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THE LEVEL OF NEGATIVE EMOTIONS, COPING WITH STRESS AND SOCIAL SUPPORT FOR PARENTS OF CHILDREN WITH EPILEPSY

Abstract: Introduction: Child epilepsy can be source of negative emotions and stress in parents. Social support is an external personal resource coupled with the process of coping with difficult situations.

Aim: The aim of the study evaluation the severity of negative emotions and ways of dealing with the stress of parents of children with epilepsy in relation to the received social support. Materials and Methods: The study was conducted in one of the children's hospitals in Małopolska, on 213 parents (148 women and 65 men) aged 21 to 66 years. The study used: HADS-M (Hospital Anxiety and Depression Scale Modified HADS-M, BSSS (Berlin Social Suport Scale), Inventory for Measurement Coping Mini-COPE and the author's questionnaire. Statistical analysis used Pearson and Spearman's correlation and Mann-Whitney test and t-test. Calculations were performed using IBM SPSS Statistics 20 Statistical significance was p ≤ 0.05 .

Results: The dominant emotion that accompanied the parents was anxiety. Parents have used more strategies based on active coping, and seeking emotional support or instrumental. It has been shown there is a correlation between the level of intensity of negative emotions and social support, and also correlation between social support and ways of coping with stress.

Conclusion: Parents expressed negative emotions but not of high severity which may be related to the choice of active coping strategies. Steps should be taken not only to assess the prevalence of negative emotions in a group of parents, but also to reduce the level of their intensity by exposing the importance of social support.

Key words: child's illness, parents, negative emotions, coping strategies, social support.

INTRODUCTION

Epilepsy, a disease of chronic nature, is regarded as unpleasant or dramatic experience generating a range of emotions (eg anxiety, depression, aggression) in parents [1–4]. Regardless the stage of the disease, its manifestations and treatment [1] raises the need to take action in dealing with this situation [4], which is easier to overcome with social support.

The effect of negative emotional states is stress and in the case of families with chronically ill children it is experienced more often and more dramatically

[5–7]. Literature confirms that the ways of coping with stress are dependent on many factors, with social support being of great importance [8]. Among the forms of assistance and support for families with chronically ill children one can distinguish institutional forms of assistance, parents associations, foundations and parents education and psychotherapy [9, 2, 10].

AIM

The aim of the study was to evaluate the severity of negative emotions in parents of children with epilepsy and ways to deal with the stress in relation to the received social support.

MATERIAL AND METHODOLOGY

Anonymous survey of a voluntary nature with the consideration of Declaration of Helsinki of 213 parents (148 women and 65 men) aged 21 to 66 years (average 39.93; SD = 7.81) were carried out in one of the children's hospitals in the Małopolska. Average number of children that had tests was 2.17 (SD = 1.10).

The study used: HADS-M (Hospital Anxiety and Depression Scale Modified HADS-M (the authors of the original version: AS Zigmond, RP Snaiht, in Polish: M. Majkowicz, K. de Walden-Gałuszko, G. Chojnacka-Szawłowska) [11], to identify anxiety, depression, aggression. HADS scale consists of two independent subscales measuring levels of anxiety and depression. For these subscales the following categories were isolated: 0–7 points — normal levels of anxiety or depression, 8–10 points — the borderline level and 11–21 points — high level, appropriate for the disease [11, 12].

To measure cognitive and behavioral dimensions of social support BSSS were used (Berlin Scale Social Support (Łuszczyńska A., Kowalska M., Schwarzer R. & Schulz U.) [13], and to assess the coping it was the inventory for Measurement Coping Mini — COPE (author: Carver Ch.S, adaptation: Juczyński Z. & Ogińska-Bulik N.) [14] and the author's questionnaire for collecting socio-demographic data and disease history. Statistical analysis was performed using the nonparametric equivalent of the Pearson correlation which was dictated by the lack of normal distribution of variables (Kolmogorov-Smirnowa) and Spearman correlation. When testing the differences between the two independent variables the Mann-Whitney test was used. In addition, t-test was used for one sample. The level of significance was p ≤ 0.05 . Calculations were performed using IBM SPSS Statistics 20.

