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AUTONOMY AND COPING WITH STRESS IN PERSONS WITH ASD

AUTONOMIA I RADZENIE SOBIE ZE STRESEM OSÓB ZE SPEKTRUM AUTYZMU (ASD)

Streszczenie: Artykuł przedstawia analizę empiryczną wybranych zagadnień dotyczących autonomii osób z zaburzeniami ze spektrum autyzmu (ASD), uwzględniając psychospołeczne uwarunkowania jej rozwoju. Analiza ta stanowi próbę zidentyfikowania bezpośrednich przyczyn oraz specyficznych warunków niezbędnych do kształtowania się autonomii u osób z autyzmem, której przejawem jest zdolność do radzenia sobie ze stresem. Problematyka badawcza niniejszego studium obejmuje poziom autonomii osób z ASD, stopień ich funkcjonowania psychospołecznego w kontekście radzenia sobie ze stresem oraz ewentualne korelacje między tymi dwiema zmiennymi. W celu pozyskania danych badawczych zastosowano metodę sondażu diagnostycznego, wykorzystując następujące narzędzia: Indeks Funkcjonowania Autonomicznego (IAF), Kwestionariusz Zachowania i Osobowości dla dorosłych (AQ), Inwentarz do Pomiaru Radzenia Sobie ze Stresem C.S. Carver, w adaptacji Zygfryda Juczyńskiego i Niny Ogińskiej-Bulik (Mini-COPE) oraz autorski Kwestionariusz Wywiadu, stworzony na potrzeby tego badania, uwzględniający wiek, płeć, stan cywilny, miejsce zamieszkania, wykształcenie, dochody, wcześniejsze terapie oraz bieżący stan zdrowia badanych.

Słowa kluczowe: Autonomia, stres, zaburzenia ze spektrum autyzmu (ang. autism spectrum disorder, ASD)

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Abstract: This article presents empirical analysis of selected issues related to autonomy of persons with ASD, along with the psychosocial conditions of its development. This analysis is an attempt to determine direct causes and particular types of conditions necessary for the development of autonomy in people with autism, manifested in the capacity of coping with stress. The research problems in this study concern the level of autonomy in people with ASD, the level of their psychosocial functioning in the dimension of coping with stress, and the potential correlations between the two parameters. A diagnostic survey method was used to obtain the research material, which employed the following research tools: Index of Autonomous Functioning, The Autism-Spectrum Quotient, Coping Inventory, the author's own Interview Questionnaire, developed for the purposes of our study regarding age, gender, marital status, residence, education, income, past therapy and current health conditions.

Keywords: Autonomy, stress, ASD

Introduction

Since the time of Immanuel Kant, autonomy seems to be understood as synonymous with human dignity. It represents an intrinsic value of any system that claims to respect human dignity (May 2011). According to the founder of critical philosophy, autonomy of the will is this property of the will that makes it a law to itself (Kant, 1998). In his understanding, the key role of the autonomy of the will is to allow one's own life choices or at least to ensure the right to make them. People should act in such a way that their rules of conduct could be formulated as a universal ethical norm. In other words, ethical systems do not have to be built on any particular order of being (orthonomy), or any external authority, but can be directed by the self-determined practical reason (Kamiński, 1989).

Autonomy of people with ASD – research review

Research on autonomy of people on the autism spectrum has rather been scarce so far (Prokopiak, 2023). Few studies on autonomy, self-determination of persons with ASD indicate that they are likely to achieve independence only if they are endowed with adequate support and openness of the environment. Chronic anxiety is an inseparable companion of their lives, which are further complicated by the difficulties and limitations resulting from how autistic individuals function socially (Szmania, 2016:331-349). Research on ASD has mainly focused on behaviours and abilities, and on teaching skills to conform to social norms. It is often recognised that people on the autism spectrum lack abilities of self-reflection, which makes it hard for them to be "authors of their own lives." Elizabeth Späth and Karin Jongsma point out that many people with ASD are aware of their own needs. Nonetheless, the authors note that their autonomy can be thwarted due to unwarranted interferences and paternalistic actions. This happens when their genuine goals, interests or talents are deemed impractical or worthless. Hence, autistic individuals can

