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STRESS AND COPING STRATEGIES IN PEOPLE WITH ASDS DURING THE COVID-19 PANDEMIC: A STUDY REPORT

Abstract

Purpose: Studying people with autism spectrum disorders (ASDs) in terms of their functioning during the Covid-19 pandemic poses a significant challenge. Given the specificity of the condition (difficulty in initiating and maintaining interpersonal relationships) and related inclusion strategies, the functioning of individuals with ASDs within a dynamically evolving social reality has come to the fore as an important issue. Due to the Covid-19 pandemic most relationships – including those which are supportive and therapeutic – are now largely 'intermediated'.

Methods: The survey research was conducted among people with the autism spectrum using questionnaires to study stress (PSS 10) and strategies for coping with stress (CISS).

Results: The conducted research showed that:

1. People with ASD during the COVID-19 pandemic experienced increased levels of perceived stress.
2. People with ASD used various strategies of coping with stress in the social, emotional and behavioral aspect
3. In people with ASD, the emotional-focused style of coping with stress was dominant.
4. Avoidance was the least frequently used stress coping strategy.

Discussing: The prevalence of the emotion-oriented strategy of coping with stress means that in stressful situations during the pandemic people with ASDs have tended to focus on themselves and their own emotional experiences. The task-oriented strategy, i.e. taking action, has been used less frequently. Coping with stress, the study participants were not inclined to engage in alternative activities during the earlier stages of the Covid-19 pandemic.

Keywords: *Autism spectrum disorders (ASDs), stress, coping, Covid-19, survey research*

Introduction

Autism spectrum disorders (ASDs)[I] (Lai et al., 2019) affect approximately 1% of general population. About 10% of people with ASDs are also diagnosed with various comorbidities (Rydzewska et al., 2019). The diversity of the condition and degrees of severity, including atypical immunological interactions, were highlighted by a team supervised by A. M. Neumeyer (2019) (Meltzer and Van De Water, 2017). Andrew A. McDonnell, Michael McCreadiet, and Paul Dickinson (2019, p. 454), as well as a team led by M. F Jalloh (2018), indicate that the problem of ASDs is frequently associated with stress, anxiety and trauma as potential behavioural patterns in people on the spectrum. The term 'anxiety' is used more often in case descriptions than 'stress' (for the differentiation of intensity). The latter can be triggered by an external factor (a stressor) that affects the interaction between the individual and the environment, e.g. the need to maintain social distance; naturally, it is difficult to explicitly identify factors that could work as stressors and cause varying degrees of anxiety and fear, including post-traumatic stress disorder (PTSD)

(Jalloh et al., 2018). People with ASDs are believed to be at a greater risk with regards to the stability of their mental condition (Cvejic et al., 2018; Lever and Geurts, 2016). For example, suicide rates are nine times higher compared to the general population (Hirvikoski et al., 2016).

Den Houting (2020) and M. Altable (2020) are among the authors who argue that restrictions introduced due to the Covid-19 pandemic may have caused changes in perceived stress levels with regards to people on the spectrum.

Stress in people with ASDs

Stress is a non-specific response from an organism to meet the 'demands' caused by 'stressors'. 'Eustress' is a type of stress that mobilises us to act, whereas 'distress' denotes unpleasant or damaging stress experiences (Selye, 1950). Moreover, according to Lazarus and Folkman (1984), 'psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being'. Psychological stress can be defined in a three-fold manner as:

- A stimulus, situation or external event with specific properties;
- A person's response, particularly emotional and internal, to a particular experience;
- A relationship between external factors and a person's characteristics.

In chronic and somatic diseases, as well as in mental disorders, stress is described according to the Conservation of Resources (COR) Theory by Steven Hobfoll (2006). Resources are anything that a person values and has at his or her disposal. They 'include the objects, conditions, personal charac-teristics, and energies that are either themselves valued for survival, directly or indirectly, or that serve as a means of achieving these resources'; indeed, they are 'resources that are valued by a broad class of individuals and that are seen as highly salient for people in general as well as the self' (Hobfoll, 2006, p. 61). According to the COR theory, stress occurs when these resources are lost, at risk of being lost, or when their investment does not yield a reasonable

gain. In this concept, more attention is paid to the costs sustained by a person attempting to adapt to the environment rather than to the identification of stressors in human life.