RESEARCH RESULTS

Results obtained from analysis of the Questionnaire HADS-M showed that the severity of anxiety in parents was at the level of 8.25 (SD = 4.23) points and the severity of depressive symptoms was lower than the severity of anxiety symptoms — average 6.02 (SD = 3.86) points. The average level of symptom severity was significantly lower than assumed for the average level of these emotions. However, in relation to the aggression obtained results show that the severity of the symptoms was on average 3.51 (SD = 1.55) points and was above the average level. Statistical analysis showed significant differences between the severity of anxiety and aggression among the parents and their gender. It was found that the greater severity of anxiety was observed in mothers (p = 0.0004), as well as symptoms of aggression (p = 0.0014).

Results of Inventory Mini-Cope showed that parents of children with epilepsy have used different strategies to cope with stress, and for certain of which there were statistically significant correlation — details are presented in the Table 1.

Table 1
Strategies for coping with stress and sex of respondents

Desline with stores storted	Male		Female		Total			
Dealing with stress strategies	average	SD	average	SD	average	SD	р	
Active dealing with stress strategies	2.27	0.63	2.26	0.60	2.27	0.61	0.09750	
Planning	2.20	0.61	2.13	0.72	2.15	0.69	0.07191	
Positive revaluation	1.73	0.69	1.83	0.71	1.80	0.70	0.3261	
Acceptance	2.10	0.64	2.09	0.74	2.10	0.71	0.9723	
Sense of humor	0.70	0.65	0.78	0.68	0.76	0.67	0.04336	
Turn towards religion	1.28	0.99	1.68	0.97	1.56	0.99	0.0080	
Searching for emotional support	1.98	0.67	2.01	0.84	2.00	0.79	0.5764	
Searching for instrumental support	1.82	0.72	1.98	0.75	1.93	0.74	0.1559	
Dealing with something	1.62	0.65	1.71	0.74	1.68	0.72	0.4040	
Denial	0.81	0.78	1.04	0.79	0.97	0.79	0.0358	
Discharge	1.21	0.57	1.44	0.72	1.37	0.69	0.0244	
Use of psychoactive substances	0.54	0.65	0.13	0.42	0.25	0.54	0.0000	
Cessation of activity	0.70	0.68	0.82	0.73	0.78	0.672	0.2614	
Blaming oneself	1.12	0.63	1.19	0.84	1.17	0.78	0.6068	

Women more often than men expressed the following symptoms: "turn to religion", "denial" and "discharge". Men significantly more often used "psychoactive substances". In terms of social support assessed using the Berlin Social Support Scale, the scales "need for support", "looking for support" and "support currently received" no statistically significant relationships in regard to gender were observed. However, significant statistical difference was only buffering — protective support; higher scores to be noted in men (p = 0.0286). Statistical analysis confirmed the existence of correlation between the level of intensity of negative emotions and social support — details are presented in the Table 2.

 ${\small \mbox{Table 2}}$ Social support and the severity of negative emotions

Social support	rho Spearmana	Anxiety	Depression	Aggression
Perceived emotional support	rho	-0.28	-0.32	-0.15
available	p	0.0000	0.0000	0.0277
Perceived instrumental support	rho	-0.32	-0.34	-0.21
available	p	0.0000	0.0000	0.0022
Coalcing account	rho	-0.22	-0.22	-0.04
Seeking support	p	0.0009	0.0010	0.5573
Currently received emotional	rho	-0.19	-0.36	-0.05
support	p	0.0066	0.0000	0.4675
Currently received the instrumental	rho	-0.22	-0.35	-0.11
support	p	0.0016	0.0000	0.0942
Currently received information	rho	-0.20	-0.36	-0.11
support	p	0.0030	0.0000	0.1071
S-4:-f4::-14	rho	-0.21	-0.32	-0.08
Satisfaction with social support	p	0.0020	0.0000	0.2651
D. C	rho	0.14	0.07	0.13
Buffering — protective support	p	0.0457	0.2782	0.0671

The results showed a correlation between social support and selected strategies for coping with stress presented in the group of mothers and fathers. Apart from the strategy: "dealing with something else", "taking psychoactive substances" and social support in a group of fathers and mothers no correlation occurred. In addition, no correlation was observed between "discharge" and social support — details are presented in the Table 3.

 $$\operatorname{Table}$$ 3 Social support and selected strategies for coping with stress presented in the group of mothers and fathers

