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## Forms of Occupational Work for Parents of Children on the Autism Spectrum during the Pandemic: Selected Aspects of Functioning and Children's Participation in Therapy

### Abstract

This study, conducted during the pandemic, examined if the occupational situation of parents of children with ASD influenced their parenting role and their children's participation in therapy. We studied three groups of parents in Poland (n=137): non-employed, stationary workers, and remote workers. We tried to establish how parents assessed their competence in implementing therapy recommendations, their child's functioning and the need for support using the Parental Stress Scale (PSS) and a questionnaire. Results showed that employment status did not affect perceived parental stress levels. The fulfilment of therapy recommendations was similar in the three groups. However, stationary workers felt more competent doing so. The study groups differed in their assessment of difficulties and expected support.

**Keywords:** *parents of children with ASD, pandemic and ASD, therapy for children with ASD, parenting stress*

## **Introduction**

Parents of children with autism face significant emotional demands due to the life-long nature of the condition (Lounds et al., 2007). The extensive support required by children with ASD can impact parents' professional occupations, resulting in reduced employment and family productivity (Ganz, 2007; Järbrink et al., 2010). The COVID-19 pandemic further challenged parents of children with disabilities, as they lost support networks and often became sole caregivers (Latzer et al., 2021). Limited access to therapeutic services added to their stress (Eshraghi et al., 2020). During the pandemic, many parents experienced unemployment, remote work, or financial and psychological challenges (Forrest et al., 2020; Turk et al., 2020). This study examines how these new circumstances have affected the child's functioning and therapeutic process.

### ***Parental Participation in Therapy for Their Children with ASD during the COVID-19 Pandemic***

Children with ASD require intensive therapeutic care and education, involving multiple providers and significant caregiver involvement (Ganz, 2007). Parents invest time in coordinating and supporting their child's development (Stein et al., 2011). Children with ASD often receive an average of 5.4 different types of services, such as speech and occupational therapy (Bitterman et al., 2008). This investment of time and effort is even higher for children with both ASD and intellectual disability (Estes et al., 2009). Raising a child with autism limits parents' time for social interactions and other activities (Gray, 2003; Sen & Yurtsever, 2007). Constant monitoring and attention are necessary, and disruptions to routines and lack of support impact parents' ability to work (Fletcher et al., 2012). The pandemic further burdened parents as they had to take on the roles of teachers and therapists (Eshraghi et al., 2020). Children with ASD faced challenges at high levels during isolation or quarantine as they have difficulty tolerating uncertainty and anxiety (e.g., Jenkinson et al., 2020).

### ***Implications of Working Parents of Children with ASD***

Parents of children with ASD often have limited time for themselves due to the child's support needs, which affects their professional lives (Montes & Halterman, 2007). Some parents are less likely to be employed or face employment-related problems due to their child's condition (Altieri & von Kluge, 2009). Parents may

need frequent leave and reduced working hours, limiting opportunities for promotion and lower earnings (Kogan et al., 2008; Montes & Halterman, 2008). It leads to fewer financial resources for personal goals and stress-reducing activities (Baker & Drapela, 2010). The role of caregiver for a child with ASD can be a powerful stressor, with challenges including the ambiguity of the diagnosis, the severity and chronic nature of the disorder, finding appropriate therapies and curricula, and coping with financial burdens (Altiere & von Kluge, 2009). Balancing therapy and education responsibilities adds to the parents' burden, especially when faced with childcare, work, and household responsibilities (Baweja et al., 2021). Adding to the caregivers' anxiety and tension levels is the severely limited psychological and social support received so far during the COVID-19 pandemic during personal encounters with therapists (Stankovic et al., 2020; White et al., 2021).

## **The Present Study**

This study aimed to examine parental work activity's impact on therapy participation for children with autism and their perceived assessment of child and family functioning. Three groups of parents were considered: non-employed, stationary working in the normal workplace, and remote working. The study was conducted during the pandemic lockdown to see how parental involvement in therapy and implementation of therapists' recommendations differed between each group. The study aimed to determine if professional involvement influenced parental stress levels based on their work situations.

## **Method**

### **Participants**

A total of 137 parents of children on the autism spectrum participated in the study (105 females, 32 males; aged 26-58 years;  $M=38.65$ ,  $SD=7.09$ ). Among the parents, 118 (86.1%) had a child diagnosed with autistic spectrum disorder only, and 19 (13.9%) had a child with both autistic spectrum disorder and intellectual disability. The participants were divided into three employment groups: unemployed (43; 31.3%), working remotely (45; 32.8%), and working in their normal workplace (49; 35.80%).

## Procedure

The study was conducted remotely during the SARS-CoV-2 epidemic from December 2020 to June 2021. Participants were recruited through children's therapy places and associations of parents of children with ASD. The study was anonymous and followed ethical research procedures. Participants were provided with information about the study and invited to participate. They were able to stop the survey at any time.