According to Uta Frith and Christopher D. Frith (2003), difficulties in the reception and communication of emotions observed in people with ASDs may function as a stressor. Accordingly, the behaviour of people with an autistic developmental profile may be an indicator of higher stress levels. McDonnell and Gayson (2014) argue that the latter may be diagnosed based on stereotypical types of behaviour (e.g. waving hands) or determined objectively (e.g. by measuring blood pressure). Transactional models of stress have also been applied (e.g. McDonell, 2015), with these focusing on the embeddedness of people with ASDs in the environment (family, peers, professional life, etc.).

This diversity of symptoms can undoubtedly be linked to various neurodevelopmental disorders (see DSM5 – American Psychiatric Association, 2013), characterised by deficits in social communication and social interaction, as well as repetitive behaviours. Heterogeneous behavioural symptoms are a result of various neuroatypical profiles (differentiated according to the nature of cognitive functions, social perception, executive functions, and specific processing of incoming information) (Lai et al., 2019). The Covid-19 pandemic, with its varying degrees of intensity, has enforced self-isolation and quarantine (in justified cases) as preventive measures; although these measures have undoubtedly contributed to the severity of ASD behaviours (Drogomyretska et al., 2020), there is potential for debate regarding the extent of this influence. For instance, Rutter et al. (2007) argue that such behaviours may also intensify in people who have been developmentally deprived from infancy and are seeking to satisfy their needs.

The intensification of autistic behaviours, which are to have a calming effect and relieve anxiety, agitation and stress, may therefore be a result of changes caused by the current situation, specifically the sudden redefinition of rules of social functioning; important examples include suspended school lessons and changes in the family's situation (e.g. remote work by caregivers, disruption of eating rituals, etc.). Limiting one's contacts, typically to the immediate family and caregivers, is an important aspect (Kumazaki et al., 2020). Restrictions may exacerbate certain health conditions (e.g. eating disorders

due to disrupted deliveries, difficulty in providing regularly consumed food products) or disrupt relaxation schedules (in adults – see Kojovic et al., 2019).

Methodology

This study was conducted by a team from the Nicolaus Copernicus University in Toruń, the University of Silesia, and the Autism Team Foundation as part of a project funded by the CRUSH grant (Research on the Covid-19 pandemic implemented at the Nicolaus Copernicus University by representatives of Social Sciences and Humanities). The entire project included two research objectives: firstly, the intention was to analyse perceived stress in people with ASDs and their coping strategies during the Covid-19 pandemic; secondly, it intended to define the scope and possibilities with regards to preventing the psychological impact of the pandemic. In the following work, the results of research related to the implementation of the first objective will be presented.

Prior to its implementation the project was approved by the Research Ethics Committee of the Nicolaus Copernicus University in Toruń. All procedures in the studies involving human participants were performed in accordance with the ethical standards of the institutional and/or national research committee, and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

The presented survey research was conducted on people diagnosed with ASDs who are active on closed-access online forums. Consent to perform the survey on these platforms was obtained as a result of our cooperation with foundations and non-governmental organisations focusing on self-help projects as well as advocates for people with disabilities, including ASDs and more severe developmental deficits.

This study has employed the following tools: the Perceived Stress Scale (PSS-10) proposed by S. Cohen, T. Kamarck and R. Mermelstein, accordingly adapted by Z. Juczyński and N. Ogińska-Bulik (2009), and the Coping Inventory for Stressful Situations (CISS) established by N.S. Endler and J.D.A. Parker in its Polish adaptation by P. Szczepaniak, J. Strelau, and K. Wrześniewski (2020). In the former test, responses were based on a four-point scale where the lowest

possible number of points was 0 and the highest 40. In the latter test, a descriptive scale was used – never, rarely, often, very often, always – with a score from 1 to 5 assigned to each answer.

The statistical analysis was performed using Statistica, version 13.3. We have also assessed the test score reliability; the Cronbach's alpha for PSS-10 was 0.87, thus facilitating further analysis regarding perceived stress in people with ASDs during the Covid-19 pandemic (Table 1).

