

Parental burnout as a health determinant in mothers raising disabled children

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A Study Design
B Data Collection
C Statistical Analysis
D Data Interpretation
E Manuscript Preparation
F Literature Search
G Funds Collection

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abstract

- Background:** The aim of the study was to determine and compare the current risk of parental burnout in mothers of children with autism and with mild and moderate intellectual disabilities.
- Material and methods:** The study was conducted among 30 mothers of children with autism, 30 mothers of children with moderate intellectual disabilities and 20 mothers of children with mild intellectual disabilities. A diagnostic survey was the research method, a survey was the technique used, and the Parental Burnout Questionnaire by M. Sekulowicz and P. Kwiatkowski was the applied research tool.
- Results:** The average level of parental burnout risk significantly differentiates the investigated mothers due to the type of the child's disability. The lowest risk of parental burnout is shown in mothers of children with autism, a slightly higher risk is characteristic of mothers of children with moderate and mild intellectual disabilities, respectively.
- Conclusions:** Mothers of children with autism and with moderate and mild intellectual disabilities show a low level of the parental burnout risk, which may indicate they are about to achieve the stage of constructive adaptation to the situation of having a child with a disability.
- Key words:** parental burnout, stress, mothers, intellectual disability, autism.

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INTRODUCTION

Parenthood is considered as one of the most demanding [1] and difficult challenges facing adults which are more and more frequently met without sufficient preparation and any support of the closest family members [2]. Being a parent is associated with significant mental and physical strain that is often a source of stress, which may lead to parental burnout [3]. It is a consequence of the continued need to adjust to the needs of the child, while at the same time reducing the time that parents could spend on their personal development or relaxation thus enabling their psychophysical regeneration and determining the comfort of parents' living [4]. It should not be equated with parental stress only, or confused with depression. Parental burnout should be placed in the continuum between stress and depression [2, 5]. Its presence is considered to be the factor that impairs parents' health [6]. The most serious consequences of parental burnout are: cardiovascular diseases and inflammatory processes of the digestive tract [7-10] and asthma, allergies, migraine [11] and cognitive disorders [12]. However, parental burnout is not a process that takes place in a repeatable manner in all parents but pertains to individual psychosomatic disorders characterised by a state of mental and physical exhaustion that arises from sudden exacerbation of problems, emotional stress, failures that, when accumulated, become difficult to control [13].

Sullivan [14] believes that there are specific situations and circumstances which intensify the process of parental burnout, such as the need to provide continuous care to a person having severe health problems or behavioural disorders [14]. Parents who take care of their sick or disabled children are in a specific and extremely difficult situation [15-17].

The birth of a child with a disability in the family changes its functioning completely. Parents who find out about their child's disability experience many negative emotions, which leads to disruptions in family relations. Parents are required to provide continuous and systematic childcare without any time to rest, which is exacerbated by the specificity of functioning of disabled children. Consequently, parents experience a loss of energy increasing as a result of permanent parental stress caused by excessive requirements faced when raising children with disabilities [18, 19]. Mrugalska [20] even refers to a crisis that appears in such difficult and unexpected circumstances. It is indicative of the exposure to the new difficult situation which is accompanied by concerns about the child's development and health, stress due to a shortage of information, embarrassment, no help from others and increasing physical fatigue that is the result of continuous mobilization and multiplying duties. Therefore, the research on parental burnout primarily focused on families with children with special needs seems justified [21-24]. They are the ones who need the specific support first followed by taking measures that may improve their functioning. It is worth noting that parental burnout is an exceptionally common problem, since according to the research by Roskam and Mikołajczak [19], this situation affects up to 14% parents of healthy children.