## Research Instruments

The study used the Parental Stress Scale (PSS) (Berry & Jones, 1995) and a questionnaire. The PSS was translated into Polish and showed high reliability ( $\alpha = 0.87$ ). The PSS measures parental stress and captures the demands and rewards of parenting. An important feature of the PSS is that it is designed for use with any parent (Louie et al., 2017). Furthermore, the test analyses parenting stresses independently of marital, financial or other life stresses (Lessenberry & Rehfeldt, 2004). Other variables, such as assessment of change in children's functioning, implementation of therapeutic recommendations, parental competence, difficulties in implementation, and assessment of family functioning, were examined using individual items derived from online forums and interviews.

## Results

### *Parental Stress Levels*

A one-way analysis of variance was conducted to compare the level of parental stress among the three groups: non-working ( $n=43$ ), remote working ( $n=45$ ), and full-time working ( $n=49$ ) parents. The results showed no statistically significant difference in parental stress levels,  $F(2, 134) = 1.41, p = .248$ . The mean levels of parental stress were 48.88 ( $SD = 9.69$ ) for non-working parents, 49.07 ( $SD = 8.97$ ) for remote working parents, and 46.29 ( $SD = 8.41$ ) for full-time working parents.

### *Assessment of Change in Children's Functioning*

Parents' assessment of change in their children's functioning before and during the pandemic was compared based on their form of work or non-employment. A one-way analysis of variance revealed no statistically significant difference among the groups,  $F(2, 134) = 0.46, p = .633$ . The mean scores for the assessment

of change were 2.42 (SD = 0.73) for non-working parents, 2.42 (SD = 0.89) for remote working parents, and 2.29 (SD = 0.74) for stationary working parents.

Kruskal-Wallis tests (Annex 1) indicated two statistically significant results in evaluating children's emotional functioning, sensory functioning, and sensory integration among the three groups. Post-hoc analyses using the Dunn-Sidak test showed one statistically significant difference in assessing emotional functioning ( $p = .017$ ). It indicated that parents working remotely reported more frequent deterioration in emotional functioning than non-working parents. However, there were no significant differences between remote and stationary working parents.

Significant differences were also found in sensory development and integration evaluation. Parents working remotely reported more frequent deterioration ( $p = .002$ ) in these areas than non-working parents and parents with stationary work ( $p = .017$ ).

#### *Implementation of Treatment Recommendations During the Pandemic*

A Fisher's exact test found no statistically significant difference in the implementation of treatment recommendations based on employment status ( $p = .489$ ). The proportion of affirmative responses was similar among non-working (88.4%), remote working (95.6%), and stationary working (91.8%) parents.

#### *Assessment of Own Competence in Implementing Treatment Recommendations Before and During the Pandemic*

The Kruskal-Wallis test showed a statistically significant difference in parents' competence in carrying out tasks before and during the pandemic (Annex 2). Post-hoc analysis revealed that the non-working group had a lower competency rating than the stationary group ( $p = .016$ ). The assessment of parents working remotely did not significantly differ from the other groups. The Kruskal-Wallis test result showed no statistically significant difference in competence from before the pandemic.

Parents' self-assessment of competence to implement treatment recommendations, when analysed using the Wilcoxon test showed a significant difference only for those working remotely ( $Z = -2.87, p = .004; r =$  The strength of the effect noted was large,  $r = 0.47$ ). No significant differences were found for remote workers compared to before the pandemic ( $Z = -1.59, p = .112$ ) or non-workers ( $Z = -0.69, p = .490$ ).

#### *Differences in Difficulty in Implementing Treatment Recommendations During the Pandemic*

Series of  $\chi^2$  and Fisher's exact tests (Annex 3) revealed a significant result for lack of time to implement treatment recommendations. The strength of the observed effect, as measured by Cramer's V coefficient, was moderately large. Post-

hoc analyses were also performed using Dunn-Sidak tests. Non-working parents reported less difficulty compared to full-time workers ( $p = .005$ ) and remote workers ( $p < .001$ ). The difference between non-working and remote workers was also significant ( $p = .012$ ). No other difficulties showed significant results.

*Differences in Assessment of Family Functioning During the Pandemic Trajectory*

Kruskal-Wallis tests yielded five statistically significant results. Post-hoc Dunn-Sidak tests were conducted. The calculations showed that two statistically significant differences were noted with regard to the perceived difficulty in the aspect of *Maintaining a routine in which the child functions well*. Non-working parents indicated less difficulty in this area compared to stationary working parents ( $p < .001$ ) and remote working parents ( $p < .001$ ). The two groups were not statistically significantly different.

