



Determinants of mental well-being among family members of individuals with Autism Spectrum Disorder (ASD)

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Abstract

Introduction and Objective. Autism spectrum disorder (ASD) poses significant clinical, social, and economic challenges, affecting not only individuals diagnosed with the condition but also their families. Increasing evidence highlights a substantial psychosocial burden among caregivers, which may translate into broader societal and economic costs. The aim of this study was to assess the mental well-being of family members of individuals with ASD and to identify its determinants in relation to selected socio-demographic factors and time since diagnosis.

Materials and Method. A cross-sectional study was conducted in February 2025 among 310 adult family members of individuals diagnosed with ASD. Data were collected using the Computer-Assisted Web Interview (CAWI) method via the Ariadna Nationwide Research Panel. Mental well-being was measured using the WHO-5 Well-Being Index.

Results. The findings revealed reduced mental well-being among respondents, with a median WHO-5 score of 44, and 57.74% of participants scoring below the threshold, indicating impaired well-being. No statistically significant differences were found in well-being depending on respondent gender ($p=0.124$), gender of the family member with ASD ($p=0.539$), or time since diagnosis ($p=0.113$). Additionally, no significant interaction effects were observed in two-way ANOVA models.

Conclusions. Reduced mental well-being appears to be a common and persistent feature among family members of individuals with ASD, independent of basic socio-demographic factors. The findings highlight the need for comprehensive, long-term support strategies addressing both psychological and socio-economic aspects of caregiving. From the perspective of health economics, improving caregiver well-being may contribute to reducing the indirect costs associated with ASD.

Key words

quality of life, ASD, indirect costs, autism spectrum disorder, mental well-being, WHO-5

INTRODUCTION

Autism spectrum disorder (ASD) constitutes a significant challenge not only clinically but also socially and economically [1–3]. In recent years, an increasing prevalence of ASD diagnoses has been observed, which translates into a growing burden on healthcare systems as well as social support systems [3–5]. The literature increasingly emphasizes that the consequences of ASD extend beyond the affected individual and involve entire families, influencing their psychosocial, professional, and economic functioning [6, 7].

From the perspective of health economics, analysis of the mental well-being of family members of individuals with ASD becomes particularly important as one of the key components of the so-called indirect costs of the disease [1, 8]. These costs include, among others, loss of productivity, reduced professional activity, absenteeism, or the need to resign from employment in order to provide care. Reduced

mental well-being among caregivers may additionally generate increased demand for healthcare services, thereby affecting the total societal costs of ASD [8, 9].

Living with ASD requires families to continuously adapt to changing caregiving demands and everyday challenges. Family adaptation is a multidimensional process involving psychological adjustment, coping strategies, resilience, family functioning, and the ability to mobilise internal and external resources. Although subjective mental well-being represents only one aspect of this broader adaptation process, it is considered an important indicator of caregivers' psychological functioning and their capacity to cope with the long-term demands associated with caring for an individual with ASD. In the present study, mental well-being was assessed using the WHO-5 Well-Being Index, which measures subjective psychological well-being rather than family adaptation as a whole.

In the context of family adaptation to living with an ASD diagnosis, socio-demographic factors play an important role, including the caregiver's gender. Studies indicate that women, who more often assume the role of primary caregivers, may experience higher levels of psychological burden and stress,

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which has consequences for both their health and economic activity. At the same time, the process of adaptation to an ASD diagnosis is dynamic and may change over time [7, 10–12]. In the first years following diagnosis, families often experience the greatest emotional and organizational burden, which may evolve over time as a result of acquiring caregiving competencies, gaining access to support, or reorganizing family life. [7, 8, 12, 13]. For these reasons, caregiver gender and time since diagnosis were selected as the primary explanatory variables in the present study.

Despite the growing interest in this area, there is still a lack of studies simultaneously analyzing the relationship between gender and time since diagnosis with the mental well-being of family members of individuals with ASD. Previous studies have demonstrated that caregiver well-being is also influenced by numerous other factors, including ASD symptom severity, level of functioning, caregiving burden, social support, and socio-economic status. Although these variables were beyond the scope of the present study, they should be considered when interpreting the findings and represent important directions for future research [6, 8, 12–16].

