

THE SENSE OF EMPOWERMENT AMONG PARENTS OF CHILDREN WITH AUTISM

Anna Banasiak

Jan Długosz University in Częstochowa, Poland

Abstract. *The aim of this study was to examine the level of a sense of empowerment among mothers and fathers of children with autism. The relationship between a sense of empowerment and socio-demographic variables characterising the respondents including the parents was also analysed. Among the participants, there were 74 parents of autistic children (39 mothers, 35 fathers), 77 parents of children with Down syndrome (40 mothers, 37 fathers) as well as 80 parents of typically developing children (40 mothers, 40 fathers). Two statistical tools, namely the non-parametric Mann-Whitney U test and Kruskal-Wallis test, were employed in this study. The results show a higher level of a sense of empowerment when it comes to the evaluation of own knowledge and competences in mothers of autistic children than in mothers of children with Down syndrome, contrary to fathers of autistic children whose level of a sense of empowerment is lower within the said scope compared with fathers of children with Down syndrome.*

Keywords: *autism, Down syndrome, parents, sense of empowerment.*

Introduction

Autism spectrum disorders (ASD) are a group of neurodevelopmental disorders characterized by deficits in social communication and repetitive, restrictive patterns of behaviour and interests (APA, 2013; WHO, 2002). The prevalence of ASD is estimated to be 1 per 1000 (Christiansen et al., 2016; Fombonne et al., 2016).

A review of source literature reveals that families of children with autism have to struggle with numerous issues and constant challenges that autism presents. In most cases, these difficulties include caring for, raising and supporting children's development (i.a. Pisula, 2009; Sakaguchi & Bepp, 2007). The different level of experienced difficulties is associated with the psychophysical state and social functioning (i.a. Benson, 2006, Błaszczyk, 2008; Tobing & Glenwick, 2006; Weiss, 2000). According to the study results, (i.a. Benson, 2006; Tobing et al., 2006), mothers of children with autism tend to have a decreased level of parenting competences, feel unsure when making their own decision and suffer from strong doubts about their right attitudes towards their own children. It is well known that insufficient knowledge and a general lack of

necessary skills to manage the behaviour of children with autism are the most common problems parents encounter on a daily basis (Pisula, 2009; Tobing et al., 2006). A dearth of well qualified and trained services that could efficiently support parents seems to aggravate an already difficult situation (Bishop et al., 2007; Ignasiak et al., 2005 Pisula, 2010; Sakaguchi & Beppu, 2007). Therefore, the parents remain involved in children's treatment. They take responsibility for the effort in the therapeutic process necessary to reach the treatment goal. Moreover, the parents take a great role in establishing centres and other facilities providing development for autistic children (Wachtel & Carter, 2008).

It should be emphasised that the functioning of parents caring for their offspring with autism depends to a large extent on their quality and quantity of resources as well as the effective use of them when confronting stress. Thus, a new research trend focuses, to a lesser extent, on identifying the source of stressor. Instead, research concentrates primarily on the activities undertaken by individuals in difficult and overwhelming situations (i.a. Carr, 2005; Gray, 2006; Pisula & Kossakowska, 2010; Pottie et al., 2008). It turns out that the change of interest in the research may have been influenced by the fact that the effects of stress confrontation have been more influenced by the ability to deal with stress than the objective nature of a stressor.

Despite little knowledge of a sense of empowerment among parents of children diagnosed with autism, it appears to be an important aspect of adjusting to new challenges faced by families caring for children with developmental disorders. Empowerment means acquiring a number of desirable competences enabling individuals to gain greater control over their own life (Koren et al., 1992). A. Smokowska-Reichmann (1999) defines the term "empowerment" as a process of regaining a sense of personal power or control over one's life as well as resources of energy and competences that affect one's life. The phenomenon of empowerment can be understood as both the process (that empowers and strengthens competences, control, power and skills) and the outcome of a process (means, strategy and method) of the widely understood educational and therapeutic activities. It is worth emphasising that even though the sense of empowerment has been an increasingly recognised concept for more 40 years and has been used promiscuously to refer to a wide range of practices, it must be conceded that it is less developed from many psychological and pedagogical points of view. There are many different ways that the sense of empowerment has been applied and defined. For these studies, the concept is primarily defined as "the capacity of individuals or groups to act on their own authority and to achieve a greater measure of control over their lives and destiny" (Koren et al., 1992: p. 308). Hence, the term is understood as the process which enables

individuals to act effectively to gain greater power and control over their lives and their environment.

