Parental stress observed among mothers of autistic children


The aim of the research presented in this article was to determine the level of parental stress among mothers of autistic children. Thirty-nine mothers of autistic children, forty mothers of children with Down syndrome as well as forty mothers of children with developing normally took part in the study. We used the Questionnaire on Resources and Stress (QRS, designed by J. Holroyd) to assess the parental stress among families of developmentally delayed children or children with intellectual disabilities. The results of the study indicate that, comparing to mothers of children with Down syndrome and mothers of children developing well, mothers of autistic children are the ones who experience the highest level of parental stress. Potential sources of coping strategies among mothers of children that suffer from autism are associated with relatively low stress levels as a result of disharmony within the family, personal issues, the child’s health situation and financial problems.

**KEY WORDS:** autism, parental stress, mothers

**Introduction**

So called *autism spectrum disorders* (ASD) are currently classified as neural development disorders. According to the latest version of the DSM-V Diagnostic and Statistical Manual of Mental Disor-
ders\(^1\) of the American Psychiatric Association, autism spectrum disorders are characterised by difficulties in social communication, the formation of social relations, accompanied by rigid/limited behaviour, interest and activity patterns.

It is worth noting that despite numerous studies concerning the etiology of autism, frequently with the use of technologically advanced methods, we still do not know the root cause of this disorder. A multi-factor genetic and environmental basis is presently most often indicated within the pathogenesis of autism, stressing the importance of interactions between the nervous and immunological systems\(^2\).

Contemporary knowledge also does not explain the rising volume of diagnoses of autism spectrum disorders among children. Autism, once included in the group of rare disorders, is currently included in the most common developmental problems in children. Research presented by the Centres for Disease Control and Prevention of the United States\(^3\) show that disorders from the autism spectrum are currently found in one in 68 persons. The results of tests\(^4\) from other countries also indicate a high and steadily rising tendency of diagnosing such disorders in children. This is the cause that year after year, more and more persons, e.g. children diagnosed with ASD and their families require professional support.

\(^1\) APA 2013. In Poland, for the purpose of diagnosis of autism, utilised are criteria of the ICD-10 classification, drawn up by the WHO, 2002; however, the latest classification of the APA is noteworthy as it reflects very well the contemporary knowledge on autism. These issues, however, will not form a part of this paper.


Subject literature devotes much space to difficulties of parents related to the education and care for a disabled child. Mothers, perceived by the social environment as the main caretakers, are of particular interest to researchers. As a consequence of such social expectations, in many cases the mothers themselves see themselves as indispensable, irreplaceable in terms of the duties arising from the care and rehabilitation of a child. The execution of the role of the mother – the mother of a disabled child, is for many becoming the superordinate direction of self-fulfilment.

As proven by numerous studies, development disorders in children markedly influence physical health, psychological well being of mothers as well as the evaluation of the quality of life. Permanent difficulties accompanying the mothers of children with development disorders can lead to changes in one’s self image. As studies show, such situations facilitate the reduction of one’s

self-appraisal, in particular in terms of the evaluation of one’s parental competences, as well as the experience of lack of fulfilment in the mother role. There also exist empirical studies, however that prove that the experiences gathered by mothers in course of caring for a child with developmental problems can become the source of the feeling of one’s own self-worth, importance, and an improvement in one’s self-appraisal.

It needs to be stressed that parents caring for a disabled child do not form a homogeneous group with respect to the represented properties, behaviour patterns or states. Within the context of parental stress, this differentiation depends on three basic sets of factors, e.g. factors characterising the child (e.g. the type and degree of their disability, their personality and temperament); factors characterising the parent (e.g. age, gender, education level and psychological constitution) and so-called external factors, which include e.g. the way the diagnosis is conveyed to the parents, the quality of relations with specialists, the availability of special services for the child and themselves, the attitudes of the environment concerning the child’s disability, membership in social organisations/associations, the possibility of finding rest and the economic situation of the family.