experience injustice on various levels (Späth, Jongsma, 2020:73-20; Leadbitter et al., 2021)). Szafrańska points to a serious problem of adults with ASD having no formal, meaningful occupation and being left under formal parental care. Lack of specialized support or its inadequate forms (Leadbitter et al., 2021; Lei & Russell, 2021) often worsen their functioning, including inability to develop their experience of personal independence, especially when they suffer from health complications (Seltzer et al., 2010; Szafrańska, 2018). These observations apply equally to people diagnosed with Asperger Syndrome – in accord with the ICD-10 classification (Szafrańska, 2018). Research shows that the higher the self-determination of individuals with ASD and the higher the level of their adaptive skills, the higher the level of experienced social support and coping with stress (Oswald et al., 2018). Undeniably, achieving a satisfactory quality of life should be the main goal of clinical interventions targeting people with ASD. Thus, life quality enhancement needs to be a key element in the design of developmental therapies. Nevertheless, knowledge about both objective and subjective conditions that are predictors of higher life satisfaction in individuals with autism is still largely underdeveloped.

Adolescents, in particular, score very low on self-determination scales, compared to scores in other areas of quality of life (Lei & Russell, 2021). These results unveil a necessity to adapt the therapeutic methodologies to improve this subjective assessment (Cuesta-Gomez et al., 2016; Henderson, 2022)). Individuals with ASD establish self-advocacy groups, by which they seek space for autonomy (Błeszyński, 2019; Kanar, 2019; Stefańska-Klar, 2017a).

Research objectives

The empirical research undertaken in this article deals with autonomy of people with ASD and the psychosocial conditions underlying its development. The research is intended to identify direct causes and particular conditions necessary for the development of autonomy in persons with ASD and its relationship with coping with stress.

The research is theoretically anchored in the three-component model of autonomy, which sees autonomy is an internal attribute of a person. According to this theory, human autonomy manifests itself through authorship (the person feels to be the author of their own behaviour), interest-taking (reflection on internal and external events) and the absence of external pressure or control. Autonomy develops throughout lifetime, enabling people to make choices, taking into account their own and others' needs, to regulate their own behaviour and to build relationships based on reciprocity. Individuals may experience differences in autonomy levels, which may result from changes in levels of behavioural regulation. Thus, human behaviour can vary from being highly autonomous, regulated by the agentive individual, to being mainly subjected to external influences and motivators (Ryan, Deci, 2000; Ryan, Deci, 2006).

The theoretical investigations and the questions that the author of this article posed to herself led her to formulate the following research problems:

1. What is the level of autonomy of people with ASD?
2. What is the level of psychosocial functioning in the dimension of coping with stress in people with ASD?
3. What relationships obtain between the level of autonomy and the level of psychosocial functioning in the dimension of coping with stress in people with ASD?

The research project was approved by the Research Ethics Committee of the Faculty of Pedagogy and Psychology of the Maria Curie-Skłodowska University in Lublin. Participation in the study was voluntary and anonymous. The subjects had the right to withdraw from the study at any time without giving reasons. Each questionnaire contained a written instruction. Throughout the research procedure it was also possible to obtain procedural guidelines from therapists trained in the field. The respondents were each time informed about the purpose of the research.

Research method

A diagnostic survey method was used to obtain the research material. The following research tools were employed: Index of Autonomous Functioning (IAF) (Weinstein, Przybylski, Ryan, 2012), The Autism-Spectrum Quotient – Adult Behaviour and Personality Questionnaire (AQ), Mini-COPE Coping Inventory and the author's own Interview Questionnaire, developed for the purposes of this study regarding age, gender, marital status, residence, education, income, past therapy and current health conditions.

Respondents: main characteristics

Own research was conducted in a group of 69 adults with ASD. The mean respondent age (N = 69) was 29.74 (SD = 7.88). The mean age of those respondents with ASD who answered all questions (N = 56) was 30.18 (SD = 8.11).

The respondent group (N = 69) were 32 females and 37 males with ASD. Most of them were single (69.6%), while over 20% of respondents were married. Nearly 35% of respondents lived independent lives, while over 46% still lived with their parents. Among those who completed all questionnaires there were 28 women and 28 men with ASD. Over 73% of these latter respondents were single, while nearly 18% were married. With a mean respondent age at around 30, a relatively large number of the respondents continued to live with their parents. Flats inhabited by the respondents mostly consisted of 2-3 rooms (over 63%). 57% of the respondents lived in the company of other people (one/two), while ten respondents (over 14%) lived alone. More than 69% of those who participated in the survey lived in a large city (with population over 100,000).

