providing needed services. However, parents often lack the knowledge, resources and skills to help them overcome the challenges that arise in caring for an adolescent child with disabilities (Vanegas & Abdelrahim, 2016). Research already conducted shows that close ties with parents and peers are a protective factor which helps to meet their emotional needs and has a significant impact on preventive interactions (Wang et al., 2020). Young people's loneliness can motivate them to take on new challenges or form new relationships with their peers. On the other hand, it is worth noting that

excessive closeness to parents may result in the adolescent not wanting close contact with peers, which may limit the expected flexibility to adapt (Morrison & Zetlin, 1988) and may prevent future intimate friendships, thus limiting effective intervention (Wang et al., 2020). It can also pose a threat to the formation of children's autonomy (Treder-Rochna & Jodzio, 2018).

The level of education of the mothers surveyed was related to their sense of loneliness, i.e. educated mothers had a lower sense of loneliness and at the same time influenced the assessment of the partner, i.e. the father of the child with intellectual disabilities, regarding the family as cohesive. Similarly, other studies found that educated mothers of children with intellectual disabilities experienced lower levels of stress, greater control over their children, and used more coping strategies (Villavicencio & López-Larrosa, 2020; Dudek, 2017). As the mothers' education increased, the level of parental loneliness decreased and the sense of cohesion in the family increased, according to the fathers surveyed. The research confirmed that the level of cohesion in the group of surveyed mothers of young people with intellectual disabilities was higher when they were in two-parent families. They could then count on the help of their husband, i.e. the father of the child with disabilities. In this case the mothers evaluated the family as cohesive, full of emotional closeness. Similar results were recorded in relation to the perceived sense of loneliness of mothers of children with intellectual disabilities, with the correlation being clearly weaker. The obtained results show the importance of a two-parent family for the mental well-being of mothers of children with disabilities. Analogous relationships were not observed in the group of fathers surveyed, who in a high percentage indicated a high level of adaptability of their families, while parents with a child with intellectual disabilities needed to support each other more without expecting mainly external support during the SARS-CoV-2 coronavirus pandemic. Similar studies with the use of FACES III also showed significant differences between family cohesion and adaptability depending on the type of family structure (Villarreal-Zegarra & Paz-Jesus, 2017).

The presented research is part of the discussion on the functioning of families raising a child with intellectual disability during the pandemic. This difficult, unusual situation results in many negative consequences for both the people with disabilities themselves and their relatives. The obtained results contribute to the knowledge of the functioning of families with a child with disabilities during the isolation caused by the pandemic, with regard to selected aspects of the family system. The findings can be helpful in developing supportive and therapeutic measures in working with people with disabilities and their families. The proposal presented here shows the family from a systems perspective and, in this context, can provide interesting material for further research and analysis with regard to preventive interventions, so that in the situation of the next pandemic challenges, a family with a child with intellectual disabilities might receive systemic support to counter loneliness and strengthen the cohesion and adaptability of the family system. This study provides a source for comparative research in this area.

The presented problem is not exhausted and should be further explored in order to be able to develop more improved prophylactic and preventive strategies for work with the family and with young people with intellectual disabilities. The results of the study encourage further research on the cohesion and adaptability of families with children with disabilities and the sense of loneliness in the time of the SARS-CoV-2 coronavirus pandemic.

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