Table 1. *Test score reliability – PSS-10*

Variable	Mean if item deleted	Value if item deleted	Std dev if item deleted	Item total correlation	Alpha if item deleted
pss1	20.75	48.91	6.99	0.66	0.86
pss2	20.62	49.32	7.02	0.66	0.86
pss3	20.20	50.49	7.10	0.7	0.8
pss4	21.63	54.05	7.35	0.4	0.87
pss5	21.13	54.78	7.40	0.41	0.87
pss6	20.85	50.9	7.13	0.552	0.87
pss7	21.37	52.07	7.21	0.60	0.86
pss8	20.51	52.84	7.26	0.53	0.87
pss9	20.70	47.5	6.89	0.71	0.85
pss10	20.92	47.3	6.87	0.76	0.85

Mean=23.2, Standard deviation=7.91273, Cronbach's alpha: .87, Standardised alpha: .87, Average inter-item correlation: .433

With respect to CISS, three subscales were employed: task-oriented strategy, emotion-oriented strategy, and avoidance-oriented strategy. In terms of the test score reliability, the following results were obtained:
- A Cronbach's alpha for the task-oriented strategy of 0.76;
- A Cronbach's alpha for the emotion-oriented strategy of 0.70;
- A Cronbach's alpha for the avoidance-oriented strategy of 0.53.

The respective calculations are presented in Tables 2, 3, and 4. Once again, the results facilitate further analysis with regards to the topic under study.

Table 2. *Test score reliability – CISS: Task-oriented strategy (TOS)*

Variable	Mean if item deleted	Value if item deleted	Std dev if item deleted	Item total correlation	Alpha if item deleted
CISS 21	10.88	4.63	2.15	0.63	0.66
CISS 6	10.46	4.93	2.22	0.64	0.66
CISS 26	11.28	5.56	2.35	0.54	0.71
CISS 24	10.35	5.47	2.33	0.44	0.77

Mean=14.33, Standard deviation=2.92, Cronbach's alpha: .76, Standardised alpha: .76, Average inter-item correlation: .45

Table 3. *Test score reliability – CISS: Emotion-oriented strategy (EOS)*

Variable	Mean if item deleted	Value if item deleted	Std dev if item deleted	Item total correlation	Alpha if item deleted
CISS 13	11.67	4.81	2.19	0.55	0.59
CISS 19	11.28	5.44	2.33	0.58	0.60
CISS 14	11.82	4.63	2.15	0.61	0.55
CISS 38	12.14	5.43	2.33	0.28	0.78

Mean=15.64, Standard deviation=2.88, Cronbach's alpha: .70, Standardised alpha: .72 Average inter-item correlation: .41

Table 4. *Test score reliability – CISS: Avoidance-oriented strategy (AOS)*

Variable	Mean if item deleted	Value if item deleted	Std dev if item deleted	Item total correlation	Alpha if item deleted
CISS 44	11.20	9.36	3.05	0.38	0.43
CISS11	11.56	7.95	2.820756	0.51	0.33
CISS 40	11.20	9.27	3.044850	0.37	0.43
CISS 12	11.46	10.53	3.246194	0.17	0.56
CISS 31	11.23	11.91	3.451409	0.09	0.58

Mean=14.16, Standard deviation=3.72, Cronbach's alpha: .53, Standardised alpha: .52, Average inter-item correlation: .18

A total of 90 respondents participated in the study, including: 60 females, 24 males, and six people who did not specify their gender. The average age of the respondents was 34, with the oldest participant being 56 and the youngest being 11. The respondents defined their education as: higher (58 respondents), upper secondary (25), lower secondary (3), vocational (2), and primary (2). All respondents were residents of Poland.

ANALYSIS

The first question of interest to us concerned the level of stress experienced by people with ASDs during the Covid-19 pandemic. Our analysis revealed that the average level of stress perceived by the 90 respondents oscillated around 23 points and was therefore elevated (Table 5).

Table 5. *Stress as perceived by people with ASDs during the Covid-19 pandemic*

Variables	Valid	Mean	Minimum	Maximum	Std dev
pss1	90	2.44	0.00	4.00	1.23
pss2	90	2.57	0.00	4.00	1.19
pss3	90	3.00	1.00	4.00	1.03
pss4	90	1.56	0.00	4.00	1.04
pss5	90	2.06	0.00	4.00	1.00
pss6	90	2.34	0.00	4.00	1.27
pss7	90	1.82	0.00	4.00	1.01
pss8	90	2.68	0.00	4.00	1.03
pss9	90	2.41	0.00	4.00	1.29
pss10	90	2.27	0.00	4.00	1.25
Total pss	90	23.20	4.00	39.00	7.91

The levels of perceived stress were reported as low by 11 respondents (up to the sten score of 4), medium by 23 respondents (sten score: 5–7), and high by 56 respondents (sten score: 8–10). The results are presented in Table 6.

