Interdisciplinary Contexts of Special Pedagogy NUMBER 19/2017

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How parents of autistic children deal with stress

ABSTRACT: Mieczysław Dudek, *How parents of autistic children deal with stress*. Interdisciplinary Contexts of Special Pedagogy, No. 19, Poznań 2017. Pp. 127–145. Adam Mickiewicz University Press. ISSN 2300-391X

The appearance of a child with a disability is always a source of tremendous stress in the family. This problem is particularly evident in the case of an autistic child because of its unpredictable and untypical development. Every person during their life develops certain mechanisms to deal with difficult situations. According to Lazarus and Folkman (1987), dealing with stress mainly relies on specific intellectual activities and appropriate actions to control the requirements assessed by the person as burdensome or beyond his/her current possibilities. There are many ways of dealing with stress. The most common strategies include those focused on solving the problem (SSZ), emotional overreaction (SSE) and avoidance of stress (SSU) by engaging in substitute activities (ACZ) or seeking social interaction (CSA). It is assumed that an effective way to deal with stress consists in relating the needs and capabilities of an individual. The aim of this article was to investigate the ways of dealing with stress among 130 parents of autistic children.

KEY WORDS: autism, family, stress, dealing with stress,

Introduction

A child's illness or developmental disorder affects the family system and is a source of stress, anxiety and fear for every family member. Having a child with developmental problems affects the existing order in the family and weakens the sense of security. Parents of children with developmental problems are exposed to specific stress factors in their family environment and have no chance to change their situation. Long-term care for a disabled child results in serious physical and mental costs for the parent.¹ This problem is especially evident when having a child with autism because of its unpredictable and untypical development.² Current research confirms that parents of children with autism experience significantly greater stress and anxiety than parents who care for children with the Down syndrome or cerebral palsy.³

An important factor affecting the extent and intensity of parental problems is the difficult and often late diagnosis of autism in the child. The socioeconomic status of the family is equally important, as well as parents' education, place of residence and access to specialized early diagnosis and treatment institutions and the professional organization of care and support for the autistic child. In the absence of these type of institutions, parents are responsible for organizing and coordinating the necessary therapies, education and rehabilitation of the child, and sometimes even providing therapy under the supervision of professionals.⁴ What is particularly bur-

¹ A. Twardowski, Sytuacja rodzin dzieci niepełnosprawnych, [in:] Dziecko niepełnosprawne w rodzinie, I. Obuchowska, ed., WSiP, Warsaw 2008. A. Garncarz-Podlasko, Sytuacja psychospołeczna rodziców dzieci autystycznych w kontekście zespołu wypalania sił, [in:] T. Gałkowski, J. Kossewska, ed., Autyzm wyzwaniem naszych czasów. Wydawnictwo Naukowe Akademii Pedagogicznej. Kraków 2001, pp. 209-217.

² M. Sekułowicz, Niektóre problemy funkcjonowania rodziny dziecka autystycznego, [in:] Autyzm kontrowersje i wyzwania, W. Dykcik, ed., Wyd. Eruditus. Poznań 1994, pp. 201–207; K. Patyk, Rodzice dzieci autystycznych wobec sytuacji trudnych. "Problemy Opiekuńczo-Wychowawcze" 2009; pp. 34-42.

³ E. Pisula, *Małe dziecko z autyzmem*, Gdańskie Wyd. Psychologiczne 2005, pp. 13–23. N. Johnson, M. Frenn, S. Feetham, P. Simpson, *Autism spectrum disorder: parenting stress, family functioning and health- related quality of life*. Fam Syst Health, 2011, 29, pp. 232–252.

⁴ E. Pisula, D. Noińska, Stres rodzicielski i percepcja doświadczeń związanych z opieką nad dzieckiem u rodziców dzieci z autyzmem uczestniczących w różnych formach terapii, "Psychologia Rozwojowa" 2011, Vol. 16, no 3, pp. 75–88.

densome for the parents is the lack of knowledge about the available therapies and the necessity to make the right choices concerning the child's therapeutic options (parents generally lack support in this area). In Poland, the situation of families with children with autism is still bad. Although access to diagnostic and therapeutic services has improved, it still depends on the economic possibilities of the family and their place of residence.⁵ In this situation, the Internet is becoming increasingly important. Parents with access to the Internet will find a lot of necessary information, as well as gain the opportunity to exchange opinions with others (Parental Forums).

