

Levels of happiness and depression in parents of children with autism spectrum disorder in Poland

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There are numerous factors that determine the sense of happiness and level of depression in caregivers of children with autism spectrum disorder (ASD). The aim of this paper is to evaluate happiness and depression in/among families with an ASD child and compare with families with neurotypical children. The study included 182 participants. The participants answered questions for two questionnaires: Beck Depression Inventory and Oxford Happiness Questionnaire. The outcome of the study identified significant differences for sense of happiness and level of depression among the parents of children with ASD compared with the parents of neurotypical children. It was shown that parents of children with ASD reported a lower sense of happiness and a higher level of depression compared to the parents of neurotypical children. They also showed a significantly higher level of depression relative to the decreased level of happiness. Moreover, parents who have a university education degree and a child with ASD showed a higher sense of happiness and a lower level of depression than parents who had a secondary education degree, in the studied groups.

Key words: autism spectrum disorder, depression, happiness, mental health, parenting

INTRODUCTION

Autism spectrum disorder (ASD) refers to neurodevelopmental disabilities characterized by difficulty in initiating and maintaining social relationships, as well as repetitive behavioral patterns and interests (Faras et al., 2010). The World Health Organization (WHO) estimates that the prevalence of ASD is approximately 0.76% and the CDC reported that the actual number of people with autism might be significantly higher (Hodges et al., 2020). Among people diagnosed with ASD, there is a dominance of male cases. Recent research data shows that the male-to-female ratio for ASD diagnosis in children is estimated at 3:1 (Hodges et al., 2020).

Caring for a child with ASD challenges the parents and predisposes them to depression, anxiety and psychosomatic disorders, as well as significantly affecting the functioning of the whole family (Dunn et al.,

2019). If the child has a co-occurring intellectual disability, it prominently obstructs the parents' ability to develop a strong bond with a child (Marshall et al., 2018). Families of children with autism are more vulnerable to additional stressors, such as stigmatization, social discrimination, sense of seclusion and incomprehension (Dunn et al., 2019). Recent studies showed that mothers of children with intellectual disabilities were more likely to suffer from depressive and anxiety disorders and reported chronic stress more frequently in comparison with fathers (Dunn et al., 2019). Moreover, additional risk factors that contribute to developing psychological distress in parents of children with ASD include the large amount of time and energy spent on caregiving, lack of financial support, marital problems, fear for the uncertain future of the child and necessary adjustments to the current lifestyle (both social and professional) to accommodate the child's needs (Dykens et al., 2014; Yamaoka et al., 2015; Chan et al.,

2018). In relation to the duty of taking care of a child with autism, parents and caregivers are forced to leave their jobs or reduce working hours, which leads to lower household income and consequently escalated economic pressure, thereby increasing the level of the parents' stress (Chan et al., 2018).

The WHO ranked depression as one of the leading and most frequently diagnosed diseases worldwide. The prevalence of depression was estimated to be about 6% overall (Malhi and Mann, 2018). Studies have shown that mothers of children with ASD are three times more likely to suffer from depressive disorders and that the diagnosis of ASD itself is more stressful than the diagnoses of other neurodevelopmental disorders (Marshall et al., 2018). On the other hand, fathers of children with ASD are at lower risk of being diagnosed with depression, anxiety disorders or sleep impairment compared to mothers (Dunn et al., 2019). The differences are probably determined by the fact that the mothers are the main caregivers of the child, whereas fathers usually spend more time at work, not at home, and their support concentrates on providing for the family financially (Dunn et al., 2019).

Mental health disorder in parents could result in a significant decline in the quality of life for children and may lead to the development of emotional distress. Moreover, poor mental well-being in parents creates difficulties in the care-taking of a child with ASD and may lead to lack of patience, deterioration in ability to control emotions and delays in every aspect of a child's development (Dykens et al., 2014; Yamaoka et al., 2015).