Over 39% of the respondents had secondary education, and over 52% had a university degree. 72% completed their education in public schools, 14.5% participated in individual teaching at least for some time (M = 3.40 years, SD = 3.27) [one year (2 respondents), 2 years (4 respondents), 3-12 (4 respondents)].

All the respondents who registered in the application declared at the outset that they had been diagnosed with ASD. In Poland, such diagnoses are issued by qualified psychiatrists. The research was anonymous, and therefore it was impossible to verify whether the ASD testing tool was e.g. ADOS-2, which is a current standard in diagnosing ASD in therapy and research teams with whom the author of this study cooperates.

In the context of the above, the author decided to verify the reported diagnoses of ASD with The Autism-Spectrum Quotient – Behaviour and Personality Questionnaire for Adults (AQ) in its Polish adaption, which allowed comparing the results of respondents in this study with the results of a respondent group researched for AQ national adaptation. In many countries (Scotland, Japan, the Netherlands, USA, Canada, Italy, China) AQ is used as an autism spectrum screening test and for research purposes.

The overall result shows statistically significant differences in the responses by males and females in the study group ($p < 0.01$). Female participants of the study declared higher intensity of autistic behaviours and traits in comparison to male participants. The study group in this research declared stronger autistic behaviours and traits, verified by the AQ Questionnaire, than the average of persons participating in research for developing the Polish adaptation of AQ. It should be remarked that this state of affairs confirms the declared diagnosis of autism spectrum made by participants in this study.

Autonomy level and severity of autism spectrum behaviours – results and analysis

Consequently, differences in responses among individuals with ASD to individual items in IAF were examined. For this purpose, cluster analysis was performed, based on the results in IAF subscales. Three clusters were distinguished this way. Detailed results are presented in Table 1.

Individuals belonging to the clusters did not differ significantly ($F(2.53) = 2.770$; $p = 0.72$) in terms of their level of Authorship/congruence. Differences occurred in Susceptibility to control ($F(2.53) = 58.227$; $p < 0.001$), where the respondents in Cluster 2 exhibited significantly lower scores than the others, and in Interest-taking ($F(2.53) = 45.350$; $p < 0.001$), the respondents in Cluster 3 exhibited significantly lower scores here than the others (see Figure 1).

Analysing the data, one can identify three observable levels of autonomy. The respondents with a high level of autonomy were characterised by absence of extrinsic or intrinsic pressure as a behavioural motivator. At the same time, they revealed a spontaneous tendency to reflect openly on internal and external events in their lives. They were characterised by insight into themselves and their

Table 1. Cluster analysis of IAF subscales (N =56)

	Authorship/ congruence		Susceptibility to control		Interest-taking	
	M	*SD*	*M*	*SD*	*M*	*SD*
Cluster 1 (*N* = 18)	3.93	0.540	3.30	0.491	4.40	0.504
Cluster 2 (*N* = 24)	4.09	0.659	1.97	0.356	4.07	0.624
Cluster 3 (*N* = 14)	3.61	0.579	3.31	0.559	2.61	0.486

M - mean; *SD* - standard deviation.