The authors of the research on parental burnout show the relationship that distinguishes mothers, particularly vulnerable to parental burnout [24, 17, 25]. This may be due to the higher self-assessment responses in fathers, a lower number of stress symptoms and the consequence of the traditional division of roles in the family in which the mother is primarily responsible for the care and education of the child. Sekułowicz [26] points out that living with a child with

disabilities requires many sacrifices, which mainly pertains to the child's mother. Then, these mothers often perceive their situation as hopeless and are not able to deal with all the hardships associated with raising children with special needs. The birth of a child with a disability for mothers implies a permanent change of their social and existential situation. It must be emphasized that mothers have no choice and they make a sacrifice for their disabled child, abandon their own plans, work or investment in their own development. The overarching concern for them is the health and welfare of their child with disabilities [1]. Mothers of children with developmental disorders may not feel high quality women as they experience endless sorrow, regret and a sense of guilt caused by their child's disability [27]. The real life situation forces mothers to take the role of a carer/guardian, therapist and nurse, even though they are not adequately prepared for that. They accept the whole burden of duties pertaining to education and care of their children with disabilities, which may lead, for example, to the loss of personal autonomy [1, 28].

A problem that is interesting and very difficult to capture cognitively is the level of parental burnout due to the type of the child's disability. One of the studies by Pisula [29] controlled the intensity of factors contributing to the occurrence of parental burnout in statements made by parents of children with ASD and children with Down syndrome. In the results, Pisula [29] stated that as regards thirteen (out of fifteen evaluated) factors, parents of children with autism obtained higher results than parents of children with Down syndrome (e.g. sense of isolation and the lack of assistance, the feeling of confusion as to the child's possibilities, physical fatigue, frustration). Based on the author's opinion, parents of children with ASD suffer particularly from the lack of knowledge and capabilities with regard to the upbringing of their child. It suggests that parents raising children with ASD are particularly vulnerable to difficulties in tackling problems in the family and, in effect, they are more vulnerable to the occurrence of parental burnout symptoms. The results of other studies also suggest that parents of children with ASD experience greater stress than parents of children with other developmental disorders and with Down syndrome [30,31]. ASD that is clinically stable is an exceptionally severe disorder for parents who are not able to face it without the assistance of consultants and specialists. A big difficulty is a lack of any signs of commitment on the part of the child, noticeable for example as an early disturbance of non-verbal communication. In addition, the problem consists in untypical child's behaviours that are incomprehensible to other people, such as the rigid patterns of activity, resistance to changes in the environment, an increased amount of ritual operations, cognitive and motion stereotypies. Children with autism are often: hyperactive, aggressive towards each other and others. Parents do not always know the cause of such behaviour and are also not able to anticipate more difficult behaviours of their child [32]. An additional problem is the lack of universal therapeutic efforts that would provide e.g. a reduction in the frequency of occurrence of challenging behaviours or would help to develop communication. The reason for it is that, although each child with autism shows similar clinical symptoms, the combination of them together with individual personality traits, the stage of development and factors related to the environment in which they function result in the fact that every case of a child with autism should be considered separately.

The undertaken notion of specific difficulties with which mothers of children with autism are faced is of importance also to the authors of this paper. The question whether the experience of being a mother of a child with autism is associated with a greater level of parental burnout risk in comparison with mothers of children with intellectual disabilities seem to be especially interesting to them. This seems

of importance as from 2010 in Poland determination [statement] of the degree of disability due to pervasive disorders (12-C code) was introduced [33], which is just one of the many signals that the problem of diagnosis [34] and therapies that are increasingly technologically advanced e.g. in the area of medicine dedicated to autism spectrum disorders [35] are the centre of social attention. For this purpose, the research problem was formulated, namely determination of the actual parental burnout risk in mothers of children with autism and moderate and mild intellectual disabilities.

In order to verify the undertaken research problem, the following questions were formulated:

1. Are mothers of children with autism and with mild and moderate intellectual disabilities at risk of parental burnout?
2. Is the level of parental burnout risk different among the mothers of children with autism and those of children with mild and moderate intellectual disabilities?

MATERIAL AND METHODS

SUBJECTS

The study took place among 80 mothers of children with disabilities, including 30 mothers of children with autism, 30 mothers of children with moderate intellectual disabilities and 20 mothers of children with mild intellectual disabilities¹. The children of investigated mothers attended special schools in Wrocław (Lower Silesia). Children with autism - in the statement on their special educational needs - had an entry indicating the concurrent moderate or significant intellectual disability. The age of children with autism whose mothers were investigated ranges from 8 to 24 years; the age of children with both mild and moderate intellectual disabilities is between 8 to 15 years (Table 1).