However, studies show that parents of children with disabilities often find this aspect of life to be a source of satisfaction and a sense of fulfillment (Dykens, 2015). It has been reported that mothers of children with ASD experience a high sense of happiness, which is probably related to a feeling of inner strength and love, together with the fact that the child itself can be a source of happiness in life (Findler et al., 2016). Both the sense of happiness and the level of depression are determined by numerous factors, such as social and financial support, sense of guilt, child's intellectual disabilities and, essentially, the ability to cope with chronic stress (Findler et al., 2016).

The aim of the paper is to evaluate happiness and depression in families with an ASD child and compare with the functioning of families with neurotypical children.

METHODS

The present study used two types of questionnaires.

A Polish language adaptation of the Oxford Happiness Questionnaire (OKS) was used for psychometric

evaluation of happiness level (Poprawa, 2012), and the Beck Depression Inventory (BDI) was used to assess depression levels. Both questionnaires constitute useful tools that scale the whole spectrum of factors that affect human mental well-being.

Data collection and participants

The inclusion criteria was 'having a child'; the study group included 182 people who met the criteria and 75 of them had a child with ASD. A minority of participants declared their place of residence as a city of more than 500 thousand residents, amounting to 33.4% of the participants. Regarding education, 61.4% of participants had a higher education of up to a master degree, 24% secondary education and 12.8% held a degree of PhD or higher.

Participants were recruited via the Medical University Website (www.ump.edu.pl). From the study group, children were diagnosed with autism using DSM-V criteria by medical staff in a psychological and pedagogical clinic in their city of residence. Diagnosis was self-reported by the survey completed by parents. In terms of respondents' child's age: 22.3% of the parents had a child aged 2, 19.6% had a one-year-old, 5.2% had a 3-year-old and the children above three years old represented a marginal percentage of the study. Single parents constituted 6.8% of the study (25 persons).

RESULTS

Descriptive statistics were obtained using the SPSS Statistics 25 program for the results of the OKS and the BDI. For the entire group of parents surveyed, Kolmogorov-Smirnov test results indicated a lack of compliance with the normal distribution for the variables sense of happiness and level of depression. Sense of happiness was characterized by a left-skewed and platykurtic distribution, which means that it was dominated by higher-than-average results and the group itself was quite diverse. The level of depression was characterized by a right-skewed and leptokurtic distribution, which means that the results were below average and the group itself was not very diverse.

For the group of parents of children with an autism spectrum disorder, the results of the Kolmogorov-Smirnov test indicated compliance with the normal distribution for the variable sense of happiness and lack of compliance with the normal distribution for the variable level of depression. For the group of parents of children without a diagnosis of autism spectrum disorder, the results of the Kolmogorov-Smirnov test

indicated a lack of compliance with the normal distribution for the variables sense of happiness and level of depression. Because there were variables that did not have a normal distribution, non-parametric tests were used to verify the hypotheses.

Analysis of the collected research data was performed to verify the seven initial research hypotheses. To test the hypothesis that the parents of children with ASD have a lower sense of happiness and a greater level of depression than the parents of children without ASD, we performed the Mann-Whitney U test. For parents of children with ASD: $N=74$; sense of happiness, $M=112.19$; level of depression, $M=14.96$; Mann-Whitney $U=-4.90$, $p<0.001$ (Table 1). For parents of children without ASD: $N=108$; sense of happiness, $M=128.35$; level of depression, $M=7.21$; Mann-Whitney $U=-5.62$, $p<0.001$. The results indicated significant differences in the sense of happiness and the level of depression between parents of children with an autism spectrum disorder and parents of children without an autism spectrum disorder. Parents of children with an autism spectrum disorder had a lower sense of happiness and a greater level of depression than parents of children without an autism spectrum disorder.

The norms of the BDI are: 0-10 points, no depression or depressed mood; 11-27, moderate depression; 28 or more, severe depression. The norms for the OKS (at age $>30 \leq 60$) are: 74-97 points, low sense of happiness; 98-129 points, average sense of happiness; 130-144 points, high sense of happiness; 145-156 points, very high sense of happiness. Parents of children with autism spectrum disorder had average levels of happiness

and a moderate level of depression. Compared to parents of children without autism spectrum disorder, they also had an average level of happiness and did not show depression (Poprawa, 2012).