The aim of this study was to assess the mental well-being of family members of individuals diagnosed with autism spectrum disorder (ASD), measured using the WHO-5 scale, and to identify its determinants in the context of selected socio-demographic and temporal factors.

MATERIALS AND METHOD

The study had a cross-sectional design and was conducted in February 2025 among family members of individuals diagnosed with autism spectrum disorder (ASD). A total of 310 respondents meeting the inclusion criteria were included in the analysis. The study intentionally included family members with different degrees of kinship (including parents, siblings, grandparents, and extended family members) to capture a broad perspective on the impact of ASD on family members.

Data collection was carried out using the Computer-Assisted Web Interview (CAWI) method via the Ariadna Nationwide Research Panel. This panel is one of the largest research tools in Poland, enabling the implementation of quantitative studies across diverse respondent populations. The CAWI approach allowed access to geographically diverse respondents while ensuring standardized data collection, participant anonymity, and minimizing interviewer-related bias. The questionnaire was available online, and respondents completed it independently.

Participation in the study was voluntary and anonymous. Before starting the survey, participants were informed about the aim and nature of the study, as well as their right to withdraw at any stage without providing a reason. Providing informed consent was a prerequisite for participation.

The inclusion criteria were: (1) age of at least 18 years, (2) declaration of having a family member with a confirmed ASD diagnosis, and (3) provision of informed consent to participate. The exclusion criteria included: (1) failure to meet the above conditions and (2) incomplete questionnaire responses preventing inclusion in the statistical analysis.

The research tool was a structured questionnaire consisting of two parts. The first part included socio-demographic questions, such as the respondent's age and gender, the gender

of the family member with ASD, degree of kinship, and time elapsed since diagnosis. The second part included the WHO-5 (World Health Organization Well-Being Index), used to assess subjective mental well-being over the previous two weeks. The WHO-5 consists of five items rated on a scale from 0 – 5, yielding a raw score ranging from 0 – 25, which is then converted to a 0 – 100 scale. Higher scores indicate better mental well-being, while a score below 50 is interpreted as reduced well-being.

The main dependent variable in the study was the level of mental well-being measured using the WHO-5 scale. Key independent variables included respondent gender, the gender of the family member with ASD, and time since ASD diagnosis, categorized into four groups: up to 1 year, 1 – 5 years, 6 – 10 years, and more than 10 years. These categories were selected to reflect different stages following the ASD diagnosis, ranging from the initial adaptation period to longer-term family experience, and to facilitate comparisons across different periods after diagnosis. The analyses also included interactions between gender and time since diagnosis, as well as between the gender of the family member with ASD and time since diagnosis.

The study was conducted in accordance with the principles of the Declaration of Helsinki. The project received a positive opinion from the Bioethics Committee of the Centre of Postgraduate Medical Education in Warsaw, Poland (Decision No. 25/2024 of April 10, 2024).

Description of statistical methods. Statistical analyses were performed using Statistica 14 (Cloud Software Group, Inc., San Ramon, CA, USA, 2023; Data Science Workbench, version 14, <http://tibco.com>). The characteristics of the study sample were described using frequencies and percentages for nominal and ordinal socio-demographic variables, as well as selected descriptive statistics for continuous variables. Results obtained from the WHO-5 scale were presented using basic descriptive statistics, including measures of central tendency and dispersion such as mean, standard deviation, median, quartiles (first and third), as well as minimum and maximum values. The prevalence of poor well-being among respondents was presented in terms of frequencies and percentages.