The specificity of the problems related to the functioning of a child with autism means that it requires comprehensive help. This translates directly into the cost of treatment services – they are usually very high. Another major shortcoming is that most of the facilities offering therapeutic services are located in large urban centres. This means that some children who live away from the cities may use only consultative therapy or the services of persons who are not qualified.

The current trends in therapeutic and supportive measures for children with autism are aimed at the greatest possible activation and involvement of the parents. It is believed that for an effective therapy, it is necessary to ensure good health and well-being of both parents. Many authors emphasize the importance of professional therapeutic programs directed to parents of children with disabilities⁶, including those affected by autism.⁷

⁵ See: A. Rajner, M. Wroniszewski, *Można im pomóc. Specjalistyczne usługi* opiekuńcze dla dzieci z autyzmem. SYNAPSIS, Warsaw 2002.

⁶ E. g.: M. Dudek, Dzieci z zespołem ADHD w środowisku rodzinnym. Studium empiryczne. Wydaw. Adam Marszałek, Toruń 2015.

⁷ E. g.: P. Randall, J. Parker, Autyzm. Jak pomóc rodzinie. GWP, Gdańsk 2016; H. Jaklewicz, Autyzm wczesnodziecięcy. Diagnoza, przebieg, leczenie. GWP; Gdańsk 1993; T. Gałkowski, Dziecko autystyczne w środowisku rodzinnym, WSiP, Warsaw 1995.

Parental stress

The problem of stress of parents raising children with autism is an important issue because of the specificity of the emotional impact of the parent (especially the condition of the parent) on the child and the way the whole family functions. The confirmation of autism is a strong stress factor for all family members and has a significant impact on the relationships between them. This is confirmed by the results of research which has been carried out in the world for more than forty years. In the available literature, the authors tend to use a general definition of stress, in which they accentuate the causes, symptoms or consequences of stress. The variables that are most frequently mentioned in the basic definitions include: size, intensity, length and unpredictability of the stressors.⁸

According to H. Seyle, the creator of the physiological theory of stress, it is a non-specific reaction of the body to the demands placed upon it.⁹ Stress can be positive (eustres) or negative (distress). The so-called *positive stress* leads to the development of a person's personality and motivates him/her to act, while distress leads to suffering and disorganization in action.

In psychological terms, due to the variety of theories relating to the theory of stress, it is described and defined in different ways. I.L.Janis, the creator of the theory of emotional tension, describes stress as a change in the environment, which in the case of an average person triggers a high degree of emotional tension that interferes with normal functioning.¹⁰

⁸ E. Pisula, *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*, Wydawnictwa UW, Warsaw 1998, p. 48; J. Pyżalski, *Wypalenie zawodowe a zdrowie i zachowania zdrowotne pedagogów placówek resocjalizacyjnych*, "Medycyna Pracy", 2002, 6; 495–499; R. Lazarus, S. Folkman, *Stress, appraisal, and coping*. New York: Springer. International Classification of Diseases 10th Revision. World Health Organization. 2010. R.S. Lazarus, *Paradygmat stresu i radzenia sobie*, "Nowiny Psychologiczne" 1986, 3–4 (40–41).

⁹ H. Selye, Stres okiełznany, PIW, Warsaw 1979, p. 25.

¹⁰ See: J.F. Terelak, *Psychologia stresu*, Oficyna Wydawnicza Branta, Bydgoszcz 2001, p. 77.

The definition of I. Janis includes two aspects of stress:

- 1) a stressful situation described by impulses causing behavioural disorders;
- 2) a stress reaction, understood as any change in external behaviour, feelings, attitudes, which are triggered by stress

A slightly different approach to stress is proposed by Heshen-Niejodek, who defines it "as a specific relation between a person and the environment that is perceived by the person as overburdening or exceeding his/her resources and threatening their wellbeing".¹¹

Although there is general agreement on the view that distress has a negative impact on every dimension of human life, there is a belief that it is not stress itself that is most harmful to man, but rather the **feeling of inability to control events that cause stress**.¹² The authors of this view assume that a person who has basic knowledge of the sources and effects of stress is able to identify the its early signs more easily and more quickly, and to fully assess the pressure exerted on him/her.¹³ As a result, the person is also aware of the physical and psychological effects of stress.

Overloading of parents with long-term care for autistic children, accompanied by constant stress and lack of adequate family support, can lead to the appearance of the **burn-out syndrome**.¹⁴ It is mainly expressed in the form of loss of mental and physical strength.