We examined the sense of happiness and the level of depression in single parents raising a child with ASD ($N=13$; sense of happiness, $M=114.23$; level of depression, $M=14.69$; Mann-Whitney $U=-0.19$, $p=0.848$) and compared with parents raising a child with autism in a two-parent family ($N=61$; sense of happiness, $M=111.75$; level of depression, $M=15.02$; Mann-Whitney $U=-0.06$, $p=0.949$), in terms of sense of happiness and level of depression. The results from the Mann-Whitney U test indicated that no significant differences existed for sense of happiness and level of depression between single parents bringing up children with an autism spectrum disorder and two parents together raising children with an autism spectrum disorder (Table 2).

To verify whether single parents of a child with ASD ($N=13$) showed a lower sense of happiness ($M=114.23$) and higher levels of depression ($M=14.69$) than single parents of children without ASD ($N=12$, sense of happiness $M=124.25$; level of depression $M=8.50$), we performed the Mann-Whitney U test (Table 3).

The results of the Mann-Whitney U test (sense of happiness, Mann-Whitney $U=0.19$, $p=0.205$; level of depression, Mann-Whitney $U=0.13$, $p=0.137$) indicated no significant differences for sense of happiness and level of depression between single parents of children with an autism spectrum disorder and single parents of children without an autism spectrum disorder.

Table 1. Having an autism spectrum child and happiness and depression (U Mann-Whitney test).

Variable	Parents of children with autism spectrum disorder ($N=74$)	Parents of children without autism spectrum disorder ($N=108$)	U Mann-Whitney	p
	M	M		
Sense of happiness	112.19	128.35	-4.90	<0.001
Level of depression	14.96	7.21	-5.62	<0.001

Table 2. Single parents raising a child with the autism spectrum and parents raising a child in a full family versus happiness and depression (U Mann-Whitney test).

Variable	Single parents raising a child with the autism ($N=13$)	Parents raising a child in a full family ($N=61$)	U Mann-Whitney	p
	M	M		
Sense of happiness	114.23	111.75	-0.19	0.848
Level of depression	14.69	15.02	-0.06	0.949

Table 3. Single parenting a child with the autism spectrum disorder and single parents with children without an autism spectrum disorder versus happiness and depression (U Mann-Whitney test).

Variable	Single parenting a child with the autism spectrum disorder (N=13)	Single parents with children without an autism spectrum disorder (N=12)	U Mann-Whitney	p
	M	M		
Sense of happiness	114.23	124.25	0.19	0.205
Level of depression	14.69	8.50	0.13	0.137

We calculated Spearman's rank correlation coefficient (Spearman's rho) to test the hypothesis that the greater number of years that have passed since a child was diagnosed with an autism spectrum disorder, the greater his parents' sense of happiness and the lower the level of depression. The Spearman's rho test result indicated a significant correlation between the time elapsed since a child was diagnosed with ASD and the sense of happiness ($r_s=0.104$) and depression level in parents ($r_s=-0.102$). To test if there is a greater level of depression and lower level of happiness in parents of children with ASD, we also used Spearman's rho. The Spearman's rho test result indicated a significant, strong, negative relationship between the level of depression and the feeling of happiness in parents of children with an autism spectrum disorder ($r_s=-0.857$). This means that parents of children with ASD have a greater level of depression and a lower level of happiness.

The Spearman's rho test (sense of happiness, $r_s=-0.025$; level of depression, $r_s=0.064$), indicated no significant relationship between the age of parents of children with ASD and feeling of happiness or depression.