Table 6. *PSS-10: Sten score distribution*

Sten	Number	Cumulative	Percentage	Cumulative %	% total	Cumulative %
3	5	5	5.55	5.5	5.55	5.55
4	6	11	6.66	12.2	6.66	12.22
5	8	19	8.88	21.1	8.88	21.11
6	11	30	12.22	33.3	12.22	33.33
7	4	34	4.44	37.7	4.44	37.77
8	21	55	23.33	61.11	23.33	61.11
9	19	74	21.11	82.22	21.11	82.22
10	16	90	17.77	100.00	17.77	100.00
ND	0	90	0.00		0.00	100.00

When answering the questions regarding their perception of stress during the Covid-19 pandemic, some respondents also shared their subjective observations. One of them, a male aged 30, wrote: *I try not to lose faith that the pandemic will end sooner or later, but it is getting more and more difficult for me.* Another person, a female aged 28, described her feeling of stress as follows: *At the beginning it was difficult for me to get used to 'forced caging' and not being able to go to places I know and like (the cinema, restaurants, even the church, as all of them were closed). I counted days, as reported on TV, until everything would reopen. It got better with time when everything went back to normal. Before that I would hide and cry because I was afraid that all the people I like (including celebrities) would die and I would have no one to love. It is OK now, but I still find it difficult to do what I did before the pandemic. My online relationships died a natural death, and with time I came to the conclusion that no one was worthy of my feelings and tears. I am incapable of loving anyone right now. I have locked all my love in a little clay pot.*

Another female respondent, aged 44, used the following words to describe her condition: *I'm generally nervous about the situation with the labour market and the external situation in general. People are panicking too much, which doesn't make us feel good.*

Interestingly, one 34-year-old female noticed that the Covid-19 restrictions had a positive impact on her while also highlighting certain risks: *The pandemic forced others to move everything online, which I like very much. However, I'm terrified whenever I have to go out – to the shop or to the vet – because people won't wear masks, and if you tell them to put a mask on, they can be aggressive.*

Our second area of interest included coping strategies employed by people with ASDs during the Covid-19 pandemic. Three strategy types were studied: the task-oriented, emotion-oriented, and avoidance-oriented. The respondents were asked to complete the questionnaire and mark one of the possible responses (never, rarely, sometimes, often, very often), which were then assigned a score from 1 to 5. Our analysis shows that the emotion-oriented strategy prevailed among the vast majority of respondents (mean: 3.91), followed by the task-oriented strategy (3.58) and the avoidance-oriented strategy (2.83). The results are presented in Table 7.

Table 7. *Coping strategies employed by people with ASDs during the Covid-19 pandemic*

Variable	Valid	Mean	Minimum	Maximum	Std dev
TOS item	90	3.58	1.25	5.00	0.73
EOS item	90	3.91	2.25	5.00	0.72
AOS item	90	2.83	1.40	4.40	0.74

Using the Friedman test for the analysis of variance by ranks, Kendall's coefficient of concordance (Kendall's *W*) was calculated and differences were established in the frequency of use of coping strategies by the respondents. Once again, the most frequently applied was the emotion-oriented strategy followed by the task – and avoidance-oriented strategies (Chi square: 0.34). The results are presented in Table 8.

Table 8. *Frequency of use of coping strategies by people with ASDs during the pandemic*

Variable	Mean rank	Total ranks	Mean	Std dev
TOS item	2.127778	191.5000	3.583333	0.732473
EOS item	2.505556	225.5000	3.911111	0.721180
AOS item	1.366667	123.0000	2.833333	0.745473

Friedman ANOVA and Kendall's coefficient of concordance, Chi square, ANOVA (N=90, df=2) = 62.48, p = .00, coefficient of concordance = .34