Table 1. Characteristics of the test group

	Mothers of children with autism	Mothers of children with moderate ID*	Mothers of children with mild ID*
Number of mothers	30	30	20
Education of mothers [degree and number]	Secondary = 8 Higher = 22	data not available	data not available
Child's age [years]	M = 13.83 SD = 3.68	8-15 **	8-15 **

*ID - intellectual disabilities

** only information on the age range of children with moderate and mild intellectual disabilities is available [36]

STUDY ORGANISATION AND METHODOLOGY

The study was carried out from January to March 2018. The applied research method was a diagnostic survey; the technique used was a questionnaire, whereas the research tool was the Parental Burnout Questionnaire by Sekułowicz and Kwiatkowski [37]. The questionnaire was developed as a screening tool, so that one could evaluate the risk of parental burnout and is intended to take speedier action in the area of assistance for parents and entire families. It includes 12 items which consist of two subscales: emotional exhaustion and helplessness.

¹ The data on the assessment of the risk of parental burnout among mothers of children with mild and moderate intellectual disabilities come from the unpublished master's thesis by Alicja Więcław, M.A., on: Parental burnout in mothers of children with intellectual disabilities, supervised by: Prof. Marta Wieczorek, PhD AWF (University School of Physical Education in Wrocław, 2018) [36].

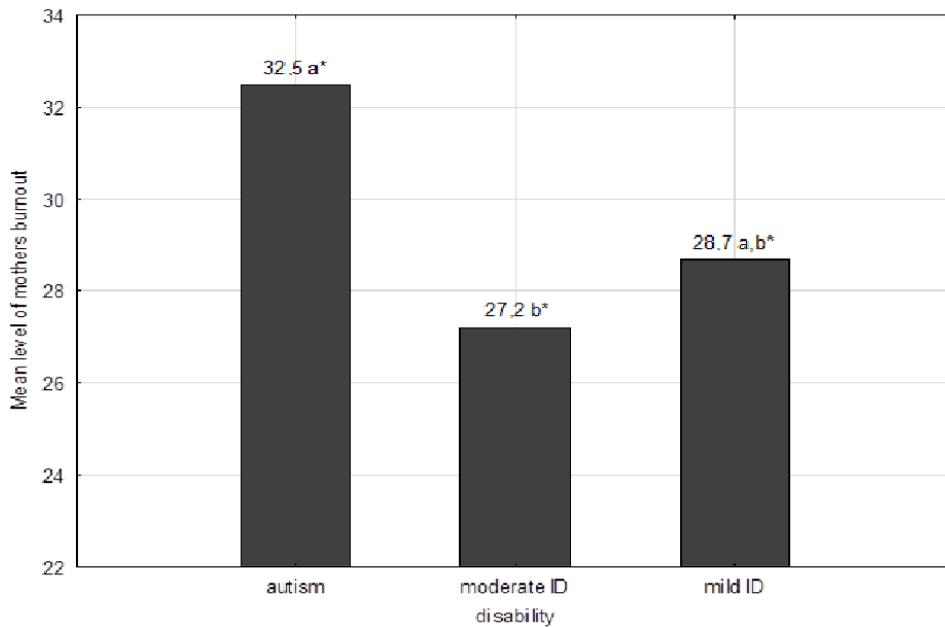
Parents make estimates based on a 4-step scale - to what extent the statement pertains to their situation (1 - very often 2 - sometimes 3 - rarely; 4 - never). The tool enables us to sum up the results of both subscales into one general indicator, describing the level (indicating the risk) of parental burnout. Both subscales have satisfactory internal consistency (Cronbach's Alfa > 0.80) [37]. Sekułowicz [38] assumed that a high risk of parental burnout occurs in subjects who obtain the average value of general indicator of parental burnout below 25 points. The range between 25 and 36 points translates into a low risk of parental burnout, and above 36 points signifies a very low risk. This means that the higher the average values in questionnaire subscales (emotional exhaustion and helplessness) and the general indicator (both subscales combined) are achieved by subjects, the lesser the risk of parental burnout is.

The data obtained were subjected three times to one-way ANOVA based on the following formula: 3 (type of child's disability: autism vs. moderate intellectual disability vs. mild intellectual disability) separately for dependent variables: the level of parental burnout (general indicator) and emotional exhaustion and helplessness (subscales of the questionnaire) in mothers of children of disabilities. The calculation was performed using the Statistica data analysis system.