To test whether parents that had only graduated from high school and have children with ASD max 18 years-old show a lower sense of happiness and a greater level of depression than parents with higher education with children with ASD, we performed the Mann-Whitney U test. The Mann-Whitney U test revealed significant differences for sense of happiness (variables: education professional and high school, $M=102.88$; higher education, $M=116.94$; Mann-Whitney $U=-2.74$; $p=0.006$) and level of depression (variables:

education professional and high school, $M=18.80$; higher education, $M=13.00$; Mann-Whitney $U=-2.56$; $p=0.010$) between parents with vocational and secondary education that have children with ASD ($N=25$) and parents with higher education that have children with ASD ($N=49$) (Table 4).

Parents who graduated only from high school and have children with ASD showed a lower sense of happiness and a greater level of depression than parents who have higher education and have children with ASD.

DISCUSSION

The long-lasting character of autism in children has deep implications for parents, who face a lot of emotional consequences during the process of upbringing the child (Ooi et al., 2016). It creates a wide range of new challenges and assumes the fact that the parents (especially mothers) are usually the main caregivers of the child with ASD (Gray, 2003). After receiving the diagnosis, there is a common process of lowering the expectations towards the child and it usually leads to uncertainty about the future – not only the future of the child but of the whole family (Poslawsky et al., 2014; Kostiukow et al., 2019).

Raising a child with autism is usually described as difficult, due to the occurrence of inappropriate behaviors. It often leads to increased levels of stress and affects the daily lifestyle of parents. Intemperate and unpredictable tantrums and aggression are often experienced in response to changes in daily routine or the surroundings. The aggression is also associated

Table 4. Education of parents of child with autism spectrum disorder and happiness and depression (U Mann-Whitney test).

Variable	Education professional and high school (N=25)	Higher education (N=49)	U Mann-Whitney	p
	M	M		
Sense of happiness	102.88	116.94	-2.74	0.006
Level of depression	18.80	13.00	-2.56	0.010

with destructive behaviors at home and in the closest environments (Myers et al., 2009). The parents are chronically burdened by additional expenditures on furniture and household item replacements (Fletcher et al., 2012). Violence is not only directed towards objects but also towards the nearest people – siblings and parents (Aylaz et al., 2012). All this makes parenthood demanding and difficult (Ludlow et al., 2012).

The present study, evaluating happiness levels and prevalence of depression in parents of children with ASD, was based on two types of psychometric tools to specifically analyze the selected parameters. BDI has previously been used for evaluation in these social groups. Results from various scientific groups support the findings of our study and show that the parents of children with ASD and behavioral disorders are statistically and clinically experiencing a higher level of parental stress than the parents of typically developing children (Dumas et al., 1991; Firat et al., 2002).

Both the mothers and the fathers reported clinically significant anxiety and depression three to five times more frequently compared with the adult population of parents without a child with ASD. Undoubtedly, the daily stress related to raising a child with autism is associated with severe angst and depression (Bitsika et al., 2013). Despite prominent stress and depression, parents of such children are also characterized by a high level of insecurity compared with control groups of parents raising a typically developing child (Brobst et al., 2009; Hoffman et al., 2009; Lee et al., 2009; Kostukow et al., 2019). Moreover, the studied social group is also at greater risk of developing elements of stress, depression and insecurity compared with the parents of children with other disabilities (Abbeduto et al., 2004; Pisula, 2007), including intellectual disability (Firat et al., 2002). The results of this study are commensurate with the findings of other researchers (Brobst et al., 2009; Hoffman et al., 2009; Lee et al., 2009; Kostukow et al., 2019). The first hypothesis has been validated – that parents of children with ASD have a lower sense of happiness and a greater level of depression than parents of neurotypical children.

Brobst et al. (2009), in his study, found that over 50% of mothers of children with autism are characterized by a significant decrease in the level of happiness and, simultaneously, an increased level of depression, compared to only 15–21% in other groups (including the mothers of children with other disabilities or without any) (Olsson and Hwang, 2001). The results also validated the fifth hypothesis – that, in parents of children with ASD, the higher the level of depression the lower the sense of happiness that is reported.