Differences in WHO-5 scores depending on respondent gender, the gender of the family member with ASD, and time since diagnosis were analyzed using Student's t-test for two groups and one-way ANOVA for more than two groups. Additionally, two-way ANOVA was used to analyze interactions between gender and time since diagnosis, as well as between the gender of the family member with ASD and time since diagnosis. The assumptions of normality were tested using the Shapiro–Wilk test, and homogeneity of variances was assessed using Levene's test. In both cases, non-significant results ($p > 0.05$) were obtained, indicating that the assumptions were met. The assumptions for parametric analyses were met (all $p > 0.05$). A significance level of $\alpha = 0.05$ was adopted for all analyses.

RESULTS

The characteristics of respondents and their family members diagnosed with ASD are presented in Table 1. The study included 310 individuals whose family members had an ASD diagnosis, including 77.74% women, 20.97% men, and

four individuals who provided other responses. Among family members with ASD, males (59.03%) predominated over females (40.32%). The median age was 35 years among respondents (Q1=28, Q3=46) and 14 years among related individuals (Q1=9, Q3=24). Family members with ASD were most often children (27.10%) or siblings (23.87%) of the respondents, while one-third consisted of more distant relatives. The time since ASD diagnosis was most commonly 1–5 years (52.26%)

Table 1. Characteristics of respondents and their family members diagnosed with ASD. Continuous variables

Variable	M	SD	Me (Q1–Q3)	Min–Max
Respondent age	38.06	13.87	35.0 (28–46)	15–77
Age of family member with ASD	17.91	12.75	14.0 (9–24)	1–74
Categorical variables				
Variable	Category	n	%	
Respondent gender	Female	241	77.74	
	Male	65	20.97	
	Other	1	0.32	
	Prefer not to say	3	0.97	
Gender of family member with ASD	Female	125	40.32	
	Male	183	59.03	
	Other	2	0.65	
Degree of kinship	Child	84	27.10	
	Sibling	74	23.87	
	Parent	16	5.16	
	Grandchild	23	7.42	
	Other	113	36.45	
Time since ASD diagnosis	Up to 1 year	53	17.10	
	1–5 years	162	52.26	
	6–10 years	51	16.45	
	>10 years	44	14.19	

As shown in Table 2, the WHO-5 scores were highly variable (coefficient of variation=46.63%), with a median of 44 (Q1=28.0, Q3=60.0), indicating slightly reduced well-being among respondents. Reduced well-being, according to WHO guidelines (scores < 50), was observed in more than half of the participants (n=179, 57.74%). No statistically

Table 2. Well-being (WHO-5) by respondent gender and gender of family member with ASD

Group	M	SD	Min	Max	Me	Q1	Q3
Overall	44.22	20.62	0.0	100.0	44.0	28.0	60.0
Respondent gender							
Gender	M	SD	Min	Max	Me	Q1	Q3
Female	43.39	20.54	0.0	100.0	44.0	28.0	56.0
Male	47.82	20.64	0.0	88.0	52.0	36.0	60.0

t-test: t = -1.542, df = 304, p = 0.124, Cohen's d = -0.215

Gender of family member with ASD							
Gender	M	SD	Min	Max	Me	Q1	Q3
Female	43.42	19.65	0.0	88.0	44.0	28.0	60.0
Male	44.90	21.26	0.0	100.0	44.0	28.0	60.0

t-test: t = -0.615, df = 306, p = 0.539, Cohen's d = -0.072

significant differences in well-being were found with respect to respondent gender (p=0.124) or the gender of the family member diagnosed with ASD (p=0.539). However, it can be noted that men exhibited slightly higher WHO-5 scores.

The well-being of respondents did not significantly depend on the time since ASD diagnosis in a family member (p=0.113). However, slightly better well-being was observed among respondents whose family members had been diagnosed 6 – 10 years ago or more than 10 years ago (Tab. 3).

The two-way ANOVA did not reveal a significant effect of respondent gender (p=0.140), time since ASD diagnosis in a family member (p=0.128), or the interaction between gender and time since diagnosis (p=0.745). No statistically significant differences in respondents' mental well-being were observed according to the analyzed factors. However, the observed effect sizes were small, indicating that the practical impact of these variables on subjective well-being was limited in the present sample (Tab. 4, Fig. 1).