Strategies for dealing with stress		rho Spearmana	Perceived emotional support	Perceived instrumental support available	Need for support	Seeking support	Currently received emotional support	Currently received the instrumental support	Currently received information support	Buffering — protective support
Strategies for dealing with stress		rho	0.310	0.18	0.26	0.17	0.04	0.08	0.02	0.210
	F	p	0.0002	0.0255	0.0016	0.0384	0.6186	0.3294	0.7794	0.2174
	M	rho	0.31	0.29	0.19	0.26	0.14	0.33	0.27	-0.01
		p	0.0121	0.0174	0.1229	0.0334	0.2707	0.0074	0.0312	0.9507
Turn towards religion		rho	0.12	0.15	0.18	0.13	-0.01	-0.03	-0.04	0.05
	F	p	0.1555	0.0710	0.0245	0.1165	0.8713	0.7061	0.6541	0.5068
	M	rho	-0.04	0.09	-0.14	-0.14	0.26	0.08	0.05	0.30
		р	0.7645	0.4595	0.2672	0.2547	0.0400	0.5295	0.7165	0.0146
Searching for emotional support	F	rho	0.54	0.47	0.62	0.57	0.37	0.47	0.48	0.46
		p	0.0000	0.0001	0.0000	0.0000	0.0021	0.0001	0.0000	0.0001
	M	rho	0.54	0.47	0.62	0.57	0.37	0.47	0.48	-0.10
		р	0.0000	0.0001	0.0000	0.0000	0.0021	0.0001	0.0000	0.4426
Searching for instrumental support		rho	0.50	0.51	0.32	0.32	0.39	0.54	0.44	0.53
	F	р	0.0000	0.0000	0.0001	0.0001	0.0000	0.0000	0.0000	0.0000
	M	rho	0.48	0.41	0.60	0.58	0.25	0.39	0.32	-0.25
		p	0.0000	0.0006	0.0000	0.0000	0.0479	0.0012	0.0085	0.0473

DISCUSSION

The situation of parents with chronically ill children is analyzed in terms of adaptation to stress, experiencing extreme traumatic events, a greater incidence of somatic and mental disorders and the need for support from family members and society [15, 16].

The study on the reaction of the parents were conducted primarily among mothers, considered more vulnerable to the emotional burden [17] in relation to perception of the father as a person not interested in participating in the diagnosis and treatment process [18]. However, the father plays a valuable role in child's development also providing material support for the family [19]. In our study, the group of respondents consisted of both fathers and mothers, and just like other authors confirmed, with much larger involvement of mothers. However, the reasons behind the observation were not analyzed.

The research on parents' emotions of children with other diseases confirmed experience of mostly fear. The results of our study have shown that the dominant feeling was also higher anxiety level and its severity was observed in the group of mothers who also had a higher level of aggression. This allows the conclusion that the child's chronic disease, regardless of its nature, triggers a state of anxiety as well as sadness, feelings of hopelessness, depression and somatic complaints [20–25]. Our results also confirmed the presence of depressive symptoms, but their severity was low and not dependent on the gender of the respondents. However, it cannot exclude the existence of concealed depression or development of depressive disorders in the future.

The correlation between social support and the intensity of negative emotions proves that parents that evaluated the "currently received and perceived support available" to be on a higher level, experienced anxiety and depression less intensively. It can be assumed that the aid already received was adequate and in addition the feeling was built that in the event of difficulties parents have people ready to help them in solving the problem.

Experiencing negative emotions by parents in relation to a child with a chronic illness raises the need to address the strategies to cope with a difficult situation. Our results showed that among parents the strategies based on active coping, and seeking emotional or instrumental support dominated with significant frequency. Analysis of the results confirmed the existence of the relationship between ways of coping with stress and gender. According to the analysis of the literature coping with stress in difficult situations such as chronic disease of the child, used by mothers and fathers, varies and is determined by different circumstances [26–31].

Social support is an important element influencing the way of coping with the stress of illness of the child [32, 33]. Our results also confirmed the existence of correlations in this regard. It is highly possible that the support is sufficient in the current situation and at the same time allows parents to look optimistically to the future with confidence that there is help available in situations in which they cannot help themselves. It can be assumed that the availability of assistance from others generates the active involvement of parents in reducing the effects of the stressor — the chronic illness of their child.