The studies that analysed the influence of the type of disability in the child’s development on parental stress do not permit a clear conclusion concerning the relationship between these variables. Some papers indicate the existence of a relation between the type of disorder and the level and character of the related stress. As certain

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studies show\textsuperscript{10} it is higher in mothers of autistic children than in mothers of children with Down syndrome, as well as mothers of children with cerebral palsy. It must be noted that there exists research, the results of which do not confirm a difference\textsuperscript{11}. For instance, S. E. Waisbren\textsuperscript{12} had shown that in terms of physical health, social activity, marriage relations or future plans, parents of disabled children did not differ from parents caring for a neurotypical child, of the same age.

Assumptions and organisation of own research

The research process was supposed to provide answers to the basic research problem formulated as follows: What is the level of experienced parental stress in mothers of autistic children (making up the basic group, GA) as compared to the stress disclosed by mothers of children with Down syndrome (first comparative group, GD) and mothers of properly-developing children (second comparative group, GN).

The hypothetical reply given based on an analysis of available theoretical and empirical studies assumes the presence of differences in terms of the level of experienced parental stress between the...
studied groups of mothers, whereby mothers of autistic children will be characterised by the highest levels of experienced stress.

The proprietary study utilised the following tools: an abbreviated, 11-factor version of the Questionnaire on Resources and Stress (QRS) for families with chronically ill or disabled members by J. Holroyd, as adapted by E. Pisula, and own survey questionnaires.

The QRS scale is composed of eleven scale units included in three main fields. They measure the subjective assessment of burdens by stressors related to care for the child, and the availability of aid resources for coping. The distinguished fields are: problems of the child (dependence on care cognitive disturbances and deficits, physical development limitations); issues of the interviewee (the perspective of the need of constant care for the child, lack of personal reinforcements, stress related to the terminal illness, preferences for institutional care, personal burdens); family problems (limitations of family options, disharmony within the family, financial issues).

The tool presented above fulfils the conditions of psychometric correctness (the Polish version also shows a high degree of reliability at $r = 0.70$), and was used on numerous occasions by researchers with different interviewee groups.

In order to determine the socio-demographic data for the three analysed groups of mothers, as well as information related to the child’s disability (or lack thereof), proprietary questionnaires were used.

The study encompassed 39 mothers of children with autism, 40 mothers of children with Down syndrome and the same number of mothers of children developing correctly. All children of the analysed mothers attended schools or therapeutic facilities.

The mothers from the basic group were selected based on several criteria, e. g. the diagnosis of the child – childhood autism, made at least three years before the study; age of the child – 7÷17 years; no other disturbances present along with the autism (e. g. Down syndrome, cerebral palsy, other diagnosed deficiencies). The groups
compared with the group of mothers of autistic children were chosen based on a modified random choice.

The comparison of distribution of the demographic characteristics of the studied mothers, using the non-parametric Kolmogorov-Smirnov test showed that there were no differences between the group of mothers with autistic children and that of mothers with children with Down syndrome in terms of age, education level, the inhabited environment, professional activity and the age of the child. Similarly, no differences for the demographic variables were found in the comparative groups. A difference in child age was found between the group of mothers of autistic children and the group of neurotypical mothers - there were more children aged 12-17 in the group of mothers of properly-developing children.

The mean age of mothers with autistic children was ca. 40 years (mean 39.54; standard deviation 7.54), for mothers of children with Down syndrome it was 43 years (mean 42.9; standard deviation 7.65), and for mothers of neurotypical children it was 37 years (mean 37.15; standard deviation 4.94). Most of the analysed mothers had higher education (GA 29 persons, 39.2%; GD 18 persons, 45%; GN 22 persons, 55%) and came from large urban environments - above 100,000 inhabitants (GA 25 persons, 64.1%; GD 22 persons, 55%; GN 28 persons, 70%).

**Results**

Due to the lack of normality in the distribution of the measured variable across the individual mother groups, the analyses used the non-parametric Mann-Whitney U test.

Analysed were the results of the eleven scales of the QRS. The results of the analysis are presented in table 1.