¹¹ I. Heszen-Niejodek, *Teoria stresu psychologicznego i radzenia sobie*, [in:] *Psychologia*, Vol. 3, J. Strelau, ed., GWP 1999, p. 467.

¹² I.L. Janis, *Psychological stress: Psychoanalytic and behavioral studies of surgical patients.* Wiley, New York 1958.

¹³ A. Borowicz, Stres rodziców wychowujących dzieci z niepełnosprawnością słuchową, "Niepełnosprawność – zagadnienia, problemy, rozwiązania." No II/2012(3), p. 58 (55–80).

¹⁴ T. Gałkowski, *Dziecko autystyczne w środowisku rodzinnym*, WSiP, Warsaw 1995; Pisula E., *Zespół wypalania się sił u rodziców dzieci autystycznych*, "Nowiny Pedagogiczne" 1994, p. 3.

Styles of coping with stress

It is believed that stress is an indispensable factor in the process of adapting to a difficult family situation in its daily functioning with a child with autism. The way people experience stress, as well as their ability to deal with it depends on various factors related to the social support system and personal resources. Authors dealing with this issue most often point to: optimism, mental agility, sense of coherence, internal control, and certain personality traits, such as: extraversion, ability to compromise, openness to experience.¹⁵

J. Strelau describes stress as a result of an imbalance between the requirements and capabilities of the individual and assigns a regulatory function to stress management that, according to the author, *means maintaining an adequate balance between requirements and capabilities or reducing the discrepancy between requirements and capabilities.*¹⁶

According to A.M. Colman, an individual style of dealing with stress involves a set of human traits that are directly related to stress-activated processes, and effective coping with stress is not so much the choice of style, but the skilful selection of available styles, adequate to the requirements of a specific stress situation.¹⁷

Literature on the subject depicts many ways to classify the styles of coping with stress. The classification provided by Endler and Parker is most commonly described and used in research, i.e. a style focused on the task, focused on emotions and focused on avoiding stress.¹⁸

¹⁵ E. g.: N. Ogińska-Bulik, Z. Juczyński, *Osobowość, stres a zdrowie*. Difin, Warsaw 2008; L. Huber, *Style adaptacyjne do sytuacji stresowych w różnych grupach wiekowych a choroby cywilizacyjne XXI wieku*. "Probl. Hig. Epidemiol" 2010, 91(2). pp. 268–275.

¹⁶ J. Strelau, *Temperament a stres: Temperament jako czynnik moderujący stresory, stan, i skutki stresu oraz radzenie sobie ze stresem,* [in:] I. Heszen-Niejodek, Z. Ratajczak, ed. *Człowiek w sytuacji stresu,* Wydaw. U.Ś., Katowice 1996, p. 95.

¹⁷ A.M. Colman, Słownik psychologii, PWN, Warsaw 2009, p. 710.

¹⁸ N.S. Endler, J.D.A., Parker, *Coping Inventary for Stressful Situations (CISS): Manual. Multi-Health Systems.* Toronto 1990.

Aim of the work

The aim of the study was to try to answer the following research questions:

- What are the differences in the style of coping with stress in the group of mothers and fathers?
- What are the differences in the style of coping with stress in the groups of parents of autistic children and Asperger syndrome?
- What are the differences in the style of coping with stress in groups distinguished by the parents' place of residence?
- What styles of stress management are preferred by parents with children with autism?

Methodology

The study was based on the diagnostic test method using the following techniques:

1. The CISS Questionnaire (Endler, Parker) designed to measure stress management styles. The CISS questionnaire consists of 48 statements concerning various human behaviours taken in stressful situations. The surveyed person is supposed to determine on a 5-grade scale the frequency with which he/she undertakes a given activity in difficult, stressful situations. The results are presented on three subscales: SSZ – style focused on the task; SSE – style focused on emotions; SSU – style focused on avoidance. The latter style can take two forms: ACZ – engaging in substitute activities and PKT – looking for social interactions. The raw results were converted into standardized units called stens, taking into account the age criterion.

The CISS Questionnaire is characterized by high internal consistency of particular scales (coefficients in the range of 0.78–0.90) and satisfactory stability (correlation coefficients between the two tests at 2–3 weeks intervals ranging from 0.73 to 0.80).¹⁹

¹⁹ J. Strelau, A. Jaworowska, K. Wrześniewski, P. Szczepaniak, *Kwestionariusz Radzenia Sobie w Sytuacjach Stresowych. Podręcznik do polskiej normalizacji.* Pracownia Testów Psychologicznych PTP, Warsaw 2009.