In the case of illness of a child, parents often relate to faith seeking consolation. In our study, only mothers used the strategy of "turning to religion",

which can prove that the present situation was beyond their capacity to deal with it. Religion thus became a source of support. Our study confirmed that the parents of both sexes, who sought information, understanding and moral support were more open and obtained the assistance under the social support along with a sense of anticipation of this support in the future.

The results obtained in the course of the following study can serve as a direction for further exploration in the area of social support as a factor relevant in strategies of dealing with stress and negative emotions in parents of children with epilepsy.

CONCLUSIONS

Parents experienced negative emotions that were not of high severity, which may be related to the active coping strategies chosen.

Necessary steps should be taken not only to assess the occurrence of negative emotions in a group of parents but also to reduce the level of their intensity by highlighting the importance of social support.

REFERENCES

- 1. Scambler G., Hopkins A.: Generating a model of epileptic stigma: The role of qualitative analysis. Soc Sci Med. 1990; 30: 1187–1194. 2. Sendecka E., Wiśniewska E., Krajewska-Kułak E., Kułak W.: Funkcjonowanie społeczne rodziny z dzieckiem niepełnosprawnym. Neurologia Dziecięca. 2010; 37: 67–73. 3. Mirkowska-Mankiewicz A.: Jakość życia osób niepełnosprawnych intelektualnie. Preselekcja QOL Kwestionariusz Jakości Życia. Sztuka Leczenia. 1995; 5: 15–21. 4. Patkiewicz J.: Udział rodziny w kompleksowej rehabilitacji i życiu dzieci i młodzieży niepełnosprawnej. Polskie Towarzystwo Walki z Kalectwem Oddział Wojewódzki we Wrocławiu. Wrocław 1999. 5. Jankowski K.: Człowiek i choroba. Wydawnictwo PWN. Warszawa 1975. 6. Duffy L.V.: Parental coping and childhood epilepsy: the need for future research. J Neurosci Nurs. 2011 Feb; 43 (1): 29–35. 7. Rodenburg R., Meijer A.M., Deković, Aldenkamp A.P.: Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. Epilepsy Behavior. 2007; 11 (2): 197–207. 8. Kulczyńska S.: O stresie i sposobach radzenia sobie z nim. Niebieska Linia. 2003, 5. 9. Obuchowska I. (red.): Dziecko niepełnosprawne w rodzinie. WSiP. Warszawa 2008. 10. Rozenek H., Owczarek K.: Padaczka u dziecka i jej wpływ na wybrane aspekty funkcjonowania rodziny. Neurol Dziec. 2008; 34: 55–59.
- 11. de Walden-Gałuszko K., Majkowicz M., Szawłowska-Chojnacka G., Magiera P.: Jakość życia pacjentów z chorobą nowotworową badania własne. W: de Walden-Gałuszko K., Majkowicz M. (red.). Jakość życia w chorobie nowotworowej. Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 1994: 89–164. 12. Majkowicz M., Chojnacka-Szawłowska G.: Metodologiczne problemy badania jakości życia. W: de Walden-Gałuszko K., Majkowicz M. (red.). Jakość życia w chorobie nowotworowej. Wydawnictwo Uniwersytetu Gdańskiego, Gdańsk 1994: 84–147. 13. Łuszczyńska A., Kowalska M., Mazurkiewicz M., et al.: Berlińskie Skale Wsparcia Społecznego (BSSS): wyniki wstępnych badań nad adaptacją skal i ich własnościami psychometrycznymi. Studia Psychologiczne. 2006; 44 (3): 17–27. 14. Juczyński Z.: Narzędzia pomiaru w promocji i psychologii zdrowia. Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego, Warszawa 2001. 15. Baleja-Stawicka I., Rabe-Jabłońska J.: Stan psychiczny i jakość życia matek opiekujących się dziećmi z upośledzeniem