As can be inferred from the table above, within five of the eleven scales of the QRS, mothers of children with autism had yielded results that were significantly higher than those for mothers of children with Down syndrome. If compared to results of mothers of correctly
Table 1. Parental stress levels in mothers of autistic children, mothers of children with Down syndrome and mothers of children developing correctly - descriptive statistics and results of the Mann-Whitney U test

<table>
<thead>
<tr>
<th>Stress level indicator</th>
<th>Mothers of children with autism</th>
<th>Mothers of children with Down syndrome</th>
<th>Mothers of children developing correctly</th>
<th>Mothers of children with autism / Mothers of children with Down syndrome</th>
<th>Mothers of children with autism / Mothers of children developing correctly</th>
<th>Mothers of children with Down syndrome / Mothers of children developing correctly</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>QRS1</td>
<td>3.487</td>
<td>1.500</td>
<td>2.500</td>
<td>1.072</td>
<td>1.100</td>
<td>1.136</td>
</tr>
<tr>
<td>QRS2</td>
<td>4.128</td>
<td>1.453</td>
<td>2.700</td>
<td>1.584</td>
<td>0.600</td>
<td>1.158</td>
</tr>
<tr>
<td>QRS3</td>
<td>4.513</td>
<td>1.152</td>
<td>2.450</td>
<td>1.627</td>
<td>0.700</td>
<td>0.714</td>
</tr>
<tr>
<td>QRS4</td>
<td>5.821</td>
<td>0.384</td>
<td>5.350</td>
<td>1.108</td>
<td>1.350</td>
<td>1.314</td>
</tr>
<tr>
<td>QRS5</td>
<td>1.513</td>
<td>1.615</td>
<td>1.000</td>
<td>1.140</td>
<td>0.600</td>
<td>0.800</td>
</tr>
<tr>
<td>QRS6</td>
<td>1.410</td>
<td>1.644</td>
<td>1.150</td>
<td>1.276</td>
<td>1.250</td>
<td>0.942</td>
</tr>
<tr>
<td>QRS7</td>
<td>2.897</td>
<td>1.057</td>
<td>2.300</td>
<td>1.229</td>
<td>1.050</td>
<td>0.865</td>
</tr>
<tr>
<td>QRS8</td>
<td>0.256</td>
<td>0.898</td>
<td>0.300</td>
<td>0.900</td>
<td>0.050</td>
<td>0.218</td>
</tr>
<tr>
<td>QRS9</td>
<td>4.282</td>
<td>1.085</td>
<td>2.700</td>
<td>1.646</td>
<td>2.700</td>
<td>1.847</td>
</tr>
<tr>
<td>QRS10</td>
<td>0.821</td>
<td>0.930</td>
<td>0.550</td>
<td>0.589</td>
<td>1.350</td>
<td>0.910</td>
</tr>
<tr>
<td>QRS11</td>
<td>4.590</td>
<td>1.295</td>
<td>4.150</td>
<td>1.314</td>
<td>3.250</td>
<td>1.445</td>
</tr>
</tbody>
</table>

* - significant difference at a level of α < 0.05; Scales of the QRS (1-11): QRS1 – care dependence; QRS2 – cognitive disturbances and deficits; QRS3 – physical development limitations; QRS4 – perspective of need of constant care for the child; QRS5 – lack of personal reinforcements; QRS6 – stress related to the health and/or terminal illness of the child; QRS7 – preference for institutional care; QRS8 – personal burdens; QRS9 – limitations of family options; QRS10 – disharmony within the family; QRS11 – financial problems.

M – arithmetic mean; SD – standard deviation; U – test value; p – significance level.
developing children, mothers of children with autism had yielded significantly higher stress level results in seven scales. Below are presented detailed descriptions of the results achieved by the tested mothers in the groups distinguished by the type of the child’s disturbance.