The key questions asked by researchers relate to what individuals think about their social environment; what they know about social institutions and organisations; whether they are aware of what changes should be made and how to make them. Furthermore, the questions also focus on whether they are willing to act in order to make changes in their lives. Nowadays, there are many social institutions and the increasing complexity of social life, therefore it seems important to figure out the mechanisms of human consciousness shared by individuals within society and to find out about possible changes in social environment in order to be able to influence various decisions.

The concept of the sense of empowerment enables one to analyse both a situation of people with disabilities and their family members who can also receive specialist services. Four factors of the process of empowerment can be described regarding the families of children with developmental disorders (Koren et al., 1992):

- the ability to protect children's interests, including parents' thoughts, beliefs and behaviour interacting with the health care system;
- knowledge, that is, the gathered information on the system and services available to them as well as the abilities to apply the acquired knowledge;
- competences including one's own abilities and parenting skills;
- self-efficacy understood as perceptions of one's own efficacy to influence the actions that can affect the health care system in favour of the children's needs and interests.

The above-mentioned factors of the sense of empowerment will be analysed in detail in this study.

Own research

This study aimed to answer the question – Are there any differences between the sense of empowerment experienced by mothers and fathers of children with autism, Down syndrome and typically developing children?

The women have already answered this question, whereas the question has not been asked to the men yet.

Respondents

The research covered a group of 231 persons, including 74 parents of children with autism ('A' group) (39 mothers and 35 fathers), 77 parents of

children with Down syndrome ('D' group) (40 mothers and 37 fathers) and 80 parents of typically developed children ('N' group) (40 mothers and 40 fathers).

The average age of mothers of children with autism was ca. 40 years (mean 39,54; standard deviation 7,54), and when it comes to fathers it was 43 years (mean 43,14; standard deviation 8,32). Majority of parents had a university degree (29 persons, 39,2 %) and came from big urban environments – over 100 thousand citizens (48 persons, 65 %). Apart from that, majority of parents with autism was professionally active (50 persons, 68 %).

The comparison, made with the use of a nonparametric test by Kolmogorov-Smirnov with respect to demographic distributions, revealed that there were not differences between groups of parents of autistic children and parents of children with Down syndrome with regard to the level of education, a parent's age, living environment, professional activity and a child's age.

There was a difference with respect to the child's age between groups of parents of autistic children and parents of typically developed children – in the group of neurotypical children there were more children aged 12-17 ($p < 0,025^*$, mean A: 1,55, N: 1,30, standard deviation A 0,50, standard deviation N 0,46). Distribution of demographic variables in the groups of parents with Down syndrome and typically developed children was also comparable. There were significant differences only when it comes to a parent's age ($p < 0,001^*$; mean D 2,27; mean N 2,62; standard deviation D 0,55; standard deviation N 0,56) and a child's age ($p < 0,001^*$; mean D 1,30; mean N 1,66; standard deviation D 0,46; standard deviation N 0,47). In the group of parents of children with Down syndrome there were more persons aged over 40 and more children aged 12-17.

A group of parents of autistic children was selected with respect to some criteria such as a child's diagnosis (psychiatric diagnosis, children's autism), a child's age – from 7 to 17 years old; a lack of other disorders (e.g., children's cerebral palsy, Down syndrome, other diagnosed disorders).

The groups being compared with a group of parents of autistic children were selected on the basis of a modified random sampling.

Research instruments

For the purpose of measuring family empowerment there has been used FES scale, created by Paul E. Koren, Neal DeChillo and Barbara J. Friesen from Portland State University (1992). Good psychometric features of this scale have been confirmed (Singh et al., 1995). The scale measures family empowerment experienced by an individual with regard to its family, service system for children and a community/political environment. It also allows to define the way the family empowerment is expressed. It consists of 34 items which are assessed

by respondents on a 5-level scale from 1- totally untrue to 5- absolutely true. Sample answers are as follows: (7) I do know what to do when problems with my child arise. (19) I tell specialists what I think about the services that my child gets. The total scores are the sum of the positions on the following levels (family- 12 position, services-12 position, social and political environment – 10 position). This scale measures 4 elements of family empowerment: system support, knowledge, competences and self-effectiveness.