RESULTS

ANOVA showed the statistically significant main effect $F(6.150)=5,2716$; $p < 0.001$; $\eta^2 = 0.09$, which indicates that the average level of parental burnout risk differentiates investigated mothers due to the type of the child's disability. The post-hoc analysis using the Bonferroni correction showed statistically significant differences in the compared groups of mothers. The lowest risk of parental burnout is shown by mothers of children with autism ($M = 32.5$; $SD = 5.03$), whereas the highest one is presented by mothers of children with moderate ($M = 27.2$; $SD = 8.81$) and mild ($M = 28.7$; $M = 8.47$) intellectual disabilities. The statistically significant differences were observed between mothers of children with autism and mothers of children with moderate intellectual disabilities. The results indicate a low risk of parental burnout in all investigated mothers, although the results obtained by mothers of children with mild and moderate intellectual disabilities show a tendency toward the threshold values ($M < 25$) pointing to the high risk of parental efficacy crisis [51] (Fig. 1).

Each of the Parental Burnout Questionnaire subscales was analysed using one-way analysis of variance. For the emotional exhaustion subscale ANOVA showed the statistically significant main effect $F(6.150) = 5,2716$; $p < 0.001$; $\eta^2 = 0.22$, which indicates that the emotional exhaustion is different in investigated mothers due to the type of their child's disability. The post-hoc analysis using the Bonferroni correction confirmed the statistical significance of certain differences in the compared groups of mothers. The obtained model of results shows that the lowest level of emotional exhaustion is present in mothers of children with autism ($M = 18.4$; $SD = 2.32$), and the highest level of emotional exhaustion occurs in mothers of children with moderate ($M = 13.96$; $SD = 4.45$) and mild ($M = 14.75$; $SD = 4.78$) intellectual disabilities. Only the mean values regarding the level of emotional exhaustion in the above-mentioned mothers of children with autism and moderate intellectual disabilities differ from each other in a statistically significant manner (Fig. 2).



*Mean values without a common letter marking are statistically significant at least at the level of 0.05 (post-hoc analysis with Bonferroni correction).

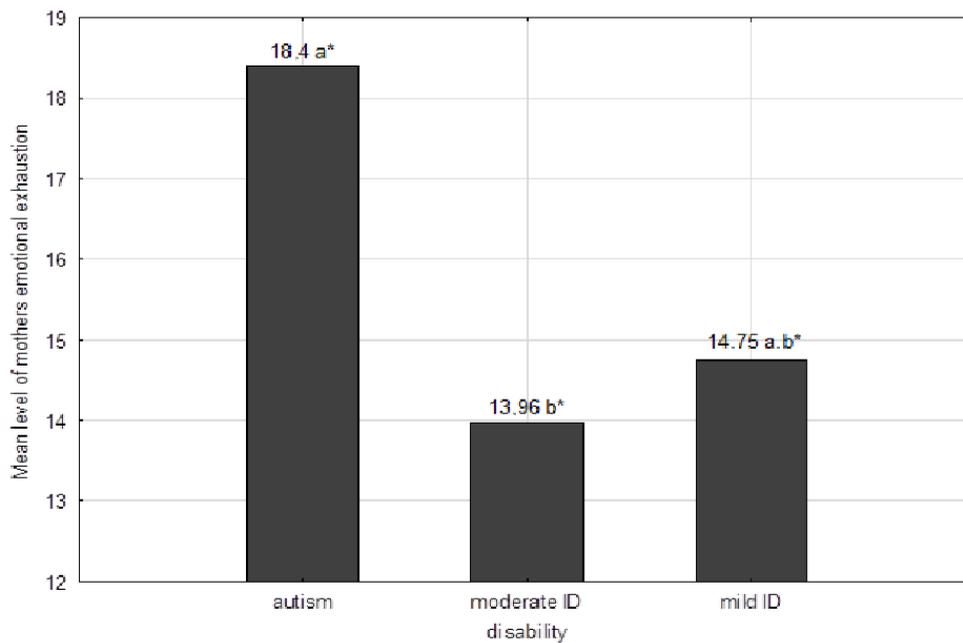
Notice: the higher the average value, the lower the risk of parental burnout.

autism - mothers of children with autism,

moderate ID - mothers of children with moderate intellectual disabilities

mild ID - mothers of children with mild intellectual disabilities

Fig. 1. The mean level of parental burnout risk in investigated mothers depending on the type of their children's disability



*Mean values without a common letter marking are statistically significant, at least at the level of 0.05 (post-hoc analysis using the Bonferroni correction).

