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3 Mental well-being of parents of children with autism spectrum disorder in Slovenia

Abstract

Introduction: Autism spectrum disorder refers to neurodevelopmental disabilities that affect social, communicative, and behavioural development. Parents of children with autism spectrum disorder often face parenting challenges, such as difficulties understanding and communicating with their children. Such factors can lead to poor mental well-being. Mental well-being is a state of positive psychological and emotional health.

Methods: A cross-sectional study was conducted to determine whether there was a relationship between parental mental well-being and family experience. The Autism Family Experience Questionnaire measured family experience and quality of life. The Warwick Edinburgh Mental Well-being Scale measured parents' mental well-being.

Results: A total of 101 parents of children with autism spectrum disorder from Slovenia participated in the study. A small correlation between parental mental well-being and the positive family experience was found. The mental well-being of parents negatively correlates with family life and child symptoms and positively with the experience of being a parent and child development. Parents reported poor support from the health system. Parents who devote more time to themselves also have better mental well-being. Parents report a lack of support from health professionals, resulting in poor mental well-being.

Discussion and conclusion: An integrated person-centred approach should be introduced to reduce stress, emotional burden, and physical fatigue by the parents of children with autism spectrum disorder and improve their mental well-being. Future research could investigate possible solutions for improving the mental well-being of parents of children with autism spectrum disorder.

Keywords: Autism spectrum disorder, mental well-being, child, parenting, cross-sectional studies

3.1 Introduction

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition characterized by persistent communication and social interaction impairment and restricted and repetitive activities, behaviour, and interests [1]. Parenting a child with ASD can present a daily challenge for parents and can significantly affect their mental well-being [2, 3], quality of life [4, 5], and family life [6]. Furthermore, parents of children with ASD often experience increased stress, symptoms of depression, or other psychological problems [7–9]. Elevated stress levels may occur when parents' demand exceed their coping resources [2].

Mental well-being is a positive state of psychological and emotional health [10]. It varies among the different sociocultural contexts of each individual [11]. Numerous factors can affect the well-being of parents of children with ASD. Authors argued that behavioural problems are the most important predictors of parental stress in children with ASD and other disabilities [12]. Other key factors include the child's age [13], regulatory problems, and increased autism severity [12]. Parents with increased self-blame because of their child's health condition or despair have poorer mental well-being [14]. Other factors that may impact parents' mental well-being are inadequate access to mental health services [15], poor physical health [16], and lower quality of life [17]. Contextual factors contributing to stress include financial strain [18], misunderstanding of child's condition, judgement and stigma related to child's condition [12], a lack of cooperation between parents and healthcare workers [19], lack of understanding and support from family, and even from some professionals [12].

There is very little research into the experiences of parents and families of children with ASD in Slovenia. Support services may not be as well developed in Slovenia as in other countries in Europe or the United States of America (USA). A 2017 Slovene study by Schmidt et al. [20] highlighted the need for appropriate and efficient support for families with children with ASD. Slovenian parents stated in an online blog that no comprehensive treatment is available within the healthcare system and that appropriate treatment is not accessible to all parents [21]. There is a gap in understanding Slovene families' needs, that is, how parents experience parenting a child with ASD and its effect on their mental well-being. The chapter aims to explore whether there are differences in ASD family experiences or parental mental well-being related to different demographic factors and find out if there is an association between parent mental well-being and family experience with ASD.

3.2 Methods

A cross-sectional study was conducted to determine whether there was a relationship between parental mental well-being and family experience with ASD.

3.2.1 Participants

Participants were recruited over 60 days (March–May 2018) via e-mail addresses obtained from non-governmental services (NGOs) and social media invitations. A total of 101 parents of children with ASD participated in the study: 86 (85.1%) were mothers and 15 (14.9%) were fathers (Tab. 3.1).

Tab. 3.1: Sample characteristics.

Variables	<i>n</i>	%
Gender		
Male	15	14.9
Female	86	85.1
Employment		
Yes	79	78.2
No	22	21.8
Highest educational level		
Unfinished elementary school	1	1.0
Secondary school	28	27.7
Higher education program	16	15.8
University-level programs (first degree)	21	20.8
Master level (second degree)	34	33.6
PhD level (third degree)	1	1.1

n, number of participants; %, per cent.

3.2.2 Measures

The Autism Family Experience Questionnaire (AFEQ) is a scale developed in the UK to measure family experience, quality of life, and prioritized outcomes for early intervention in families of children with ASD [22]. The questionnaire is divided into four subdomains. The first domain (experience being a parent of a child with autism) relates to parental battles and realistic expectations about the child’s development. The second domain (family life) was developed based on wider family attitudes, routines, and structures at home. The third domain (child development) refers to the child’s development, understanding, and social relationships. The fourth domain (child symptoms) refers to the feelings and behaviour of the child. Data from the AFEQ within non-United Kingdom (UK) cultural contexts have not been published.