2. Interview (own survey) concerning the socio-economic situation of the respondents.

Results of research

The presented research results form part of a wider research project implemented in the period from January 2016 to April 2017 in three provinces: Mazowieckie, Lubelskie and Podkarpackie. Of the total number of respondents, there were 132 parents of autistic children, including 105 mothers and 27 fathers. The average age of the respondents is 40.3 years, including fathers 41.9 and mothers 38.7.

Table 1 shows the data on the differences in the CISS scores achieved by mothers and fathers. The analysis of the results indicates that there is a difference between the parents in relation to the style focused on avoidance – SSU (p < 0.05) and involvement in substitute activities – ACZ (p < 0.05). In both cases, mothers show a greater tendency to use these styles than fathers.

Styles of coping with stress	Sex	Ν	$\overline{\mathbf{x}}$	s	p U Mann Whitney's test
SSZ - Style focused on the task	1 2	105 27	57.14 57.96	8.42 6.58	0.633
SSE – Style focused on emotions	1 2	105 27	42.28 38.25	11.81 9.46	0.131
SSU – Style focused on avoidance	1 2	105 27	44,70 40,22	8.52 9.54	0.020*
ACZ – involvement in substitute activities	1 2	105 27	19.94 17.37	5.06 4.93	0.028*
PKT - looking for social interaction	1 2	105 27	16.60 15.55	3.8 3.895	0.178

 Table 1. Differences in the arithmetic mean and standard deviation of the CISS scale for men and women (1-mothers, 2-fathers)

p < 0.05

The arithmetic mean and standard deviation achieved by parents of children with autism and parents of children with Asperger syndrome on the CISS scale were then compared (Table 2). The differences have turned out to be insignificant in all subscales measuring the different styles of coping with stress.

Table 2. Differences in the arithmetic mean and standard deviation achieved by parents of children with autism and Asperger syndrome on the CISS scale (1 – parents of children with autism, 2 – parents of children with Asperger syndrome)

Styles of coping with stress	Groups	Ν	$\overline{\mathbf{x}}$	s	P U Mann Whitney's test
SSZ – Style focused on the task	1 2	100 32	58.03 55.06	8.34 6.77	0.066
SSE – Style focused on emotions	1 2	100 32	41.90 40.09	11.54 11.24	0.592
SSU – Style focused on avoidance	1 2	100 32	44.59 41.28	9.11 7.78	0.096
ACZ – involvement in substitute activities	1 2	100 32	19.81 18.18	5.25 4.58	0.098
PKT – searching for social interaction	1 2	100 32	16.65 15.56	3.88 3.78	0.222

The literature on the subject often underlines that the place of residence has a great impact on the situation of the family with a child with a disability or developmental disorder.²⁰. For this reason it was considered necessary to compare the results obtained by parents living in different environments (Table 3). Comparison of the arithmetic mean and standard deviation (ANOVA) on the CISS scale obtained by people living in large cities, small towns and in the countryside shows significant differences in the SSZ scale – measuring

²⁰ E. g.: W. Otrębski, K. Konefał, K. Mariańczyk, M.M. Kulikn, *Wspieranie rodziny z niepełnosprawnym dzieckiem wyzwaniem dla pracy socjalnej*. Europerspektywa Beata Romejko, Lublin 2011; A. Twardowski, *Sytuacja rodzin dzieci niepełnosprawnych*, [in:] *Dziecko niepełnosprawne w rodzinie*, ed. I. Obuchowska, WSiP, Warsaw 2008.

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ide)	Group	COLIPATION		B-C												B-C	
countrys	S		8.04	7.72	7.84	11.58	10.81	12.03	9.45	7.90	8.88	5.15	4.94	5.35	3.89	3.62	3.87
town, C –	X		57.25	54.58	59.61	41.53	42.11	40.84	43.46	42.19	45.47	19.34	19.19	19.68	16.15	15.44	17.43
3 - small t	Ν	Î	52	36	44	52	36	14	52	36	44	52	36	71	52	36	44
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their place of residence (A - big city, B - small town, C - countryside)	d		0.020*			0.885			0.247			806.0			0.052*		
of reside	df			2		5			2			7			7		
neir place	F			4.026		0.122			1.415			0.096			2,841		
tl	Styles of coping with	centic		332 - Juyle rocuseu on the task			55E - Style focused on emotions		SSU - style focused on avoidance			ACZ - involvement in substitute activities			PKT - searching for social interaction		