Notice: the higher the average value, the lesser the risk of parental burnout.

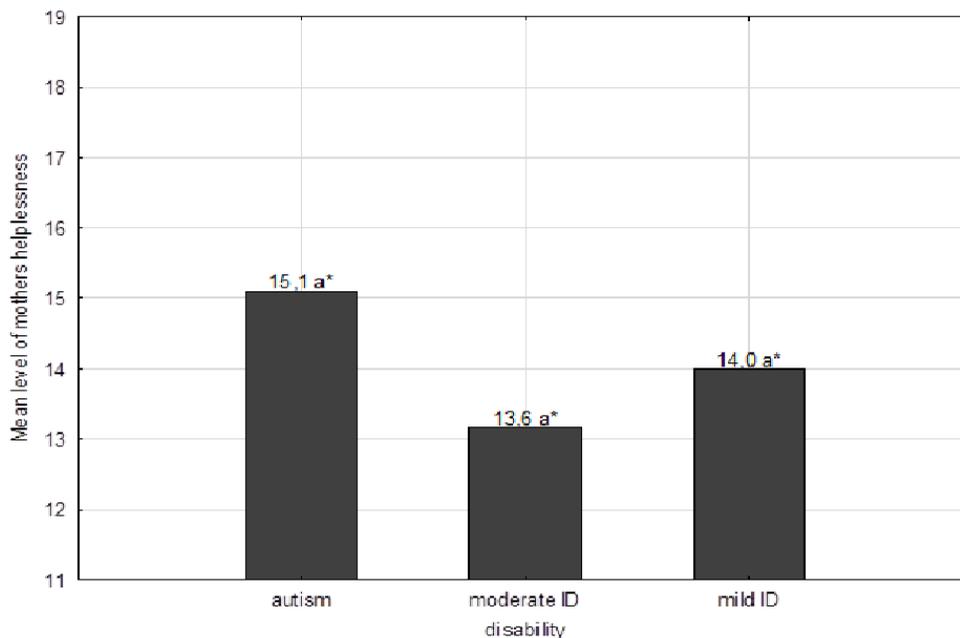
autism - mothers of children with autism

moderate ID - mothers of children with moderate intellectual disabilities

mild ID - mothers of children with mild intellectual disabilities

Fig. 2. The mean level of emotional exhaustion in investigated mothers depending on the type of their children's disability

For the helplessness subscale, ANOVA revealed the statistically significant main effect $F(6,150) = 5,2716; p < 0.001; \eta^2 = 0.04$, which indicates that the helplessness divides the investigated mothers due to the type of their child's disability. The post hoc analysis with the use of the Bonferroni correction taking into account the number of comparisons made did not reveal statically significant differences in the compared groups of mothers. The lowest level of helplessness was found in mothers of children with autism ($M = 15.1; SD = 3.13$), and the highest one in mothers of children with moderate ($M = 13.6; SD = 4.64$) and mild ($M = 14.0; SD = 4.27$) intellectual disabilities, respectively (Fig. 3).



*Mean values without a common letter marking are statistically significant at least at the level of 0.05 (post-hoc analysis with the use of Bonferroni correction).

Notice: the higher the mean value, the lesser the risk of parental burnout.

autism - mothers of children with autism

moderate ID - mothers of children with moderate intellectual disabilities

mild ID- mothers of children with mild intellectual disabilities

Fig. 3. The mean level of helplessness in investigated mothers depending on the type of their child's disability

