THE SENSE OF EMPOWERMENT AND THE LEVEL OF PARENTING STRESS EXPERIENCED BY MOTHERS OF CHILDREN WITH AUTISM

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Abstract

The primary focus of this paper is to analyse the relationship between the level of parenting stress and the sense of empowerment among mothers of children with developmental disorders.
Three groups of mothers participated in the study in which mothers raising children with autism were a major group whereas mothers of children with Down syndrome as well as mothers of children developing normally were comparison groups.
119 respondents participated in the study. The shortened version of Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members – QRS and The Empowerment Scale were used for the study purposes. The obtained results indicate a strong correlation between the level of empowerment and the level of parenting stress.

Keywords

autism, sense of empowerment, parenting stress, parents, Down syndrome

INTRODUCTION

The analysis of subject literature provides an overview of publications on how to handle difficult situations, in particular resources available to parents. There have been numerous studies investigating the situation of parents of children diagnosed with developmental disorders in terms of parenting stress and its source. It is widely known that families with a disabled child cannot be thought of as a homogeneous group, what is more, the families adapt over time and successfully cope in a variety of ways (i.a. Brown et al., 2006; Lewis et al., 2006; Pisula, 2012). Therefore, current scientific interests focus

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on existing opportunities and families' resources as well as actions taken by an individual in the face of tough times (i.a. Byra and Parchomiuk, 2018; Pisula and Kossakowska, 2010; Ruiz-Robledillo et al., 2014). This specific research approach plays an important role in the context of the study results (i.a. Hastings, 2009; Osborne et al., 2008) both highlighting the relationship between stress levels and parents' perception of their children's abilities and revealing that pessimistic parents are less likely to initiate intervention for their children.

Importantly, the results demonstrate clearly that parents of autistic children report higher levels of parenting stress than parents of children developing normally (Banasiak, 2017; Yamada et al., 2007) and parents of children with other developmental disabilities (Hayes and Watson, 2013; Pisula and Porębowicz-Dörsmann, 2017; Valicenti-McDermott et al., 2015). In the autism community, the most common challenges faced by parents of autistic children are associated with co-dependency between them and their children, highly unpredictable behaviour in autistic children (Barroso et al., 2018; DesChamps et al., 2020). Grappling with subjective lack of knowledge and child care skills, apparent unawareness of what to expect over time, limited access to professionals specialising in supporting autistic individuals can directly impact mental health of parents who have autistic children (Banasiak, 2018; Sakaguchi and Beppu, 2007; Wachtel and Carter, 2008). The stress experienced by parents of children with autism can lead to health problems. It can also trigger excessive anxiety and feelings of depression (Davis and Carter, 2008; Phetrasuwan and Shandor Miles, 2009). Moreover, stress affects various aspects of family life, including marriage relationships, interactions between family members and family atmosphere (Brown et al., 2020; Hutton and Caron, 2005).

Managing stress while caring for a child with autism includes setting lower expectations for autistic children, but they have to face new challenges then. On the other hand, there are still some barriers to increasing and widening access to resources available for autistic family. Therefore, coping skills used by parents of children with autism are associated with empowerment.

The term "empowerment" is essentially related to the English word "power" and means "strength". At its core, empowerment involves reducing feelings of powerlessness, enhancing and boosting feelings of power or reducing feelings that an individual's life can be influenced by other people, organisations and social environment (Koren, DeChillo and Friesen, 1992). Empowerment can be described as a process by which people gain control of their own lives. It seems that four factors affecting the empowerment process for families raising children with developmental disorders are as follows: capacity to protect children's interests, knowledge, competences and a sense of self-efficacy. In this paper, the sense of empowerment is defined as "people's enduring capacity to act in their own name and gain greater control of their own lives and destinies" (Koren, DeChillo and Friesen, 1992, p. 308).

The assessment of the situation of parents bringing up children with autism appears particularly important, especially with regard to the sense of empowerment. As mentioned before, all expectations about caring for a child can lead to feelings

of isolation and helplessness (Pisula, 2009; Weiss, 2002), which can subsequently create a lack of motivation to build a sense of empowerment and take control of one's own life. It is generally observed that parents often struggle to get a correct diagnosis and receive access to appropriate education or therapies. It is crucial to note that these actions can influence the sense of empowerment. Many parents often find it useful to be actively involved in taking action setting up organisations, offering great support to help their own children and others with similar difficulties (Pisula, 2012). Some studies show that mothers of children with autism display a higher of empowerment than mothers of children with intellectual disabilities or cerebral palsy (Pisula and Mazur, 2006). Fathers of autistic children, on the other hand, assess their own knowledge and competences at a lower level compared with fathers of children with Down syndrome and children who grow and develop properly (Pisula and Banasiak, 2019). Furthermore, it has been shown that there are not only negative correlations between a sense of empowerment and parental frustration (Weiss and Lunsky, 2011) as well as emotion-focused coping strategies (Pisula and Banasiak, 2019), but also positive correlations with quality of life (Weiss and Lunsky, 2011).