A Polish version of this instrument in translation by Ewa Pisula has been used in the research. A factor analysis of scores in the Polish research sample of 113 mothers of children with developmental disabilities confirmed the existence of factors differentiated in the original version (Pisula, 2005).

Results of own research

In order to compare the family empowerment in mothers from the research groups there has been carried out an analysis with the use of Mann-Whitney U test. The scores are presented in table 1.

Table 1 The level of empowerment in mothers of children with autism spectrum disability, mothers of children with Down syndrome and mothers of typically developed children – descriptive statistics and scores of the Mann-Whitney U test

Indicator of empowerment	Mothers of children with autism		Mothers of children with Down syndrome		Mothers of typically developed children		Mothers of children with autism/ Mothers of children with Down syndrome		Mothers of children with autism/ Mothers of typically developed children		Mothers of children with Down syndrome / Mothers of typically developed children	
	M	SD	M	SD	M	SD	U _(39;40)	p	U _(39;40)	p	U _(40;40)	p
System support	30,2	5,745	27,1	5,756	29,8	6,869	607,0	0,091	737,0	0,677	606,0	0,063
Knowledge	33,7	4,979	29,8	5,721	33,4	7,046	538,0	0,018*	768,0	0,910	604,0	0,060
Competences	34,6	3,417	31,4	5,055	33,6	4,477	271,0	0,000*	729,0	0,620	690,0	0,292
Self-effectiveness	16,0	3,190	13,7	3,358	15,7	2,452	745,0	0,735	672,0	0,292	656,0	0,167

* - a significant difference on the significance level $\alpha < 0,05$; M – arithmetic mean; SD – standard deviation; U – test value; p – significance level

Analysing table 1 with regard to two indicators of empowerment, mothers of children with autism scored higher than mothers of children with Down

syndrome. It referred to knowledge and competences. The other differences between groups were not statistically significant.

Results of analysis carried out in three groups of fathers are presented in table 2.

Table 2 The level of empowerment in fathers of children with autism, fathers of children with Down syndrome, and fathers of typically developed children – descriptive statistics and scores of the Mann-Whitney U test

Indicator of empowerment	Fathers of children with autism		Fathers of children with Down syndrome		Fathers of typically developed children		Fathers of children with autism / Fathers of children with Down syndrome		Fathers of children with autism / Fathers of typically developed children		Fathers of children with Down syndrome / Fathers of typically developed children	
	M	SD	M	SD	M	SD	U _(35;37)	p	U _(N35;40)	p	U _(37;40)	p
System support	27,0	6,148	32,4	5,286	29,0	4,857	557,5	0,313	678,0	0,819	606,0	0,173
Knowledge	30,4	4,385	36,6	4,810	32,9	4,555	466,5	0,042*	690,0	0,920	503,0	0,016*
Competences	35,8	4,048	39,3	3,480	35,5	4,005	347,5	0,001*	652,0	0,852	650,0	0,362
Self-effectiveness	13,8	2,731	16,3	2,648	13,9	2,580	642,5	0,960	688,0	0,903	725,0	0,882

* - a significant difference on the significance level $\alpha < 0,05$; M – arithmetic mean; SD – standard deviation; U – test value; p – significance level

The Mann-Whitney U test identified that in the two spheres differentiated on the FES scale, fathers of children with autism scored lower than fathers of children with Down syndrome. The differences were observed with regard to knowledge and competences. In all cases, fathers of children with autism scored lower than fathers of children with Down syndrome. When it comes to the assessment of knowledge indicator, there has been a difference between fathers of children with Down syndrome and fathers of typically developed children. Fathers of children with Down syndrome scored higher than fathers of abled children.

Discussion of results

This research paper referred to differences between parents (mothers and fathers) of children with autism and parents of children with Down syndrome, and parents of typically developed children with respect to family

empowerment. Four indicators of family empowerment calculated on the basis of scores according to FES scale have been analysed. These indicators are: system service, knowledge, competences and self-effectiveness.

The analysis presented therein revealed little significant differences with regard to indicators of family empowerment among mothers in groups under research. Significant differences have been observed only among mothers of children with developmental disorders. Mothers of children with autism scored higher with regard to knowledge and competences than mothers of children with Down syndrome.