Field I – stress related to the problems of the child

Stress related to the dependence of the child on care (QRS 1)

In this field, mothers of children with development issues (e.g. with autism and Down syndrome) differed significantly from mothers of children developing correctly. They perceived their children as more dependent on care. In terms of the discussed stress indicator, differences were also noted between mothers of children with autism and mothers of children with Down syndrome. The former experienced more stress due to dependence on care than mothers of children with Down syndrome.

Stress related to cognitive disturbances and deficits (QRS 2)

Mothers of children with development issues perceived burdens related to cognitive disturbances and deficits of the child as greater than the mothers of children developing correctly. Statistically significant differences were also recorded between mothers of children with autism and mothers of children with Down syndrome. For mothers of children with autism, the stress level was in this area clearly higher than among mothers of children with Down syndrome.

Stress related to limitations in the child’s physical development (QRS 3)

Limitations in the child’s physical development were evaluated as higher by mothers of children suffering from developmental deficiencies as compared to the mothers of children developing cor-
rectly. It also turned out that mothers of children with autism experienced greater stress due to limitations in the child’s physical development than mothers of children with Down syndrome.

Field II – issues of the interviewee

Stress related to the perspective of need of constant care for the child (QRS 4)

Both mothers of children with autism, as well as mothers of children with Down syndrome experienced stress related to the perspective of the need of constant care for the child at similar levels. As compared to mothers of children developing correctly, in turn, both among mothers of children with Down syndrome, as well as mothers of children with autism, the stress level in this area was significantly higher.

Stress related the lack of personal reinforcements (QRS 5)

The lack of personal reinforcements was evaluated as higher by mothers of children with autism as compared to mothers of children developing correctly. The evaluation of the discussed factor did not yield differences between mothers of children with autism and mothers of children with Down syndrome and mothers of children with Down syndrome as compared to mothers of children developing correctly.

Stress related to the health and/ or terminal illness of the child (QRS 6)

The analysis of the stress level between the mother groups did not yield any statistically significant differences between the analysed groups.

Stress related to preferences for institutional care (QRS 7)

Mothers of children with development disorders (e.g. autism and Down syndrome) experienced higher levels of stress than
mothers of children developing correctly. Differences were also noted between the groups of mothers of children with autism and with Down syndrome. Mothers of children with autism experienced higher stress related to the preference for institutional care than mothers of children with Down syndrome.

Stress related to personal burdens (QRS 8).

Within this scale, the mothers of children with autism and with Down syndrome did not differ from the mothers of children developing correctly. There also were no significant differences between the groups of mothers of children with development issues.

Field III – issues of the family

Stress related to limitations of family options (QRS 9)

Limitations of family options related to care for the child were evaluated as higher by mothers of children with autism as compared to the mothers of children with Down syndrome and the mothers of children developing correctly. Within this scale, there were no differences between the mothers of children with Down syndrome and the mothers of children without disabilities.

Stress related to disharmony within the family (QRS 10)

Within the scope of the discussed stress factor, there were no differences between the mothers of children with autism and mothers of children with Down syndrome and mothers of children without disabilities. Mothers of children developing correctly, in turn, yielded in this regard a significantly higher stress level than mothers of children with Down syndrome.

Stress related to financial problems (QRS 11)

The analysis of stress levels in this area did not yield statistically significant differences.
Discussion

The present study assumed that mothers of children with autism would be characterised by a higher stress level than the mothers of children with Down syndrome and mothers of children developing correctly. As was estimated, the most differences were noted between the mothers of children with autism and mothers of children functioning correctly. In seven areas distinguished in the QRS, mothers of children with autism yielded higher results than mothers of children developing correctly. For five factors of the QRS, the results of mothers of children with autism were higher than those of mothers of children with Down syndrome.

Mothers of children with autism, compared to mothers of children without disabilities, evaluated their children as more dependent on care, and their cognitive development and physical development possibilities as more limited. They also experienced more stress related to the perspective of constant care for the child and with preferences for institutional care. Similarly, the lack of personal reinforcements was evaluated as higher by mothers of children with autism than by mothers of children developing correctly. Compared to mothers of children with Down syndrome, mothers of children with autism experienced a higher level of stress related to dependence on care, cognitive disturbances and deficits, limitations in physical development and limited abilities of the family. In addition, the mothers of children with autism, as compared to the mothers of children with Down syndrome, experienced higher levels of stress in relation to the preference for institutional care.