The AFEQ questionnaire was translated to Slovenian following a standardized procedure [23]. First, two independent bilingual translators performed a translation of the questionnaire from the original English into the Slovenian language. The first translator (LCB) was aware of the concepts in the questionnaire and aimed to provide a translation in which meanings were consistent with the original instrument. The second translator (SK) was not unaware of the questionnaire's objective. Disagreements were discussed with a third researcher (GS). Second, the translated version of the questionnaire was back-translated into English. Differences with the original version were discussed with the questionnaire author (KL) and adjusted accordingly to ensure that the original meaning was maintained.

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) is a scale developed in the UK in 2006. It is a 14-item, 5-level scale ranging from “none of the time” to “all the time”. It measures all attributes of mental well-being, except spirituality [24].

A bespoke questionnaire consisted of 14 questions: parentage; gender; employment; education level; region; number of children in the family and number of children with ASD; age of the child with ASD; hours devoted to care of the child with ASD and to themselves; satisfaction with life; satisfaction with healthcare support; help with child with ASD; involvement in school; and support from NGOs.

3.2.3 Data analysis

Data were analysed using descriptive and inferential statistics in R statistical computing environment [25]. AFEQ items that were negatively worded were scored in reverse order, consistent with the scoring guidelines. A minimum possible score of AFEQ was 48 and a maximum of 240, where lower scores represent better experience. A minimum score of WEMWBS was 14 and a maximum of 70, where higher scores represent better mental well-being. All items were worded positively in WEMWBS. The total score for both scales was calculated by totalling the scores for each item with equal weights. No missing data were recorded. Since none of the tested sub-groups deviated from the normal distribution, we used Pearson correlation coefficient (r_p) to measure correlation, a t -test of independent samples when comparing the mean values of two groups, and an ANOVA analysis of variance analyses the differences among group means. When comparing the AFEQ mean to the original study from the UK, a one-sample t -test was used.

3.3 Results

3.3.1 Descriptive data and internal consistency

A summary of variables related to family and satisfaction with life is presented in Tab. 3.2.

Tab. 3.2: Summary of variables related to family, time devoted to child and self, and satisfaction-related questions.

Variables	<i>n</i>	%
Number of children in the family		
One	33	32.7
Two	45	44.6
Three	15	14.9
Four or more	8	7.8
Hours devoted to the care of a child with ASD (per day)		
1–6	69	68.4
7–12	19	18.8
13–18	2	2.0
19–24	11	10.8
Hours devoted to self-care (per day)		
Zero	34	33.7
One	42	41.6
Two	18	17.7
Three or more	7	7.0
General satisfaction with life		
Yes	43	42.6
No	34	33.7
I do not know	21	20.7
I do not want to answer	3	3.0
Satisfaction with healthcare support		
Satisfied	5	5.0
Unsatisfied	90	89.1
Do not know	6	5.9

n, number of participants; %, per cent.

The minimum score on the AFEQ was 123, and the maximum was 158, with a mean of 138.3 (SD = 7.9). The mean of the AFEQ in this study was lower (i.e., better) than baseline scores in the original [22] study and slightly higher compared the follow-up period to original study at ($M = 141.0$, $SD = 21.3$, $p < 0.001$; $M = 133.0$, $SD = 22.8$, $p < 0.001$).

Nevertheless, the minimum value was 123 when the original study minimum was 81.8 (78.1 at follow-up), suggesting a smaller range of experience in the Slovenian sample. Cronbach's α for AFEQ total score was 0.648. The relatively low alpha value in AFEQ may be due to poor interrelatedness between items or heterogeneous constructs.

A minimum score of WEMWBS was 24 and a maximum of 67, with a mean of 46.3 (SD = 8.8). According to the National Health Service (NHS) [26] classification, the mean score of the mental well-being of parents in this sample was average. Cronbach's α for WEMWBS was 0.918. A high alpha value in WEMWBS shows that items correlate and have a high degree of internal consistency.

3.3.2 Relationship between autism family experience, parental mental well-being, and demographic factors

There was a very small and non-significant difference ($t(99) = 1.036, p = 0.303$) in family experience with autism scores of fathers ($M = 140.3, SD = 7.4$) compared with mothers ($M = 138.0, SD = 7.9$). Family experience with ASD differed according to the employment status of the parents ($t(99) = -2.412, p = 0.018$), where employed parents achieved a mean score of 137.4 (SD = 7.5) and unemployed parents achieved a score of 141.8 (SD = 8.3). The correlation between family experience with autism and levels of education was not significant ($r_p = -0.093, n = 101, p = 0.355$). We were also not able to confirm significant differences in family experience among parents with different number of children ($F(5, 95) = 2.139, p = 0.067$). Parents who devote more time to themselves scored higher in WEMWBS score, suggesting better mental well-being ($r_p = 0.224, n = 101, p = 0.025$). The correlation between WEMWBS score and time devoted to children was small and non-significant ($r_p = -0.106, n = 101, p = 0.294$).