^{*} p < 0.05; ** p < 0.01

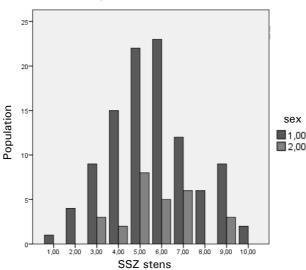
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the style focused on solutions/tasks F (2) = 4.026; p < 0.020 and PKT – measuring the style focused on searching for social interaction F (2) = 2.841; p < 0.052. The analysis of comparisons conducted with the NIR post-test indicates that in both cases, parents of children with autism who lived in the countryside were significantly more likely to apply the style focusing on the task (p < 0.005) and searching for social interaction (p < 0.022) than parents living in small towns.

Diagrams 1–5 show the profile of scores obtained on the CISS scale by parents of children with autism in each subscale.

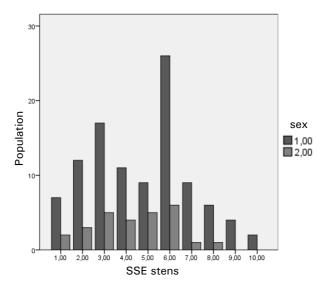
Chart 1. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on the task (SSZ)



The results obtained on the CISS scale are shown in Chart 1 and indicate the dominance of average stens among parents of children with autism. **This means that the style focused on the task** is at an average level in the population studied. **The style focused on the task** characterizes people who, while experiencing stress, try to identify the source of the problem and then **address the problem**. In situations where the solution is not possible, they try to adapt to life in the new, changed circumstances. **It is assumed that for a person with a style focused on the task this is usually very beneficial**. It allows the person who is experiencing stress to take action in a quick and effective manner and cope with the causes of stress.

Chart 2 shows the results obtained in the CISS scale defined as a style focused on emotions. The dominance of average and low stens indicates that the surveyed parents of children with autism, while experiencing stress, use **the style that focuses on emotions** in a low or average degree. Depending on what caused the stress, emotions may be different, but rather not pleasant. The strategies related to this style are mainly about **experiencing and trying to unload emotions.** This may include worrying about things, complaining to another person, as well as fantasizing or thinking "next time I'm going to do it", without taking any effort to succeed.

Chart 2. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on emotions (SSE)



The results of the subscale measuring **the style focused on avoidance – SSU** (Chart 3), clearly indicate the dominance of the average stens. This means that in the surveyed group, parents use **the style focused on avoidance** in an average degree, trying to **avoid thinking about the problem that is the source of stress**. According to the theoretical assumptions of the authors of the scale, the strategies that relate to this style focus on paying attention to something else and not thinking about the problem and its consequences.

Chart 3. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on avoidance (SSU)

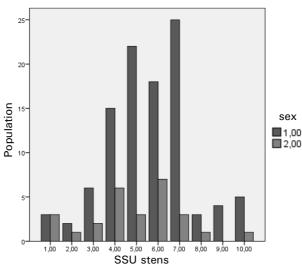
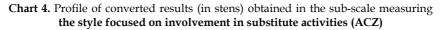


Chart 4. contains a profile of results obtained by the surveyed parents in the subscale that measures **the style focusing on engagement in substitute activities** (ACZ). The dominance of average results indicates average involvement in substitute activities in the form of avoiding stressful situations by watching TV, eating, thinking about pleasant things, dreaming.



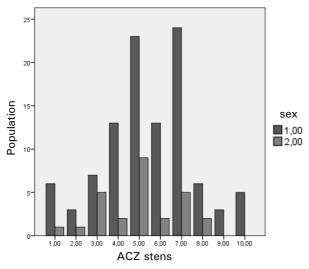
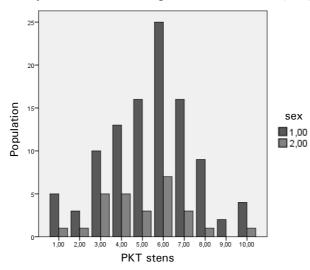


Chart 5. Profile of converted results (in stens) obtained in the sub-scale measuring the style focused on searching for social interactions (PKT)



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Chart 5 shows the results of the scale **searching for social interaction** (PKT). The dominance of average results indicates an average level of avoidance of stressful situations by entering into social interactions.