With regard to the variable *Greater involvement in the child's therapy at home*, there was one statistically significant difference. Compared to stationary working parents ( $p = .014$ ), it turned out that non-working parents had fewer difficulties with greater involvement in their children's therapy. Difficulties in engaging remote working parents were not statistically significantly different from those in the other two groups.

The difficulty scores on *Reconciling the needs of household members in a stay-at-home situation* noted two statistically significant differences. Higher scores in this regard were noted for parents who work remotely compared to those who have stationary work ( $p = .005$ ) and those who do not work ( $p = .002$ ). The two groups were not statistically significantly different.

Two statistically significant differences were noted in the question *The need to reconcile caring for a child with professional work*. A lower severity of these difficulties was noted among parents who do not work compared to those in the group who have stationary work ( $p < .001$ ) or work remotely ( $p < .001$ ). The two groups were not statistically significantly different.

When analysing the item *Availability of support from my child's therapist*, one statistically significant difference was noted – less difficulty in this area for parents working remotely compared to those in stationary work ( $p = .005$ ). The results for non-working parents were not statistically significantly different from the assessment of parents in the other two groups.

## **Discussion**

Our study examined the impact of parents' work situations during the pandemic on the well-being of both parents and children. Results revealed that parental stress, measured using the PSS scale, was similar across all groups compared. The form of work was irrelevant to the difficult task parents faced, which was the need to divide their attention between various activities and caring for their child to create a sense of balance and well-being (Woodgate et al., 2008). In a study by Deoraj Sinha et al. (2016), unemployed parents had significantly higher mean stress scores ( $F=5.439$ ,  $P=.006$ ) than those who were working. According to the authors, parents' stress levels are influenced by the type of disability, gender of the parent and child, and time spent with the child. In our study, the stress levels of non-working and remote-working parents did not significantly differ from those working in a stationary setting.

We also examined whether parents' perceptions of changes in child functioning varied among the surveyed groups. In most areas of development, parents from all work situations reported similar perceptions of changes, including skill regression. However, statistically significant differences were found in emotional functioning and senses/sensory integration. Parents working from home perceived the most deterioration in these areas, while non-working parents reported the least change in their children's behaviour compared to before the pandemic. This suggests that remote working parents may have had less time to meet their children's needs, potentially exacerbating negative behaviours.

Research (Bellomo et al., 2020) has shown that between 45% and 96% of children with ASD have significant sensory processing disorders. Individuals with ASD thrive when they can anticipate changes in their environment, but the COVID-19 pandemic disrupted predictability and stability. It is followed by increased emotional and behavioural problems, including aggression and self-aggression, and anxiety-like behaviour (Huang et al., 2021). Moreover, according to parents, their children with an ASD diagnosis experienced changes in the area of emotions and sensory functioning manifested by outbursts, psychomotor hyperactivity, and the formation of new stereotypes and obsessions related to confinement (Frankova, 2020).

Additionally, we explored whether the type of employment influenced parents' adherence to therapy recommendations, sense of competence, and experienced difficulties. Regardless of their work situation, most parents reported implementing therapists' instructions. However, differences were observed in their perceived competence. Before the pandemic, parents from all groups rated their competence

similarly, with about 75% perceiving it as low. During the pandemic, parents working in stationary jobs rated their competence higher than before, potentially due to increased involvement in their child's therapy. Non-working parents maintained comparable involvement with their children, resulting in minimal change in their perceived competence.

A study by Kurzrok et al. (2021) indicated that parents feel a greater sense of competence when involved in their child's therapy. Parental involvement in parent-child interaction reduces parental stress and enhances self-competence. The low ratings of competence in implementing recommendations may stem from parents of children with ASD perceiving their parenting role as challenging. Analyses show that interventions for families with children with ASD should focus primarily on increasing parents' sense of self-competence (Feng et al., 2022).

Parents also expressed difficulties in implementing treatment recommendations, with the type of work having minimal differentiation. However, one variable that distinguished the surveyed groups was the lack of time, which was reported as less bothersome for non-working parents and more problematic for those working remotely. Many parents faced the challenge of balancing work and implementing treatment recommendations for the first time, significantly impacting family functioning. A qualitative study by Luong et al. (2009) found that parents of children with ASD often struggled with limited time for additional activities, which can lead to difficulties in achieving personal balance.

During the COVID-19 pandemic, parents of individuals with ASD were able to gain new, positive experiences with their child (e.g., maintaining their children's daily routine, learning new skills for their child and setting boundaries), resulting in potential positive long-term effects (Mumbardó-Adam, 2021).