Some different scores were achieved in case of fathers under research. It turned out that fathers of children with autism assessed their own knowledge lower than fathers of children with Down syndrome. The result seems to be compatible with accessible information regarding the way this group of persons functions. A number of research reveals that the level of competence is lower in those taking care of a child with autism (i.a. Benson, 200; Tobing et al., 2006). Moreover, it has been emphasized that because of a lack of adequate support and access to information concerning possible services for a child and parents, they experience the feeling of guilt, helplessness and being burdened with difficulties (Pisula, 2009; Sakaguchi & Beppu, 2007). It is also well known that the source of difficulties related to taking care of children with autism is a lack of appropriate knowledge and competences essential in looking after a child (cf. Gałkowski, 1995; Pisula, 1998). In the context of such information it might be expected that parents of children with autism would present a lower level of empowerment than parents of children in other groups. It also seems that the assessment of one's own situation is not without significance when it comes to empowerment experienced by parents. Those parents who are less burdened with taking care of a child, have more resources which can be used for an active approach to difficult situations later on. They have more time during which they can search for support, some help for a child and themselves. I will get back to that issue while presenting an analysis of a correlation between empowerment and a level of stress.

However, there was a possibility of achieving a totally opposite result than the one scored by fathers. It is observable in the scores of mothers. An assumption of such a way of thinking is a fact that parents (mainly mothers) of children with autism are actively engaged in activities towards foundation of therapeutic centres and schools (Kwaśniewska, 2010; Perzanowska, 1997; Vasileva, 2010). This is somehow a forced activity, because their children have a very limited access to both social and educational services. Many newly established educational facilities for children with autism have been a result of efforts taken by parents, affiliated in social organizations and associations (e.g., The National Autism Association). The described activity forces to acquire

knowledge regarding functioning system care and services (health services, educational services) and skills that would enable a parent to provide a child with an adequate support, that might have had an impact on the results of this research.

The result is compatible with results of other studies in which the Family Empowerment Scale was used. E. Pisula (2005) revealed that the level of empowerment with regard to competences and knowledge is higher in mothers of children with autism than in mothers of children with other developmental disorders. In another research paper (Pisula & Mazur, 2006) describing the same research instrument as it was referred to in this study, it was stated that mothers of children with autism, in comparison with mothers of children with Down syndrome, assessed their effectiveness, a possibility of securing the interests of a child and one's own knowledge higher.

On the other hand, A. Fleischmann (2004), making an analysis of autistic children's parents published in the internet, states that over time their faith in own possibilities and skills increases as well as the acceptance of a child. Similar results were revealed by D. E. Gray's (2002) research in which the same group of parents participated twice within the time interval of 10 years. Parents of older autistic children declared that their health condition and well-being were good. The relations between them and their relatives were recognized as correct too. Moreover, the perception of their own situation changed for better as well. Parents assessed it as an easier and less overwhelming one.

Taking into consideration a fact that the issues under analysis is very extensive, the presented research paper does not discuss it at length. However, all the conclusions give certain information regarding the situation of parents of children with autism, and can be helpful while planning programs of comprehensive support for parents and children. Family empowerment, thanks to giving parents a chance that reassures them about their own possibilities of handling problems, should become one of the key tasks for those working with parents of disabled children.

Family empowerment should be based on an active participation of parents in decision-making with respect to therapies and a child's rehabilitation (Koren et al., 1992). As the studies reveal (Pisula, 2005), such an aware participation in the processes shaping the situation and a possibility of taking part in decision-making, has a positive effect on a mental well-being, the feeling of control and independence of an individual.