Table 3. Well-being (WHO-5) by time since ASD diagnosis

Time since diagnosis	M	SD	Min	Max	Me	Q1	Q3
Overall	44.22	20.62	0.0	100.0	44.0	28.0	60.0
Up to 1 year	43.40	23.39	0.0	88.0	48.0	24.0	60.0
1–5 years	42.02	19.19	4.0	100.0	40.0	28.0	56.0
6–10 years	49.02	21.13	4.0	92.0	48.0	36.0	64.0
>10 years	47.73	20.91	0.0	88.0	48.0	36.0	60.0

ANOVA: F(3,306) = 2.004, p = 0.113, $\eta^2 = 0.019$

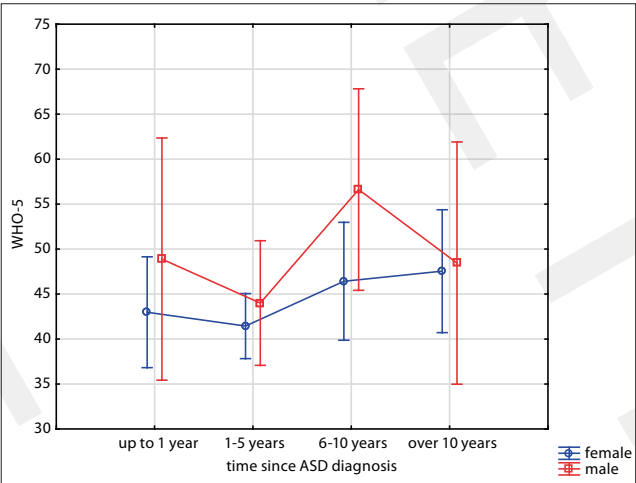


Figure 1. Well-being of respondents according to the WHO-5 scale depending on respondent gender and time since ASD diagnosis in a family member

Table 4. Two-way ANOVA: respondent gender × time since diagnosis

Variable	F	df	p	η^2p
Gender	2.192	1	0.140	0.007
Time since diagnosis	1.908	3	0.128	0.019
Gender × Time	0.411	3	0.745	0.004

η^2p – effect size, partial eta squared

Based on the two-way ANOVA, no significant effect of the gender of the family member with ASD was found (p=0.877), nor of time since ASD diagnosis (p=0.141). No significant interaction between the analyzed factors was observed (p=0.554). The corresponding effect sizes (partial η^2) were

also very small, indicating a limited contribution of the analyzed variables to the variability in WHO-5 scores (Tab. 5, Fig. 2).

Table 5. Two-way ANOVA: family member gender × time since diagnosis

Variable	F	df	p	η^2p
Gender of family member	0.024	1	0.877	<0.001
Time since diagnosis	1.836	3	0.141	0.018
Gender × Time	0.698	3	0.554	0.007

η^2p – effect size, partial eta squared

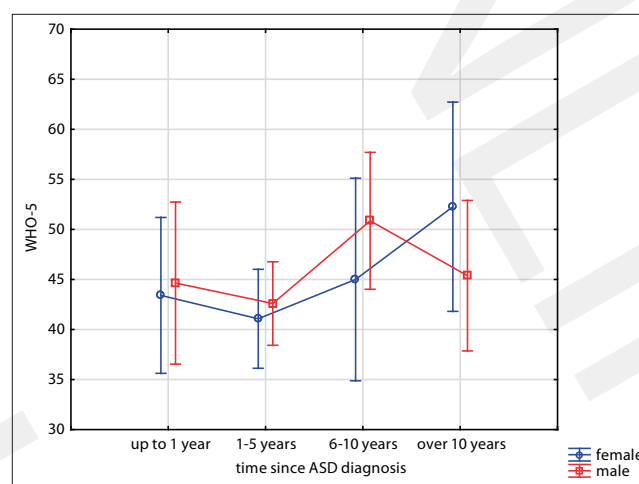


Figure 2. Well-being of respondents according to the WHO-5 scale, depending on the gender of the family member with an ASD diagnosis and time since ASD diagnosis

DISCUSSION

The obtained results indicate that the mental well-being of family members of individuals diagnosed with ASD is reduced, which is consistent with previous literature highlighting the high level of psychosocial burden in this group [6–8]. More than half of the respondents scored below the WHO-5 well-being threshold, suggesting a significant risk of impaired mental functioning. This finding aligns with a broader body of research showing that caring for an individual with ASD is associated with chronic stress, emotional burden, and the need to reorganize both family and professional life [11, 12].