## **Conclusion**

Our research has shown that remote work, compared to stationary or no work for parents of children with ASD, neither increases the level of parental stress they feel nor does it affect their sense of competence in fulfilling the recommendations of therapists. However, it turned out that this way of working causes parents to feel more difficulty in achieving a balance between work and meeting the needs of the household. They indicate a lack of time to engage in the implementation of their children's therapy. It is difficult to recommend this way of working to parents of children with ASD as a compromise in maintaining professional activity and



caring for their child. Instead, it seems that facilities for parents should be sought, e.g., flexible working hours and additional leave.

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**Annex 1. Assessment of aspects of children's functioning during the pandemic versus the type of employment or non-employment**

			does not work	working from home	normal workplace	
Social functioning	improvement	<i>N</i>	0	0	0	$H(2) = 1.38$ $p = .501$
		%	0.0%	0.0%	0.0%	
	no change	<i>N</i>	17	20	16	
		%	39.5%	44.4%	32.7%	
	deterioration	<i>N</i>	26	25	33	
		%	60.5%	55.6%	67.3%	
Emotional functioning	improvement	<i>N</i>	1	0	3	$H(2) = 6.02$ $p = .049$
		%	2.3%	0.0%	6.1%	
	no change	<i>N</i>	18	9	14	
		%	41.9%	20.0%	28.6%	
	deterioration	<i>N</i>	24	36	32	
		%	55.8%	80.0%	65.3%	
Cognitive functioning	improvement	<i>N</i>	1	3	3	$H(2) = 1.65$ $p = .438$
		%	2.3%	6.7%	6.1%	
	no change	<i>N</i>	27	31	32	
		%	62.8%	68.9%	65.3%	
	deterioration	<i>N</i>	15	11	14	
		%	34.9%	24.4%	28.6%	
Independence and capacity for self-determination	improvement	<i>N</i>	10	4	6	$H(2) = 0.03$ $p = .985$
		%	23.3%	8.9%	12.2%	
	no change	<i>N</i>	26	40	40	
		%	60.5%	88.9%	81.6%	
	deterioration	<i>N</i>	7	1	3	
		%	16.3%	2.2%	6.1%	
General physical fitness	improvement	<i>N</i>	1	1	0	$H(2) = 0.53$ $p = .768$
		%	2.3%	2.2%	0.0%	
	no change	<i>N</i>	32	32	40	
		%	74.4%	71.1%	81.6%	
	deterioration	<i>N</i>	10	12	9	
		%	23.3%	26.7%	18.4%	
Senses and sensory integration	improvement	<i>N</i>	0	0	2	$H(2) = 10.76$ $p = .005$
		%	0.0%	0.0%	4.1%	
	no change	<i>N</i>	23	9	19	
		%	53.5%	20.0%	38.8%	
	deterioration	<i>N</i>	20	36	28	
		%	46.5%	80.0%	57.1%	

**Annex 2.** Assessment of aspects of children's functioning during the pandemic versus the type of employment or non-employment

			does not work	working from home	normal workplace	
Competence before the pandemic	low	<i>N</i>	25	26	30	$H(2) = 0.39$ $p = .825$
		%	75.8%	68.4%	76.9%	
	average	<i>N</i>	5	11	5	
		%	15.2%	28.9%	12.8%	
	high	<i>N</i>	3	1	4	
		%	9.1%	2.6%	10.3%	
Competence during the pandemic	low	<i>N</i>	24	28	19	$H(2) = 6.47$ $p = .039$
		%	72.7%	63.6%	43.2%	
	average	<i>N</i>	5	10	16	
		%	15.2%	22.7%	36.4%	
	high	<i>N</i>	4	6	9	
		%	12.1%	13.6%	20.5%	

**Annex 3.** Frequency of indicating specific difficulties versus the type of employment or non-employment

		does not work	working from home	normal workplace	
Lack of clear procedures for carrying out specific activities	<i>N</i>	13	6	16	$\chi^2(2) = 5.33$ $p = .070$
	%	30.2%	13.3%	32.7%	
Lack of support for regular moni- toring of the therapeutic process by a qualified therapist	<i>N</i>	25	25	32	$\chi^2(2) = 1.01$ $p = .605$
	%	58.1%	55.6%	65.3%	
Lack of time	<i>N</i>	14	39	30	$\chi^2(2) = 26.97$ $p < .001$ $V = .44$
	%	32.6%	86.7%	61.2%	
Lack or impeded access to therapeutic assistance	<i>N</i>	6	6	5	$\chi^2(2) = 0.35$ $p = .840$
	%	14.0%	13.3%	10.2%	
Child's motivation	<i>N</i>	40	41	41	$\chi^2(2) = 2.35$ $p = .310$
	%	93.0%	91.1%	83.7%	
Parent's motivation	<i>N</i>	9	20	14	$\chi^2(2) = 5.93$ $p = .052$
	%	20.9%	44.4%	28.6%	
I don't follow the recommendations	<i>N</i>	2	0	0	$p = .097$
	%	4.7%	0.0%	0.0%	