Research problem

The presented results show that there is not an apparent relationship between stress levels and a sense of empowerment with regard to parents of children diagnosed with autism. This factor has an effect on the adaptation of parents and is linked to other resources, difficult situations and actions taken by parents. The sense of empowerment is associated with understanding and assessing the system of health educational and social services. It is also related to the ability to affect the service system in order to change it or improve its functioning.
The present study aims to investigate the relationship between parenting stress and a sense of empowerment.

Characteristics of the studied groups

The analysis was performed in three groups of mothers. Among the participants, there were mothers of children diagnosed with autism (39 mothers), mothers of children with Down syndrome (40 mothers) and mothers of children developing normally (40 mothers). This type of study provided a basis for comparing the results from the two groups of mothers of children with developmental disorders (autism and Down syndrome) and then interpret them in comparison with the results from the group of mothers of children with normal development.
The average age of mothers having children with autism was about 40 years (average 39.54; standard deviation 7.54), mothers of children with Down syndrome – 43 years (average 42.9; standard deviation 7.65) and mothers of children developing normally – 37 years (average 37.15; standard deviation 4.94). A large majority of mothers had higher

education qualifications (11 mothers of children with autism, 18 mothers of children with Down syndrome, 20 mothers of neurotypical children), moreover, they lived in big urban areas – more than 100,000 inhabitants. A large number of mothers of children with developmental disorders were not professionally active (23 mothers of children with autism, 59%; 20 mothers of children with Down syndrome, 50 %). The children of the study participants were aged 7–17 and attended school (children developing normally) or were placed in special schools as a result of intellectual disability (children with autism and Down syndrome). Parents of autistic children were mainly contacted through schools. Participation in the study was completely voluntary and anonymous.

Research tools

Two questionnaires and a demographic survey created by the author were used to measure the variables.

1. Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members – QRS (Holroyd, 1987) – a shortened version. The questionnaire was a useful way to measure the stress level and determine its profile. The tested Polish version, adapted by E. Pisula, is considered to be high in reliability (r=0.70). QRS is an 11-item scale used in three key areas: child problems, personal problems and family issues. They measure the subjective assessment of burdens by stressors related to care for the child, and the availability of resources helpful when coping with them.
2. The Empowerment Scale – FES, developed by Paul E. Koren, Neal DeChillo, and Barbara J. Friesen, was created to measure a sense of empowerment. The tested Polish version, adapted by E. Pisula, measures empowerment with respect to the family, service system for children, and larger community and political environment. The original FES consists of 34 items rated on a 5-point scale from 1 (not true at all) to 5 (very true). It measures empowerment in four forms, such as:
   - System support – thoughts, beliefs and the behaviour of parents towards healthcare workers and social service workers.
   - Knowledge – understanding the healthcare system and social services their functions and roles in order to get necessary help and support.
   - Competences – the ability to perceive one's strengths and skills as well as parental competences.
   - Self-efficacy – parents' belief in their ability to influence situations and obtain necessary services to meet parents' or their children's needs.
3. The demographic questionnaire, created by the author, was a helpful tool to collect demographic data regarding the mothers' level of education, their age, their place of residence and professional activity as well as information about developmental disorders in children (or lack of disorders), their age and school attendance.

Due to the lack of normality in the distribution of the measured variable, the non-parametric test was used in the statistical analyses.

Results of own studies

The correlation analyses using the Spearman rho test helped examine the relationship between parenting stress and empowerment.
The results of the analyses are presented in tables 1, 2, 3.

Sense of empowerment vs. stress levels of mothers of children with autism

Tab. 1 Values of rho-Spearman correlation coefficients for indicators of sense of empowerment and indicators of stress levels in mothers of children with autism