Research by other authors, who used BDI, showed that the mothers of children with autism experienced

higher levels of depression and anxiety than the fathers (Bitsika and Sharpley, 2004; Dale et al., 2006). Moreover, only a minor percentage of the tested fathers reported depressive symptoms. The majority of fathers experienced only a mild level of anxiety. This may suggest that, even though the parents of children with autism are more vulnerable to psychological distress, particular attention should be paid to the mothers of such children (Bitsika et al., 2013; Rejani et al., 2015), because they are far more anxious and depressed than the fathers (Bitsika et al., 2013).

The OKS was also used to evaluate families of a child with autism (Karimi Jozestani et al., 2015; Khorshidian and Yarali, 2018). The results of numerous findings have shown that, in all of the marital satisfaction elements (except resolving conflicts), parents of neurotypical children score markedly higher than the parents of children with ASD. The differences are statistically significant. It turns out that there is a connection between ASD in children and the happiness, as well as marital satisfaction, of the parents (Hoseinnejad et al., 2020). Meanwhile, a strong marital relationship is regarded as essential, because it provides care and emotional or physical support (Koydemir-Özden and Tosun, 2010). It has been noted that having a child with ASD leads to a tense or strengthened type of marriage. In some cases, having a child with autism brings the family together (Matthews et al., 2011), while in others it leads to divorce (Koydemir-Özden and Tosun, 2010). In the first example, parents set aside their unimportant matters, argued less and focused more on the child itself (Woodgate et al., 2008; Markoulakis et al., 2012; Zhang et al., 2015). In the second case, a decrease in time spent together due to the obligation of being caregivers to the child (Aylaz et al., 2012), arguments about parenthood (Koydemir-Özden and Tosun, 2010; Aylaz et al., 2012) and mutual blaming of each other for the medical condition of the child may occur (Myers et al., 2009; Meirsschaut et al., 2010). A large number of parents feel concerned and guilty about negligence of their other neurotypical children because of a primary focus on the child with ASD (Koydemir-Özden and Tosun, 2010; Meirsschaut et al., 2010; Schaaf et al., 2011).

In the general population, parents in well-functioning marital relationships report stress and parental burden less frequently than parents in poorly-functioning ones (Benzies et al., 2004). Mothers and fathers who are dissatisfied with their marriage report greater parental burden and stress level than parents who are satisfied in their marital relationship (Kersh et al., 2006). Researchers showed that the marriage relationship affects the parent-child rela-

tionship. Parents whose marriage is satisfying report better quality of the parent-child relationship (Krishnakumar and Buehler, 2000). Moreover, single mothers of disabled children are more likely to suffer from severe depression than mothers who live in a relationship with a partner (Olsson and Hwang, 2001).

Despite such a heavy burden being associated with raising a child with ASD, there are references in scientific literature that display the bright sides of such parenthood. In some cases, parents claim that having a child with autism changed their life perspective and enabled them to value life more (Myers et al., 2009). Parents in that group state that they became more sensitive, understanding and less demanding towards other people (Myers et al., 2009). Among these features they also mentioned greater compassion and patience as characteristics acquired during the process of raising a child with ASD (Altieri and von Kluge, 2009; Markoulakis et al., 2012). Moreover, the successful effects of raising an autistic child made the caregivers more self-confident (Zhang et al., 2015). It usually applied to parents with higher education, which has been validated by this study. As it turns out, in families of children with ASD, parents with a higher education have a greater sense of happiness and lower level of depression than parents without university education in the same group.

This study, as well as other research concerning the psychological condition of the parents of autistic children, has emphasized the necessity of creating special healthcare conditions that should apply not only to the child but the whole family system.

CONCLUSION

Parents of children with ASD have a lower sense of happiness and a greater level of depression than the parents of neurotypical children.

It was confirmed that parents of children with ASD experience a higher level of depression than level of happiness.

Parents with a secondary education that have children ASD have a lower sense of happiness and a greater level of depression than parents with a university degree that have children with an autism spectrum disorder.

Families of children with ASD should be provided psychological support. It is recommended that such families should attend additional courses, training and postgraduate studies in order to increase their ability to cope with atypical behaviors of their child and to improve their sense of happiness and reduce depressive symptoms.

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