Contrary to some previous studies, the present analysis did not reveal significant differences in well-being depending on respondent gender. Although the literature often points to a higher burden among women [12–14], particularly mothers serving as primary caregivers, the results suggest that negative psychosocial consequences may affect both genders to a similar extent. It is possible that the lack of observed differences reflects evolving social roles in caregiving or the specific characteristics of the study sample. It also cannot be ruled out that the measurement tool used did not capture subtle qualitative differences in the experiences of women and men.

Similarly, the lack of significant differences in well-being depending on the gender of the individual with ASD is consistent with studies suggesting that family burden results primarily from the presence of the disorder itself and its

functional consequences, rather than from the demographic characteristics of the affected individual [8, 13, 14]. This finding may also indicate that factors such as symptom severity, comorbidities, or level of functioning are more important determinants than gender, representing an important direction for future research.

The absence of statistically significant associations in the present study should not be interpreted as evidence that gender or time since diagnosis are irrelevant determinants of caregivers' mental well-being. Rather, these findings indicate that no statistically significant differences were observed in this sample using the WHO-5. The lack of significance may also reflect the relatively small effect sizes, sample heterogeneity, limited statistical power for some subgroup comparisons, or the influence of other unmeasured factors, such as caregiving burden, social support, symptom severity, and socio-economic status. This finding highlights the complexity of adaptive mechanisms and suggests that other variables may play a more critical role, such as social support, access to therapeutic services, family economic status, and caregiving competencies [6, 12]. The literature emphasizes that family adaptation is often driven by the overall level of caregiving stress rather than by individual socio-demographic variables [12]. Low levels of social support are associated with higher parental stress and an increased risk of depression [8]. At the same time, access to formal therapeutic services can significantly mitigate the negative effects of caregiving for individuals with ASD [15]. Limited access to specialized care is linked to greater emotional and organizational burden on families.

The findings should not be interpreted as indicating that the ASD diagnosis itself determines the current mental well-being of family members. Rather, given the cross-sectional design and the varying time elapsed since diagnosis, the diagnosis should be regarded as a contextual factor, while current mental well-being is likely influenced by a complex interplay of caregiving burden, the individual's level of functioning, family relationships, coping strategies, social support, and other life circumstances that were beyond the scope of the present study.

Previous research suggests that caregivers' mental well-being may be influenced more strongly by factors such as ASD symptom severity, the individual's level of functioning, caregiving burden, and the availability of formal and informal social support than by basic socio-demographic characteristics alone. These factors may explain part of the variability in caregivers' well-being observed across studies, and should be considered in future research to better understand the determinants of mental well-being among family members of individuals with ASD.

Economic studies indicate that family socio-economic status influences both access to support resources and the level of caregiving stress [16–18]. Families with lower economic status are more likely to experience an accumulation of stressors, which negatively affects their mental well-being. In contrast, higher income may serve as a buffer against stress by improving access to therapies and support services [6].

Caregiving competencies developed over time may contribute to improved coping with the daily challenges associated with ASD. The process of learning coping strategies may partially explain the improvement in caregivers' psychological functioning reported in some longitudinal studies [6, 11]. However, this adaptation is not uniform,

as evidenced by research showing considerable variability in parental stress trajectories [16]. Some families maintain a high level of burden regardless of time since diagnosis, suggesting the presence of chronic stressors [8]. The literature also highlights that the severity of ASD symptoms and the child's level of functioning may be stronger predictors of caregiver well-being than demographic variables. Individual differences in family functioning may also result from comorbid conditions in individuals with ASD [2, 3].