Stress level indicators	Indicators of level of sense of empowerment							
	System support		Knowledge		Competences		Self-efficacy	
	r_{xy}	p	r_{xy}	p	r_{xy}	p	r_{xy}	p
QRS1	-0.051	0.758	0.086	0.602	**-0.446***	**0.004**	**-0.437***	**0.005**
QRS2	-0.185	0.260	0.033	0.841	-0.049	0.768	0.212	0.196
QRS3	-0.196	0.232	0.038	0.817	-0.007	0.965	**-0.386***	**0.014**
QRS4	-0.131	0.426	0.277	0.088	0.132	0.424	0.145	0.380
QRS5	**-0.543***	**0.000**	-0.199	0.225	**-0.332***	**0.039**	**-0.510***	**0.001**
QRS6	-0.160	0.330	0.136	0.409	-0.084	0.611	0.229	0.160
QRS7	**-0.478***	**0.002**	-0.080	0.628	-0.013	0.938	-0.080	0.627
QRS8	-0.118	0.475	-0.273	0.093	-0.308	0.056	-0.258	0.112
QRS9	0.260	0.110	0.081	0.625	0.203	0.215	0.121	0.463
QRS10	0.225	0.168	0.028	0.865	0.171	0.298	0.171	0.298
QRS11	-0.242	0.137	-0.247	0.129	-0.209	0.202	-0.197	0.229

p – level of significance; rxy – test score; QRS questionnaire scales (1–11); ORS1 – dependence on care; QRS2 – cognitive impairments and deficits; QRS3 – limitations in physical development; QRS4 – prospect of needing continuous care for the child; ORS5 – lack of personal reinforcements; ORS6 – stress related to the child's medical condition and/or terminal illness; ORS7 – preference for institutional care; QRS8 – personal burdens; QRS9 – limitations on family capacity; QRS10 – disharmony in the family; QRS11 – material problems

In the group of mothers of children with autism, the system support index negatively correlated with the evaluation of stress level caused by the lack of personal reinforcements (QRS 5). A negative correlation also occurred between the personal reinforcement index (system support) and the stress level resulting from the preference for institutional care (QRS 7). This means that the higher the sense of system support, the lower the stress level in mothers of children with autism.

The figures in Tab. 1. show that there were no statistically significant correlations between the index of 'knowledge' and the level of stress in the group of mothers of autistic children. Among factors calculated between the index of sense of competence and individual indicators of stress as measured by the QRS scale in the group of mothers of autistic children, two proved to be statistically significant. The evaluation of the sense of competence negatively correlated with the stress index QRS 1 – dependence on care, and the stress index QRS 5 – lack of personal reinforcement. This means that the higher the sense of competence was, the lower the stress level associated with dependence on child care and lack of personal reinforcement.

In the group of mothers of children with autism, the sense of self-efficacy correlated negatively with two QRS indicators, i.e. the level of stress related to limitations in the child's physical development (QRS 3) and the level of stress related to the lack of personal reinforcements (QRS 5). The higher the self-efficacy ratings, the lower the level of stress in this area.

Sense of empowerment vs. stress levels of mothers of children with Down syndrome

Tab. 2 Values of rho-Spearman correlation coefficients for indicators of sense of empowerment and indicators of stress levels in mothers of children with Down syndrome

Stress level indicators	Indicators of level of sense of empowerment							
	System support		Knowledge		Competences		Self-efficacy	
	r_{xy}	p	r_{xy}	p	r_{xy}	p	r_{xy}	p
QRS1	0.000	0.000	0.145	0.371	**-0.520***	**0.001**	**-0.360***	**0.023**
QRS2	-0.188	0.244	-0.163	0.321	-0.182	0.267	**-0.523***	**0.001**
QRS3	0.005	0.973	-0.069	0.671	-0.201	0.219	**-0.313***	**0.049**
QRS4	-0.127	0.436	0.084	0.608	-0.161	0.321	-0.064	0.697
QRS5	**-0.321**	**0.043**	-0.099	0.542	-0.031	0.849	-0.076	0.643
QRS6	0.278	-0.083	0.284	0.076	0.126	-0.440	**-0.358***	**0.023**
QRS7	**-0.050**	**0.758**	0.227	0.159	-0.261	0.103	0.010	0.953
QRS8	-0.029	0.858	-0.291	0.068	**-0.438***	**0.005**	**-0.470***	**0.002**
QRS9	0.224	0.165	0.098	0.547	0.021	0.896	0.106	0.514
QRS10	0.157	0.333	0.004	0.979	**-0.399***	**0.011**	-0.040	0.806
QRS11	**-0.404***	**0.010**	-0.007	0.967	-0.233	0.149	0.160	0.324

p – level of significance; rxy – test score; QRS questionnaire scales (1–11); ORS1 – dependence on care; QRS2 – cognitive impairments and deficits; QRS3 – limitations in physical development; QRS4 – prospect of needing continuous care for the child; ORS5 – lack of personal reinforcements; ORS6 – stress related to the child's medical condition and/or terminal illness; ORS7 – preference for institutional care; QRS8 – personal burdens; QRS9 – limitations on family capacity; QRS10 – disharmony in the family; QRS11 – material problems

In the group of mothers of children with Down syndrome, the index of sense of support from the system correlated negatively with the level of stress associated with the lack of personal reinforcements (QRS 5). This means that a higher sense of support from the system is accompanied by a lower level of stress related to the lack of personal reinforcements.