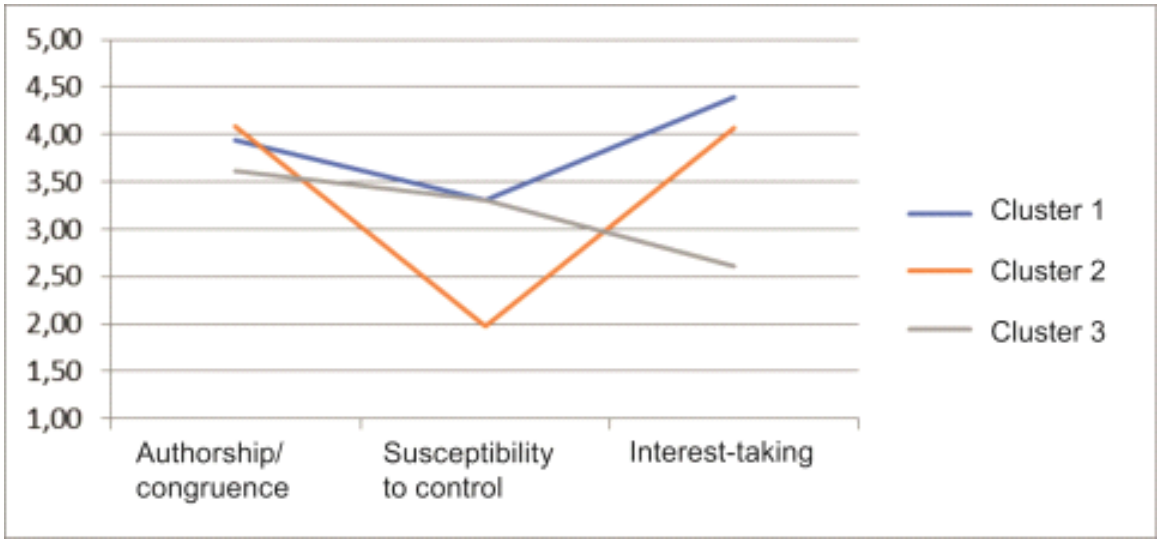

Figure 1. Cluster analysis of IAF subscales (N =56)

experiences. This was the largest group of respondents. The respondents on the autism spectrum with a medium level of autonomy sought knowledge about themselves, but at the same time experienced a sense of pressure and control. Their level of autonomy was significantly lower when compared to the first group. The respondents with high levels of control had the lowest level of autonomy, and foresaw reduced opportunities for making independent choices and taking initiative, which thwarted their engagement in learning about themselves. All the respondents displayed a similar level of Authorship, and their actions were dependent on fixed values, needs and interests.

The mean scores for autonomy obtained from the researched females and males with ASD did not reveal statistically significant differences between the gender groups. The mean scores for autonomy obtained from the respondents with ASD

and from their closed ones did not reveal statistically significant differences in their respective scores, either.

Strategies for coping with stress

The respondents with ASD obtained the highest mean scores for strategies such as Active coping, Planning and Seeking instrumental support. This is indicative of their active coping with stress. The lowest mean scores were obtained for Sense of humour, Turn to religion and Use of psychoactive substances, indicating the least frequently used coping strategies. Statistically significant differences in coping with stress in groups of females and males with ASD are found for the strategies Turn to religion ($p < 0.5$), Denial, Use of psychoactive substances ($p < 0.01$) and Withdrawal ($p < 0.1$). Males with ASD significantly more often than females used the strategies Turn to religion, Denial and Withdrawal (the former strategy shows differences in tendency), whereas females with ASD significantly more often used psychoactive substances to cope with stress.

Coping strategies and autonomy levels

In order to examine the relationship between the two variables, i.e., coping with stress of individuals with ASD and the level of their autonomy in the subscales of Authorship/congruence, Susceptibility to control, Interest-taking and Autonomy (total score), a correlation analysis was performed.

The respondents in Cluster 2, who displayed the highest level of autonomy assessed with IAF most frequently used coping strategies such as: Active coping, Planning, Seeking emotional support, Seeking instrumental support, Dealing with something else, Outburst and Blaming oneself. At the same time, they used the strategy Turn to religion significantly more often than the respondents in Cluster 3 ($p < 0.05$); they employed the strategy of Dealing with something else significantly more often than the respondents in Cluster 1 ($p < 0.05$) and Cluster 3 ($p < 0.1$); they used the strategy of Denial significantly more often than the respondents in Cluster 1 ($p < 0.001$) and Cluster 3 ($p < 0.01$); they relied on the strategy of Outburst significantly more often than the respondents in Cluster 1 ($p < 0.001$) and in Cluster 3 ($p < 0.05$); and they applied the strategy of Blaming oneself significantly more often than the respondents in Cluster 1 ($p < 0.05$) and in Cluster 3 ($p < 0.1$). To sum up, it should be noted that the respondents in Cluster 2 used a variety of coping strategies significantly more often than the other respondents with ASD.

The respondents in Cluster 1, displaying a medium level of autonomy assessed with IAF, most frequently used the following coping strategies: Active coping (significantly more often than the respondents in Cluster 3, $p < 0.1$), Planning (significantly more often than the other respondents with ASD, $p < 0.05$) and Acceptance. At the same time – as discussed above – they used stress coping

strategies such as Dealing with something else, Denial, Outburst and Blaming oneself significantly less often than the respondents in Cluster 2, who exhibited the highest level of autonomy.

Respondents in Cluster 3, with the lowest level of autonomy assessed by IAF, most often used the strategies of Active coping (significantly less often than the respondents in Cluster 1, $p < 0.1$) and Planning (significantly less often than the respondents in Cluster 1, $p < 0.05$). At the same time, they used strategies such as Dealing with something else, Denial, Outburst and Blaming oneself significantly less often compared to the respondents in Cluster 2. The respondents in Cluster 3 employed a smaller repertoire of coping strategies, and they did it less frequently.