DISCUSSION

Disabilities in children change the functioning of entire families, which may prevent living a comfortable life, especially for the child's parents, although this is by no means the rule [39]. In the present study, the authors made an attempt to estimate the extent to which the child's disability can contribute to the parental burnout in investigated mothers and to determine whether its level is associated with the type of the child's disability. On the basis of the investigation of the problems undertaken in the literature, the level of the risk of parental burnout might seem to be high in investigated mothers due to their situation. Mothers of children with disabilities are a group that is most vulnerable to the risk of parental burnout [1,19], which is caused by overburdening with long-term care and the responsibility for treatment and upbringing of a child with a disability. Often, mothers themselves are faced with difficulties of everyday life; they become passive, lose their confidence in their own strength and the ability to improve their child's health. This leads to a sense of isolation and the

desire to abandon the efforts associated with bringing up a disabled child which are ineffective. All this contributes to the emergence of an emotional crisis and further accumulation of the symptoms associated with low self-esteem; this initiates the process of parental burnout [19]. The authors' own research presented in this paper indicates a contrary effect. Regardless of the type of the child's disability (mothers of children with autism and mothers of children with mild and moderate intellectual disabilities), the risk of parental burnout in all the investigated mothers did not occur thus remaining at a low level. These results correspond with the research by Sekułowicz [38] who also showed a low risk of parental burnout in mothers of children with developmental disorders (intellectual disabilities, Down syndrome, cerebral palsy, autism spectrum disorders, rare genetic diseases). However, focusing solely on the comparison of parental burnout risk levels, which indicated only a low risk level – as regards parental burnout in the authors' own study, a significant difference was noted only among mothers of children with autism in relation to the group of mothers of children with moderate intellectual disabilities, which suggests that the type of the child's disability may be significant for initiating the process of parental burnout. The results obtained are, however, in opposition to the results of other authors who stressed the fact that the care of a child with autism has a particularly destabilising emotional effect on their carers/guardians and exposes them to multiplied stress [31, 40, 41, 42]. The level of stress experienced in this manner is not only higher in relation to that experienced by parents of healthy children, but also higher than in of parents of children with other disorders, including intellectual disabilities [39, 43, 44, 45]. Szmania [46] finds that parents of children with autism are a different group in many respects, since during the first few years of the child's life they observe correct or nearly correct development in their child. They plan the future of the child and the whole family, in which there is no place for any disability, whatsoever. Therefore, subsequently the actual problems connected with upbringing of children with autism, rapidly exhaust their psychophysical capabilities. In addition, negative experiences in parents of children with autism are intensified as a result of social stigmatization of their child, delayed diagnosis, a lack of adequate support of consultants and the growing isolation regarding their childcare [46]. It is worth noting, however, that the difference obtained by the authors indicating that mothers of children with autism can feel much less vulnerable to parental burnout than the parents of children with moderate intellectual disabilities is the same as the specific results concerning the emotional exhaustion of mothers (Fig. 2), which obviously corresponds with the results obtained by Dudek [47]. He proved that parents of children with autism, while coping with stress, apply the emotional style the least frequently (based on living emotions and trying to unload emotions), leading to rather worrying and wishful thinking than taking concrete action. No concentration on emotions in a stressful situation induced by the relationship with a child with autism may allow parents to maintain the emotional balance for a longer time. On the other hand, the lack of statistically significant differences regarding the helplessness subscale between mothers raising children with autism and with mild and moderate intellectual disabilities (Fig. 3) is in line with the explanation provided by Gosztyła and Prokopiak [48]. They claim that the level of isolation and loneliness in parents of children with autism spectrum and intellectual disabilities makes no distinction between these groups. Therefore, the possibility that the mothers investigated by the authors frequently faced with disabilities of their own child and in the fight against adversities use their personal resources that enable them to deal with difficulties of childcare and of education-related nature should also be taken into consideration in the discussion of results [49, 50]. When discussing the