In the group of mothers in question, as in the case of mothers of children with autism, the figures in Tab. 2 show that there were no statistically significant correlations between the 'knowledge' index and the level of stress.

Significant correlations were observed, however, for the index of sense of competence a negative correlation occurred between the assessment of competence and the level of stress related to dependence on care (QRS 1). Significant negative correlations also occurred between the assessment of competence and the level of stress related to personal burdens (QRS 8) and to stress related to disharmony in the family (QRS 10). Higher ratings of sense of competence in mothers of children with Down syndrome were associated with lower levels of stress in the mentioned ranges.

In the group of mothers of children with Down syndrome, correlational analysis also revealed five significant relationships between self-efficacy and parental stress. As in the case of mothers of autistic children, the self-efficacy index correlated negatively with the level of stress related to dependence on care (QRS 1) and the level of stress related to limitations in the child's physical development (QRS 3). In addition, a negative correlation was found between self-efficacy ratings and levels of stress related to the child's cognitive disorders and deficits (QRS 2), stress related to the child's health status (QRS 6) and stress related to personal burdens (QRS 8).

Sense of empowerment vs. stress levels of mothers of children developing normally

Tab. 3 Values of rho-Spearman correlation coefficients for indicators of sense of empowerment and indicators of stress level in mothers of children developing normally

Stress level indicators	Indicators of level of sense of empowerment							
	System support		Knowledge		Competences		Self-efficacy	
	r_{xy}	p	r_{xy}	p	r_{xy}	p	r_{xy}	p
QRS1	-0.259	0.106	-0.197	0.223	0.205	0.204	-0.251	0.118
QRS2	-0.118	0.468	0.192	0.236	-0.208	0.198	**-0.493***	**0.001**
QRS3	-0.066	0.687	0.089	0.586	-0.200	0.217	0.131	0.421
QRS4	-0.207	0.201	0.171	0.291	0.306	0.055	0.090	0.582
QRS5	-0.151	0.252	**-0.381***	**0.015**	-0.229	0.156	-0.217	0.179
QRS6	-0.204	0.207	**-0.381***	**0.015**	-0.073	0.656	-0.247	0.124
QRS7	0.032	0.844	0.078	0.631	0.171	0.291	-0.018	0.910
QRS8	-0.020	0.903	0.100	0.540	-0.020	0.902	-0.080	0.622
QRS9	**0.543***	**0.001**	**0.519***	**0.001**	0.210	0.193	**0.479***	**0.001**
QRS10	**-0.401***	**0.010**	0.142	0.382	-0.055	0.738	-0.209	0.196
QRS11	-0.043	0.794	**-0.328***	**0.039**	0.079	0.628	-0.151	0.352

p – level of significance; rxy – test score; QRS questionnaire scales (1–11); ORS1 – dependence on care; QRS2 – cognitive impairments and deficits; QRS3 – limitations in physical development; QRS4 – prospect of needing continuous care for the child; ORS5 – lack of personal reinforcements; ORS6 – stress related to the child's medical condition and/or terminal illness; ORS7 – preference for institutional care; QRS8 – personal burdens; QRS9 – limitations on family capacity; QRS10 – disharmony in the family; QRS11 – material problems

In the group of mothers of children developing normally, the sense of support from the system negatively correlated with the QRS 10 stress index – stress related to disharmony in the family. The obtained correlation indicates that the higher the score of support from the system, the lower the score in this stress range. In addition, there was one positive correlation in the group of mothers of children developing normally. It concerned the sense of support from the system and stress related to the limitations of the family's capabilities (QRS 9). The higher the ratings of support from the system, the higher the stress score in this area.

In the group of mothers of children developing normally, in contrast to mothers of children with developmental disorders, a number of significant correlations were observed in terms of self-assessment of knowledge. A negative correlation occurred between the assessment of knowledge and the level of stress related to material problems (QRS 11). Significant

negative correlations also occurred between self-assessment of knowledge and levels of stress related to lack of personal reinforcement (QRS 5) and stress related to the child's health (QRS 6). Higher ratings of knowledge were associated with lower levels of stress in these ranges. In addition, there was one positive correlation in the group of mothers of children developing normally. It concerned the evaluation of one's own knowledge and the level of stress related to the family's capacity constraints (QRS 9). The higher the evaluation of one's own knowledge, the higher the level of stress in this area.
The figures in Tab. 3 show that there were no statistically significant correlations between the sense of competence and the level of stress in the group of mothers of children developing normally.
However, significant correlations were found in the self-efficacy index. A negative correlation occurred between the self-efficacy rating and the level of stress related to cognitive disorders and deficits. In addition, in the group of mothers of children who are developing normally, there was a positive correlation between self-efficacy ratings and the level of stress related to family capacity constraints (QRS 9). The higher the self-efficacy scores, the higher the scores on stress related to family capacity constraints.