On the basis of the above results, one could conclude that the hypothesis assumed for the paper was confirmed. The yielded results correspond for the most part with the results of historic studies\textsuperscript{13}. However, some of the obtained results necessitate comments.

\textsuperscript{13} E. Pisula, Psychologiczne problemy rodziców dzieci z zaburzeniami rozwoju, Wydawnictwo UW, Warszawa 1998, p. 219; A. Dąbrowska, E. Pisula, Parenting stress and doping styles in mothers and fathers of pre-school children with autism and Down
An unexpected result, one relatively difficult to interpret, was found for the studied mothers in terms of stress related to limitations in physical development. As it turned out, mothers of children with autism, as compared to mothers of children with Down syndrome, have evaluated the physical abilities of their child as much more limited. Theoretically speaking, physical development – including motor development – of children with autism could be considered to be superior as compared to that of children with Down syndrome. However, due to the limited contact with an autistic child, as well as their difficulties communicating, disturbances in the pupil’s learning process and stubbornness in light of changes, the issue becomes much more complicated. Many children with autism are only fit physically in certain ranges. For instance, a child can be very fit and do complicated puzzles with great precision, at the same time having great difficulty in mastering basic tasks around them such as eating, getting dressed or activities related to hygiene. A. Dąbrowska and E. Pisula have also shown differences between the mothers of children with autism and mothers of children with Down syndrome, with the reservation, however, that it is mothers of children with Down syndrome who experienced significantly higher stress levels in relation to the physical limitations of their child. One could assume with great certainty that the differences in the results of this research can be influenced by the child’s age. The quoted study interviewed mothers of younger children (the child’s age was between two and six). In this period,
the motor development of a child experiences great changes. In addition, motor disharmonies in an autistic child of this age can be even less visible than later. A child of seven and older (with the children of the parents studied in this work being aged between seven and 17) is expected to show school-wise maturity, among others, independence in terms of its relevant daily activities as getting dressed or eating. A child within a peer group offers many opportunities for comparisons of their and other children’s skills.

The result indicating a lack of differences between the studied groups of mothers in terms of stress related to financial problems also deserves attention. One could expect that due to the costs related to the assurance of professional medical care for the child, as well as the fact that it is most often the case that only one parent works professionally, the financial situation of families with developmental issues would be difficult. Many studies yield such an image\textsuperscript{16}. In this study, however, it became evident that the standard of living of families raising children with development problems, despite all difficulties and resources invested in treatment and rehabilitation, was the same as for the families of children developing correctly. Perhaps the present socio-economic situation in Poland, the effects of post-transition changes (mass employee layoffs, shutting down uneconomic facilities, lack of creditworthiness of many families, etc.) touch upon both family groups to a similar extent. E. Minczakiewicz\textsuperscript{17} arrived at a similar result in terms of parents of children with Down syndrome and parents of children developing correctly. One should not forget however, that the studied group is not representative for the entirety of families with autistic children in Poland, and that conclusions from this study should not be overgeneralised.


In summary, the analysis of the obtained data indicated these areas of the functioning of the child, parent and environment that are related to the greatest burdens to parents of children with autism. This data seems to have a lot of practical relevance. The knowledge of the sources of parental stress in persons providing aid to families of children with developmental disturbances may contribute to the planning of more adequate and required aid. Furthermore, knowledge of the specific purposes and behaviour of a child conditioning the increase of stress levels in parents, may contribute to the arrangement of the intervention in such a way so as to minimise this stress.