Having completed the CISS questionnaire, the respondents also had the opportunity to share their subjective opinions about their coping strategies in the pandemic. Accordingly, one 26-year-old female wrote: *I can deal with stress quite well. I use it to learn, control myself, and draw conclusions. It is the panic of others that affects me because it is just as powerful as my peace.* A 29-year-old male described his strategy in these words: *I try to understand what has happened, take a direction and carry out tasks/overcome difficulties, according to the principle of 'one problem at a time'… which is not always possible.* Another female, 34, provided the following explanation regarding her mental state: *Crisis situations are my talent, but they make me emotionally drained. This is when my analytical mind takes over. As soon as the crisis is gone, I collapse like a hot air balloon emptied of air. In smaller crises, or rather problems, e.g. when I have a problem learning the programming, my procrastination kicks in: from insomnia at night to sleeping in, looking for other 'more important' responsibilities than cracking the code (I'm only beginning to recognise this mechanism). However, I totally, I mean totally, can't handle crisis situations that involve people other than my husband (social crises). I keep worrying that it is me who got something wrong, did something bad, to whom, etc.*

Another male, 30, highlighted the severity of the stress he has experienced due to Covid-19: *Since the pandemic I've been stressing out more than ever before. It has been one big rollercoaster for me. When I think to myself that it can't get any worse, it suddenly does.* A 42-year-old female shared the following thought: *I stress eat chocolate. My loved one rarely has time to help me with stress. When stressed, I try to set the most important tasks and goals for myself. I try to treat stressful situations as temporary and survive them.* When a stressful,

uncomfortable or difficult situation settles in for longer, I try to rearrange things so that it hurts me as little as possible. I run away from stress – I surf the web and visit intellectually relaxing websites. When possible, I go for a walk (I had more opportunities during the pandemic because I finally had two hours a day which I spent with the children walking in the fields. It was stressful for me to return to work because I lost this opportunity).

It can be seen that the respondents used different coping strategies. Given the dynamic socio-political situation in Poland, the wide range of unconstitutional regulations introduced during the pandemic, and the frequency of changes to the Covid-19 recommendations and restrictions, we were unable to determine to what extent the stress was the result of the pandemic itself or the resulting information chaos. People with ASDs typically need communication that is clear and well-structured; consequently, in volatile and dynamic situations they feel that they lose control and their stress levels are elevated.

Conclusions

The Covid-19 pandemic has undeniably caused a significant chaos on a global scale, leading to unexpected and unprecedented levels of stress. The pandemic and the resulting reorganisation of our life are two interconnected external factors that could have affected the perception of stress in many people. In people with ASDs, this stress could appear as a response to the dynamically changing situation and its requirements, especially the sudden redefinition of the rules of social functioning. The key findings of our study are as follows:

1. During the Covid-19 pandemic, the perceived stress in people with ASDs was elevated.
2. People with ASDs employed a variety of coping strategies to manage stressful situations (social, emotional and behavioural).
3. The emotion-oriented strategy was the most prevalent approach.
4. The avoidance-oriented strategy was the least frequently applied coping strategy within this population.

The prevalence of the emotion-oriented strategy of coping with stress means that in stressful situations during the pandemic those individuals with ASDs tended to focus on themselves and their own emotional experiences. The task-oriented strategy, which involves taking action, was used less frequently. It is interesting to note that, in terms of coping with stress, the study participants were not inclined to engage in alternative activities during the Covid-19 pandemic. The obtained results prompt the continuation of research in order to search for and develop a strategy for a healthier, more effective coping with stress by people with autism spectrum.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

COMPLIANCE WITH ETHICAL STANDARDS

Prior to its implementation, our project was approved by the Research Ethics Committee of the Nicolaus Copernicus University in Toruń. All procedures in the studies involving human participants were performed in accordance with the ethical standards of the institutional and/or national research committee, as well as the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

INFORMED CONSENT

Informed consent was obtained from all participants included in the study. The consent also included information about the publication of the obtained data.

AUTHORS' CONTRIBUTION

All authors contributed equally to the paper (25%).

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Endnotes

[I]The term 'autism spectrum disorders' is here defined similarly to the term 'autism spectrum' as used in: S. K. Kapp, (2018), Social support, well-being, and quality of life among individuals on the autism spectrum, Pediatrics, 141 (Supplement 4), and N. van Lang, A. Boomsma (2005), Structural equation analysis of a hypothesised symptom model in the autism spectrum, The Journal of Child Psychology and Psychiatry