risk of parental burnout, one should also mention the personality factors that help to anticipate them on the basis of high neuroticism and low diligence and agreeableness present at the same time in the parent concerned [51]. The involvement of fathers in their children's upbringing and sharing responsibilities together with the mother of the child are also important [49]. Research by Gosztyła [52] indicates that in addition to the presence and involvement of both parents in the education/upbringing of their child also the quality of their relationship is important. The stronger the bond between the parents, the more easily one can meet the needs of life with a child with a disability and especially with autism, which was shown in the author's research. Above all, a stable and rewarding relationship between parents is a precondition to the development of a child with autism. Another important issue is the fact that parents of one child with special educational needs and a single dysfunction experience fewer symptoms of parental burnout than parents of a child with many co-existing symptoms and parents of several disabled children (with one or more diseases) [53]. Within such a context, it can be assumed that mothers of children with moderate intellectual disabilities may face a greater number of different dysfunctions in their children than mothers of children with autism, although such a comparison, even carefully made, requires more empirical evidence [54], as it does not take into account the gravity or severity of the disorder which may ultimately determine the situation of a family raising a disabled child. Given the specificity of ASD relating to deficits in the sphere of showing socio-emotional reciprocity [55] and a lack of deficits enhanced in this area in persons with intellectual disabilities, it is worth considering to what extent each of these groups of disabled persons may be aware of the parental burnout in their parents and even feel responsible for its course [56]. Risking the conclusion that a child with intellectual disabilities is more emotionally involved than a child with autism, such a child may be expected to be in a disadvantaged developmental situation and thus to re-intensify the process of parental burnout. The age of the child can be a significant variable in the context of the risk of parental burnout as well. Among the subjects there are mothers of children with autism who have longer parental experience in relation to their children and also they present a lower risk of parental burnout. This may mean that they are more experienced in the role of a parent; therefore, they have developed ways to cope with many difficulties related to the care of their disabled child. In some children with autism, challenging behaviours may be reduced as a result of effective treatment, thus parents are able to participate more frequently in social life [48]. This is important because for prevention of parental burnout risk, social support plays an important role [17], not only on the part of consultants who offer targeted therapies to solve problems in families of children with autism, but also in the unity of other families faced with similar problems every day. Maciarz [15] points out how important the involvement of mothers in the activities of associations and foundations for children with disabilities is. Participation in the works for centres, establishing close contacts with the staff of foundations and other mothers, joint participation in rehabilitation sessions organised for children may help to achieve the constructive approach to the child's disability and reduce negative emotional states.

Presently, the situation of persons with autism and their families is more favourable in terms of the possibilities to use the proposed forms of rehabilitation and their funding or changes in the education system and the attitudes of society toward autism that are more favourable, thereby increasing the likelihood of real improvement of the quality of life in children with autism in society and in their families [46]. This is also evidenced by the attempts to use a web application to

support the process of therapy for a child with autism at home. These include AutismPro, a database enabling parents to assess the level of performance of their child with autism and to develop individually the program of intervention aimed at minimising their difficulties [57]. The Internet is more frequently the place where you can share, then exchange experiences connected with care and upbringing of children with autism with other mothers. Blogs that take the form of personal diaries are a particularly interesting form of mutual support provided by mothers of children with autism [58]. The discussed factors may reduce adverse effects of educational difficulties related to the specificity of autism on emotional experiences of mothers. Therefore, they are no longer exposed to such a high or very high risk of parental burnout.

Finally, the optimistic result showing the low risk of parental burnout in mothers of children with autism and intellectual disabilities can be explained in the light of research by Jakoniuk-Diallo and Kubiak [50] who point out that despite problems arising from the care of a child with a disability, the lack of support and inconvenience, there are many families experiencing positive emotions and happiness. Raising a child with a disability may be a source of satisfaction for parents who receive unconditional love from their child, provide him or her with the most favourable conditions for development and rehabilitation [59, 57].

CONCLUSIONS

Mothers of children with autism and mild and moderate intellectual disabilities present low levels of the risk of parental burnout, which may indicate that they are about to achieve the stage of constructive adaptation to the fact of having a child with a disability. However, special attention should be given to the possibility of an unexpected situation where mothers of children with moderate and mild intellectual disabilities will be more exposed to a high risk of parental burnout than mothers of children with autism.

Mothers raising children with moderate intellectual disabilities have a higher level of emotional exhaustion in comparison to mothers raising children with autism who due to the severity of their child's disorder choose these stress management strategies which allow them to maintain emotional balance.

Mothers of children with autism and moderate and mild intellectual disability do not differ from one another in terms of the level of helplessness, which may indicate that having a child with disabilities causes a similar experience of crisis in terms of parental competence.

This study provides knowledge that is helpful during the therapeutic intervention in families having children with intellectual disabilities or autism and is aimed to reduce the phenomenon of parental burnout.

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