umysłowym, jako czynniki wpływające na jakość opieki — przegląd piśmiennictwa. Psychiatr Psychol Klin. 2007; 7 (3): 165–169. — **16.** Sadowska L., Szpich E., Wójtowicz D., Mazur A.: Odpowiedzialność rodzicielska w procesie rozwoju dziecka niepełnosprawnego. Przegląd Medyczny Uniwersytetu Rzeszowskiego. Rzeszów 2006; 1: 11–21. — **17.** Składzień T., Górecka K., Wiśniowski Z., Jaworska I., Wójcik E., Mroczek T., Skalski J.: Lęk, depresja i drażliwość u rodziców dzieci leczonych chirurgicznie z powodu wady serca. Kardiochir Torakochir Pol. 2011; 8 (4): 479–482. — **18.** Sekułowicz M.: Rodzina wobec niepełnosprawności dziecka — problemy adaptacji i funkcjonowania. W: Kwaśniewska G. (red.). Interdyscyplinarność procesu wczesnej interwencji wobec dziecka i jego rodziny. Wydawnictwo UMCS, Lublin 2007: 44–59. — **19.** Phares V., Lopez E., Fields S., Kamoukos D., Duhig A.M.: Are fathers involved in pediatric psychology research and treatment? Pediatr Psychol. 2005; 30 (8): 631–643. — **20.** Pawełczak-Szostok M., Pilarczyk J., Pobudejska-Pieniążek A., et al.: Lęk w rodzinach dzieci chorujących na nowotwory. Psychoonkologia. 2012; 2 (16): 29–36.

21. Wolańczyk T., Kołakowski A., Pisula A., Liwska M., Złotkowska M., Srebnicki T., Bryńska A.: Poziom leku, jako stanu i jako cechy oraz nasilenie depresji u matek dzieci z zespołem nadpobudliwości psychoruchowej i zaburzeniami zachowania doniesienia wstępne. Psychiatr Pol. 2014; 48 (4): 645-652. — 22. Pawlak-Bratkowska M., Pilarz E. Tkaczyk M.: Ocena poziomu leku u rodziców dzieci z zespołem nerczycowym- sposoby radzenia sobie z nimi i metody wsparcia. Pediatria & Medycyna Rodzinna. 2013; 9 (2): 179–185. — 23. Piotrowska-Matyszczak M., Samardakiewicz M.: Style radzenia sobie rodziców w sytuacji choroby nowotworowej dziecka a poziom leku — na przykładzie stylu skoncentrowanego na zadaniu (SSZ) i stylu skoncentrowanego na emocjach (SSE). Post Nauk Med. 2013; 9: 622-626. — 24. Lawoko S., Soares J.J.: Distress and hopelessness among parents of children with congenital heart disease, parents of children with other diseases, and parents of healthy children. J Psychosom Res. 2002; 52: 193-208. — 25. Hobdell E.F., Grant M.L., Valencia I., Mare J., Kothare S.V., Ledigo, Khurana D.S.: Chronic Sorrow and Coping in Families of Children with Epilepsy. Neurosci Nurs. 2007; 39 (2): 76-82. — 26. Dabrowska A., Pisula E.: Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. J Intellectu Disabil Res. 2010; 54 (3): 266-280. — 27. Parchomiuk M.: Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych. Wydawnictwo UMCS, Lublin 2007. — 28. Kobosko J.: Radzenie sobie ze stresem i samoocena słyszących ojców a głuchota dziecka. Nowa Audiofonologia. 2013; 2 (1): 36-44. - 29. Lewoń M., Wróbel M.: Regulacja nastroju oraz radzenie sobie ze stresem wśród matek dzieci chorych na chorobe nowotworową. Psychoonkologia. 2006; 10 (2): 41-50. - 30. Chiou H.H., Hsieh L.P.: Parenting stress in parents of children with epilepsy and asthma. J Child Neurol. 2008 Mar; 23 (3): 301-306.

31. Cepuch G., Wojtas K.: Radzenie sobie ze stresem i wsparcie społeczne rodziców dzieci z chorobą zagrażającą życiu. Onkol Polska. 2011; 14 (4): 188–195. — **32.** Cepuch G., Citko J., Wojtas K.: The level of perceived stress of parents of children with cancerous disease — mechanisms of dealing with stress and social support. Folia Med Cracov. 2013; 53 (2): 87–97. — **33.** Szymańska J., Sienkiewicz E.: Wsparcie społeczne. Curr Probl Psychiatry. 2011; 12 (4): 550–553.

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