DISCUSSION AND SUMMARY

In the present study, the relationship between parental stress and sense of empowerment was found important in considering the situation of parents of children with autism. It was expected that the sense of empowerment would negatively correlate with the level of stress. Correlational analysis between variables conducted in the three groups of mothers largely confirmed expectations. In the groups of mothers of children with developmental disorders, negative correlations occurred for three indicators of sense of empowerment: support from the system, sense of competence and self-efficacy. The correlations obtained allow us to conclude that mothers of children with autism who had higher perceptions of their interactions with health care, education, and social support workers simultaneously experienced lower levels of stress in the above-mentioned scopes. In addition, mothers who rated their own abilities and competence as a parent higher experienced lower stress in terms of their child's dependence on care and lack of personal reinforcements. Also in terms of self-efficacy, there were two significant negative correlations with stress. They indicate that the higher the sense of self-efficacy, the lower the level of stress related to limitations on the child's physical development and lack of personal reinforcements.
As in the case of mothers of children with autism, there were significant negative correlations with stress in sense of competence and self-efficacy among mothers of children with Down syndrome.
Slightly different correlations were detected in the group of mothers of children developing normally, for among the 8 significant correlations, three coefficients obtained indicated positive correlations. All of them related to stress related to the limitations of the family's capabilities. It is also interesting to note that although there were no statistically significant correlations in the group of mothers of children with autism and Down syndrome on this

scale, the coefficients obtained indicated a similar direction of dependence. This regularity seems obvious, in view of the fact that the sense of empowerment associated with greater knowledge, activity, opportunities to act on behalf of the child, requires giving up many activities that meet the needs of the whole family. Giving up professional work, spending leisure time according to one's own preferences, financial constraints on the family are experiences of many families.

It is also interesting to note that the assessment of self-reported knowledge in mothers of children with autism and Down syndrome did not correlate with the results of any scale measuring stress. Interestingly, in mothers of children developing normally, the most significant correlations occurred in this area. When interpreting the results for the groups of mothers of children with developmental disorders, it should be remembered that their children received a form of institutional care (school period, 7–17 years). It can be assumed that this fact relieved the mothers from seeking knowledge about the functioning of the service system, since the child was placed in this system and these functions were taken over by the institution. Perhaps this indicator would prove significant later, when the child finds himself outside the educational service system (after age 24). Certainly, this thread requires further detailed analysis.

The results of the analysis of correlations between the analyzed variables largely confirmed expectations. Indeed, it turned out that, to a dominant degree, support from the system, a sense of knowledge, competence and self-efficacy negatively correlated with individual indicators of parental stress.

Based on the results of previous work (Benson, 2006), it could have been assumed that better knowledge of how the care and service system works and confidence in one's own ability to influence organizations and institutions that provide services to children with autism would foster a better assessment of one's own position. Indeed, it has previously been shown that a strong stressor associated with caring for an autistic child is a sense of uncertainty and confusion about where and what help to seek. It is also known that participation in the processes affecting a person's situation and the opportunity to participate in decision-making, positively affect the psychological well-being of the individual (Pisula, 2005).

The analysis conducted provides a basis for the conclusion that the sense of empowerment is related to the parental stress experienced. A higher sense of empowerment, meaning a sense of being able to influence the social environment, promotes adaptation to the challenges of caring for a child with developmental disorders. Perhaps a high assessment of one's capabilities in this regard allows one to evaluate the situation in terms of a challenge rather than a personal threat or loss. This brings the opportunity to take action to solve the problem. Successful efforts eventually lead to a reduction in the number of problems associated with caring for a child with developmental disorders.

Although the described study is not free of flaws – the relatively small groups of subjects, its internal variation, it seems, however, that the obtained results can be helpful in planning support programs for mothers of children with developmental disorders.

It is certainly worth including in them the strengthening of the family, consisting of their active participation in decision-making in the education, therapy and rehabilitation of the child. Such decision-making and confidence in their own ability to cope with difficulties promotes better judgment and mental condition.

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