The complexity of these relationships underscores the need for a multifactorial approach to analyzing caregiver well-being. Interactions between family resources and the social support system are crucial for understanding resilience mechanisms [6]. From a public health perspective, it is important to consider both formal and informal sources of support when designing interventions. Research indicates that family-centred interventions can improve not only the functioning of the child, but also the well-being of caregivers [11, 15]. Therefore, there is an increasing emphasis on the need for a systemic approach to supporting families of individuals with ASD, taking into account both psychological and economic aspects of the caregiving burden [1]. Considering the multidimensional nature of factors affecting well-being may contribute to the development of more precise and effective clinical and social interventions [8].

From a health economics perspective, the findings are particularly relevant. Reduced mental well-being among family members of individuals with ASD may lead to increased utilization of healthcare resources, including both psychiatric and primary care services. It may also result in reduced professional activity, decreased productivity, and increased absenteeism, generating substantial indirect costs [12, 16, 19]. The lack of significant differences in well-being across the analyzed variables suggests that this burden is widespread and not limited to specific subgroups [6, 8].

The results highlight the need to develop comprehensive, systemic forms of support for families of individuals with ASD, encompassing both psychological assistance and organizational solutions that facilitate balancing caregiving and professional roles. From the perspective of healthcare system efficiency, investments in improving caregivers' mental well-being may contribute to reducing the long-term costs associated with ASD, which is consistent with a value-based healthcare approach [20, 21].

In this context, special emphasis should be placed on training families to understand the nature of ASD and to become familiar with contemporary, evidence based therapeutic methods [22–24]. Providing caregivers with structured education on symptom mechanisms, behavioural strategies, and developmental trajectories can significantly reduce both the emotional and practical burden associated with daily care. Such training not only enhances parental competence and confidence but also helps minimize the discomfort and uncertainty frequently experienced by families, offering clearer guidance on how to respond to challenging behaviours and support the child's development. Importantly, access to up-to-date, reliable information gives caregivers with realistic hope for reducing symptom severity and improving long-term outcomes, which serves as a crucial protective factor for their psychological well being [25, 26].

CONCLUSIONS

The findings indicate that more than half of the surveyed family members of individuals with ASD reported reduced mental well-being according to the WHO-5. No statistically significant differences in mental well-being were observed according to respondent gender, gender of the family member with ASD, or time since diagnosis. However, these findings should be interpreted with caution, as other important determinants of caregivers' mental well-being were not assessed.

The results suggest that subjective mental well-being among family members of individuals with ASD may be influenced by factors beyond the basic socio-demographic and temporal variables analyzed in this study. Future research should include broader measures of caregiver functioning, resilience, caregiving burden, social support, and family resources to better understand the determinants of mental well-being in this population.

From the health economics perspective, reduced mental well-being among family members may contribute to the indirect costs associated with ASD. These findings support the need for comprehensive support strategies aimed at improving caregivers' mental well-being and reducing the long-term social and economic burden associated with ASD.

Limitations of the study. The present study has several limitations. First, its cross-sectional design precluded causal inference, and the absence of a comparison group limited the interpretation of the findings. Second, the study included a heterogeneous sample of family members and did not assess important factors known to influence caregivers' mental well-being, such as ASD symptom severity, level of functioning, caregiving burden, social support, or socio-economic status. The relatively small proportion of male respondents may also have limited the statistical power to detect gender differences. Finally, the WHO-5 assessed subjective psychological well-being during the previous two weeks, and should not be interpreted as a direct measure of family adaptation or other broader aspects of caregiver functioning. Therefore, the findings should be interpreted as describing the current mental well-being of family members of individuals with ASD rather than the direct impact of an ASD diagnosis. Future longitudinal studies incorporating a broader range of psychosocial and clinical variables are needed to better understand the determinants of caregivers' mental well-being.

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