References

- American Psychiatric Association (APA) (2013). *Diagnostic and Statistical Manual of Mental Disorders* (ed. 5). Washington DC: Author.
- Banasiak, A. (2013a). Stres rodzicielski ojców dzieci z autyzmem, In J. Garbula, A. Zakrzewska, W. Sawczak (ed.) *Świat rodziny. Perspektywa interdyscyplinarna wobec wyzwań i zagrożeń* (pp. 78-94). Wydawnictwo Adam Marszałek, Toruń.
- Banasiak, A. (2013). Znaczenie grup wsparcia w adaptacji rodziców dzieci z autyzmem. *Pedagogika rodziny*, 3 (4), pp. 129 – 141.
- Banasiak, A. (2016). Demografia a poziom doświadczanego stresu matek dzieci z zaburzeniami rozwoju, *Prace Naukowe Akademii im Jana Długosza w Częstochowie, Pedagogika*, vol. XXV, no. 2, 245-264.
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36, 685-695.
- Bishop, S. L., Richler, J., Cain, A. C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, 112, 450-461.
- Carr, J. (2005). Families of 30-35 year olds with Down`s syndrome. *Journal of Applied Research in Intellectual Disabilities*, 18, 75-84.
- Fleischmann, A. (2004). Narratives published on the internet by parents of children with autism: What do they reveal and why is it important? *Focus on Autism and Other Developmental Disabilities*, 19, 35-43.
- Fombonne, E., Marcin, C., Manero, A. C., Bruno, R., Diaz, C., Villalobos, M., Ramsay, K., & Nealy, B. (2016). Prevalence of autism spectrum disorders in Guanajuato, Mexico: the Leon survey. *Journal of Autism and Developmental Disorders*, 46, 1669-1685. <https://doi.org/10.1007/s10803-016-2696-6>.
- Gałkowski, T. (1995). *Dziecko autystyczne w środowisku rodzinnym i szkolnym*. Warszawa: Wydawnictwo Szkolne i Pedagogiczne.
- Gray, D. E. (2002). Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27, 215-222.
- Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, 50, 970-976.
- Koren, P., DeChillo, N. I., & Friesen, B. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37, 305-321.
- Kwaśniewska, G. (2010). Rodzina z dzieckiem z niepełnosprawnością w procesie wczesnej interwencji – kontekst teoretyczny. In: Z. Żyta (ed.), *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności* (pp. 25-41). Toruń: Wydawnictwo Edukacyjne Akapit.
- Pisula, E. (1998). *Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju*. Warszawa: Wydawnictwo UW.
- Pisula, E. (2005). Poczucie siły u matek dzieci z autyzmem. In: D. Marzec, A. Banasiak (ed.), *Dziecko z autyzmem. Rozważania teoretyczne, doniesienia z badań* (pp. 121-127). Częstochowa: Wydawnictwo AJD w Częstochowie.
- Pisula, E. (2009). Samotność wśród najbliższych. Interakcje dzieci z autyzmem z rodzicami. *Czasopismo Psychologiczne*, 15, 295-304.

- Pisula, E., & Kossakowski, Z. (2010). Sense of coherence and coping with stress among mothers and fathers of children with autism. *Autism Dev Disord*, 10.1007, 10803-010-1001-3.
- Pisula, E., & Mazur, A. (2006). Stopień nasilenia autyzmu u dziecka a percepcja i poczucie umocnienia u matek. In: T. Gałkowski i E. Pisula (ed.), *Psychologia rehabilitacyjna. Wybrane zagadnienia* (pp. 185-201). Warszawa: Wydawnictwo Instytutu Psychologii PAN.
- Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping and well-being in parents of children with autism. A multilevel modeling approach. *Journal of Family Psychology*, 22, 855-864.
- Sakaguchi, M., & Buppu, S. (2007). Structure of stressors in mothers of preschool children with autism. *Japanese Journal of Special Education*, 45, 127-136.
- Singh, N. N., Curtis, J., Ellis, C. R., Nicholson, M. W., Villani, T. M., & Wechsler, H. A. (1995). Psychometric analysis of the Family Empowerment Scale. *Journal of Emotional and Behavioral Disorders*, 3, 85-91.
- Smrokowska-Reichmann, A. (1999). Przywróć ci siły. Koncepcja empowerment w pracy socjalnej. *Wspólne Tematy*, 4, 22-34.
- Tobing, L. E., & Glenwick, D. S. (2006). Predictors and moderators of psychological distress in mothers of children with pervasive developmental disorders. *Journal of Family Social Work*, 10, 1-22.
- Wachtel, K., & Carter, A. S. (2008). Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism: The International Journal of Research and Practice*, 12, 575-594.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115-130.
- World Health Organization (WHO) (2002). *The ICD-10 classification of mental and behavioural disorders: Diagnostic criteria for research*. Geneva, Switzerland: Author.
- Vasilewa, N. (2010). Problemy wspierania dzieci z autyzmem i ich rodzin w Bułgarii. In: Z. Żyta (ed.), *Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności* (pp. 111-122). Toruń: Wydawnictwo Edukacyjne Akapit.