Generally, the analysis of the profiles of results obtained in individual CISS sub-scales shows that in the case of the surveyed parents of children with autism the style focused on emotions is the rarest. Other styles were chosen by the respondents at a similar level (average stens).

Discussion

The purpose of the study was to compare the coping styles of mothers and fathers, the parents of autistic children and parents of children with Asperger syndrome, groups of parents distinguished for their place of residence, and the analysis of dominant stress management styles among the respondents.

Comparison of the CISS scale results for mothers and fathers indicates that mothers are more likely than fathers to present the style focused on avoidance (SSU) and the style focused on involvement on substitute activities (ACZ). There is no difference in the style of coping with stress between parents with children with autism and parents with children with Asperger syndrome. In addition, parents of children with autism who live in the countryside are much more likely to apply the style that focuses on the task and searching for social interactions than parents living in small towns. The analysis of the CISS scale results allows to confirm that parents of children with autism use the style focused on emotions most rarely. The other styles were similarly (averagely) used by respondents.

The obtained results do not coincide with the views of some Polish and foreign authors. E. Pisula, referring to the different results of the study, concludes that parents of children with autism are more likely to use coping strategies that involve escaping from the stressor, and seek social support and search for solutions to the problems less often than parents with children with other developmental disorders.²¹ At the same time, the author emphasizes that parents cope by accepting the unpredictability and randomness of events and focusing on the present, on the current problems.

L. Little observes that autism diagnosed in a child burdens the mother and the father to a different extent. Mothers are more stressed about raising a disabled child, they use the help of professionals more often, and are more pessimistic when thinking about the future of the child.²² Research by K.I. Pakenham, C. Samios and K. Sofronoff has shown that the most adaptive style of coping with stress in the case of families with children with Asperger syndrome has been the style that focuses of emotions.²³

According to the authors, the fact of having a child with Asperger syndrome is a chronic, uncontrollable stressor for these parents, therefore the strategy focused on tasks may not be feasible in their case. According to K. I. Pakenham, C. Samios, K. Sofronoff, task strategies can only be successful in situations where the source of stress is modifiable, which in their opinion does not apply to a child with developmental disorders. KI Pakenham, C. Samios and K. Sofronoff conclude that, in addition to the style of coping with stress that focuses on emotions, parents of children with Asperger syndrome, also show two other strategies, namely: giving importance to the child's disability and a positive perception of his/her disorder. The results of research by K.I. Pakenham, C. Samios and K. Sofronoff show that both of these factors positively correlate with social support, feeling of self-efficacy and adaptive styles of coping with stress.²⁴

²¹ E. Pisula, Rodzice dzieci z autyzmem, PWN, Warsaw 2012.

²² Little L. Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorder. Ped. Nurs. 2002; 28, 6, 565–570.

²³ K.I. Pakenham, C. Samios, K. Sofronoff, Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. "Autism" 2005; 9, 2, 191–212.

²⁴ K.I. Pakenham, C. Samios, K. Sofronoff, *Finding meaning in parenting a child with Asperger syndrome: correlates of sense making and benefit finding.* "Res. Dev. Disabil." 2004; 25, 245–264.

Summary

The development of a child with autism is often uneven, inharmonious, unpredictable, and may indicate progress, lack of progress, as well as developmental regression. This results in the fact that the negative emotional states of parents associated with the care and education of a child with autism are present at every stage of the child's development, related to every new event in his or her life²⁵. That is why parents need constant support from loved ones, friends and professionals. ²⁶ Understanding the emotional situation of parents is a prerequisite for planning and implementing support. Parental stress management is one of the key factors to be considered in the therapy process.

The results of the analyses indicate the need for further, broader and longitudinal studies on the emotional functioning of parents of children with autism, as well as actions aimed at the support and therapy of the parents.

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²⁵ A. Banasiak, *Psychospołeczny wymiar jakości życia rodzin dzieci z autyzmem*, Prace Naukowe Akademii im. Jana Długosza w Częstochowie, Seria Psychologia, 2008, XV.

²⁶ See: M. Pągowska *Psychospołeczna sytuacja rodziny dziecka z autyzmem – etapy adaptacji do niepełnosprawności dziecka, "Szkoła Specjalna"* 2010, No 4, pp. 258–266.

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