3.3.3 Correlation between family experience with autism and parents' mental well-being

The correlation between mental well-being and family experience with autism was analysed using Pearson correlation coefficient. There was a significant negative correlation (better autism family experience correlates with higher well-being) between the two variables ($r_p = -0.312, n = 101, p < 0.001$). According to the strength levels of the correlation by Evans [27], the correlation between the two variables is small. Furthermore, subdomains of the AFEQ were also tested for correlation with WEMWBS (Tab. 3.3).

The mental well-being of parents negatively correlates with family life and child symptoms and positively with the experience of being a parent and child development.

Tab. 3.3: Correlation of autism family experience and mental well-being.

		WEMWBS	
		<i>r_p</i>	<i>p</i>
AFEQ	Family life	−0.502	< 0.001*
	Experience of being a parent	0.375	< 0.001*
	Child development	0.001	0.994
	Child symptoms	−0.306	0.002*
	AFEQ total	−0.312	0.001*

AFEQ, The Autism Family Experience Questionnaire; *p*, statistical significance; *r_p*, Pearson correlation coefficient; WEMWBS, The Warwick-Edinburgh Mental Well-being Scale; *, statistical significance *p*-value (≤ 0.05).

3.4 Discussion

The mean AFEQ score in our study was approximately three points lower (better), and there was a smaller variation in scores (SD of 7.9 compared to 21.3) compared with the baseline scores of the original study [22]. In interpreting these results, the authors must consider the differences between the participants in the UK study [22] and ours. Furthermore, this leads to a more heterogeneous response from the UK parents than in the Slovenian sample. This may be because the UK sample was young and recently diagnosed. Therefore, parents may still have been in a period of adaptation and adjustment to their child’s diagnosis leading to more variability in their reports of their family experience and quality of life. Many participants in the Slovenian sample were recruited through an NGO that supports autistic people and their parents. They might have received more support regarding their child with ASD than is typical in Slovenia, which could explain the slightly higher scores on the questionnaire.

The mean score of mental well-being for this sample ($M = 46.3$; $SD = 8.8$) would be classified as average and slightly lower than the results ($M = 47.8$; $SD = 4.7$) in a general population of parents [28]. It is perhaps surprising that the mean mental well-being score within this sample of parents of children with ASD is in the “average” range. Therefore, this seems to contradict previous findings that family members of a child with ASD experience poorer mental well-being and increased stress [29–31]. However, our study’s median of the WEMWBS is 45, which is lower ($M = 51.0$). It also seems to run contrary to the fact that 89% of the sample are dissatisfied with health-care support. The WEMWBS tool is limited only to current mental well-being, which might not correlate with long-term dissatisfaction. Further research could explore this finding further in other samples within Slovenia and similar countries.

Several factors were not associated with AFEQ scores: parent gender; education level; or several children in the family. Parental mental well-being was associated with employment status (with better family experience reported by parents in employment) and the amount of time devoted to themselves. These findings emphasize the importance of contextual factors to well-being in families of children with ASD. Employment can bring financial stability and the opportunity for parents to experience life outside the home. Time to oneself may be particularly important when raising a child with ASD and may provide opportunities to rest, exercise, and enjoy hobbies or other activities that improve well-being. Parents with more time to themselves may have increased social support, and better social support has contributed to better parental mental well-being [32]. The AFEQ is developed to measure family experience, quality of life, and prioritized outcomes for early intervention in families of children with ASD [22]. Further comparisons are impossible because the scale was not yet used together with selected factors (e.g., parent gender) in other studies.

A strong negative correlation between AFEQ total score and WEMWBS score is evidence which shows better autism family experience correlation with higher well-being. This replicates the correlation found within the UK sample [22] and offers further evidence of the external validity of the relatively new AFEQ measure. Moreover, this finding showed that parents who have better mental well-being have better family experience of ASD and vice versa. Other studies have highlighted that stress harms caregiving experiences and feelings about being a parent [33, 34].

3.4.1 Limitations

One limitation of this study is that many participating parents were recruited through an NGO supporting autistic people and their parents. Therefore, these parents may receive more support regarding their child with ASD than is typical in Slovenia. The data may not represent the full range and diversity of difficulties related to ASD. The AFEQ is a relatively new tool, and there is a minimal number of cross-cultural studies to compare our results. However, it is currently being used in several cultural contexts, so understanding how the tool works across contexts will increase. Furthermore, the UK study sample [22] was larger ($n = 145$) than the sample in our study ($n = 101$). Future studies are needed to check the validity of the AFEQ scale among different environments and study samples.

3.5 Conclusion

The findings highlight the importance of family and parental well-being. Parenting can be stressful, especially for parents caring for a child with ASD. There were high levels of dissatisfaction with healthcare support within this Slovenian sample of parents of children with ASD. When parents have good support in the healthcare system, they maintain or improve their mental well-being. The findings highlight the importance of parental well-being by working outside the home and having time to yourself. Thus, it is very important that they have appropriate support from other family members and healthcare workers. Healthcare workers must be competent and have the knowledge, skills, and attitude for informing, teaching, and helping parents of children with ASD.

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