The above-presented analysis of results also indicated areas, in which no significant differences were noted among the studied groups of mothers. These areas may be sources of strategies facilitating coping. The lowest stress levels in mothers of autistic children was recorded for the area QRS 10, e. g. stress related to disharmony within the family, area QRS 8 – personal burdens, area QRS 11 – financial problems, and area QRS 6 – stress related to the child’s health. As could be inferred, low results yielded by mothers in terms of stress related to personal burdens are related to the relatively good financial situation of the family, and accordingly, the possibility of simultaneous utilisation of aid from outside of the family.

The results concerning stress related to disharmony within the family, however, can support the notion that the fact of a child’s disability may not necessarily influence the coherence, integration or bond among its members\(^\text{18}\). In actuality, it cannot be excluded that in many cases developmental difficulties of a child can facilitate the emergence of negative emotions or the exacerbation of certain problems in the family, but a disturbance in the development of a child most probably does not constitute their original cause. It needs to be noted that not all researchers had shown a lack of disharmony within the family of an autistic child. The already quoted study by A. Żmijewska, *Zespół Aspergera w ujęciu rodzinnym – przegląd badań*, „Psychiatria Polska” 2010, 44, pp. 713–722.
A. Dąbrowska and E. Pisula had shown a markedly higher level of stress in this area in mothers of children with autism than in mothers of children with Down syndrome. It can not be excluded that the level of stress in this area varies depending on the age of the child, and, accordingly, also the duration of the parents’ relationship.

The issues of stress of parents of children with autism was handled by many scientific studied, however, the multitude of interdependencies in this area was not conclusively analysed. Times of political and economic transformation, as well as progressing globalisation, force one to consider further determining factors in analyses of difficulties stemming from the inability of parents of children with development problems to cope. The variables worth of further study are certainly: the parents’ awareness and activity in the struggle for the rights due to the child, the ability to use modern computer resources. Empirical conclusions in the area of parental stress should be verified on a permanent basis.

Finally, certain limitations of the study presented in this paper should be noted, which advise caution in terms of the interpretation of its results. The first is the size of the studied groups and the lack of their representative character. Similarly, the fact that studies were conducted in but one region of Poland (Silesian voivodeship, county of Częstochowa) does not permit a broad generalisation of the conclusions stemming from this study. A further limitation stems from the fact that the study was not longitudinal. Of particular value with respect to the analysed issues would be longitudinal studies and studies that include the variable of the functional status of the child into the analysis. Studies have accordingly shown that this variable better outlines the core of parental burdens than the typology of disability, and is of importance in terms of the final results concerning parental stress.


\[20\] Conf. M. Parchomiuk, Rodzice dzieci z mózgowym porażeniem dziecięcym wobec sytuacji trudnych, Wydawnictwo UMCS, Lublin 2007, p. 36.
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References


Krause A., Dziecko niepełnosprawne w rodzinie w perspektywie zmieniu społecznej, [w:] Rodzina osób z niepełnosprawnością intelektualną wobec węgwań współczesności, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, s. 15–25.


Minczakiewicz E., Sytuacja rodzin z dzieckiem z zespołem Downa na tle sytuacji współczesnych polskich rodzin statystycznych, w: Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010, s. 41–55.


Parchomiuk M., Zasoby osobiste matek dzieci niepełnosprawnych. „Człowiek-Niepełnosprawność-Społeczeństwo” 2012, nr 1(15) s. 44–61

Pisula E., Małe dziecko z autyzmem – diagnoza i terapia, Gdańskie Wydawnictwo Psychologiczne, Gdańsk 2005.


Pisula E., Samotność wśród najbliższych. Interakcje dzieci z autyzmem z rodzicami, „Czasopismo Psychologiczne” 2009, 15, s. 295–304.


Waisbren S.E., Parents reactions after the birth of a developmentally disabled child, “American Journal of Mental Deficiency” 1980, 84, s. 345–351.


Zasępa E., Poczucie koherencji rodziców dzieci z zaburzeniami rozwoju, w: Rodzina osób z niepełnosprawnością intelektualną wobec wyzwań współczesności, red. Z. Żyta, Wydawnictwo Edukacyjne Akapit, Toruń 2010.