Analysing the relationship between the stress coping variables of the respondents with ASD and the level of autonomy in the subscales of Authorship/congruence, Susceptibility to control, Interest-taking and Autonomy, a total score was reached, showing the correlations between all the subscales of IAF, the total score for Autonomy and the coping strategies. The more frequent use of the strategies of Denial, Blaming oneself, Dealing with something else, Outburst, Seeking emotional support, Seeking instrumental support and Turn to religion, correlated with the lower value for Susceptibility to control. The level of Autonomy on the Interest-taking subscale is higher with the more frequent use of strategies such as Active coping, Planning, Positive reconsidered and Acceptance. The level of Autonomy in the Authorship/congruence subscale is higher with the less frequent use of the strategy Blaming oneself. The level of Autonomy in the total score indicates a relationship with the strategies of Acceptance, Dealing with something else, Outburst, Turn to religion, Seeking instrumental support and Denial. The higher the level of Autonomy, the more frequent the use of the mentioned strategies.

Regression analysis revealed that the level of Autonomy on the IAF Authorship/congruence subscale increases with a decrease in the Blaming oneself strategy and with an increase in the Outburst strategy. The level of autonomy on the Susceptibility to control subscale increases with a decrease in the use of the strategies of Denial, Blaming oneself, and Dealing with something else. It is worth noting that these three variables explain 51% of the variation in the Susceptibility to control subscale scores. The level of Autonomy in the total score increases with an increase in the use of strategies of Dealing with something else and Active coping.

The respondents in the Cluster with the highest Autonomy level were significantly more likely to use coping strategies such as: Turn to religion, Dealing with something else, Denial, Outburst and Blaming oneself. The respondents in the Cluster with the middle level of Autonomy were significantly more likely to use Active coping and Planning strategies. The respondents in the Cluster with the lowest level of Autonomy significantly less frequently resorted to the strategies of Planning, Turn to religion, Denial or Outburst.

In terms of Authorship/congruence and Interest-taking in internal and external events, the respondents with ASD differed in terms of their educational background.

The respondents with the lowest level of Autonomy were significantly more likely to have a secondary education, while people with a medium level of Autonomy were significantly more likely to have a university degree.

The research helped find out that the respondents with ASD tend to cope actively with stress using strategies such as Active coping, Planning and Seeking instrumental support. They are least likely to use strategies such as Sense of humour, Turn to religion or Use of psychoactive substances. Females with ASD employ the strategies of Turn to religion and Denial significantly less frequently than males, but when coping with stress, they use psychoactive substances significantly more often. When analysing coping with stress in relation to the intensity of declared behaviours and autistic traits, it was found out that this growing intensity is accompanied with a growing use of psychoactive substances, while the use of strategies such as Positive reconsidered, Seeking emotional support, Seeking instrumental support, Denial and Outburst decreases.

Summary and conclusions

Coping with stress is very important in the lives of the respondents with ASD. These findings support previous research addressing the effects of experienced stress. These in particular include suicidal thoughts and behaviours (Cassidy, 2018:56-70), depression and anxiety (Kerns et al., 2016:329-340; Ghaziuddin, 2005; Lever, Geurts, 2016) or more frequent psychological trauma (Haruvi-Lamdan et al., 2019:22-27).

It is noteworthy that the conducted research confirms a claim that autonomy develops in relationship with others (Podgórska-Jachnik, 2018). This is also confirmed by the research conducted by the authors of IAF, who proved that people scoring high on the scale sit closer to each other, experience greater closeness with their partners, are more prosocial, report more autonomy and attribute greater contribution to their partners when dealing with team tasks (Weinstein et al., 2012). Our research shows that the level of autonomy of the respondents with ASD, despite communication and social difficulties they experience, shows dependence on parallel principles. Social skills as a predictor of a growing autonomy strongly underline the importance of relationships, human connections and encounters for people with ASD.

The presented analyses enable a conclusion that people on the autism spectrum usually cope actively with stress, make plans and seek instrumental support. However, it is noticeable that a growing severity of autistic traits is accompanied with a relatively infrequent use of strategies for getting help from people or institutions. Also noticeable is that the higher the level of autonomy of individuals with ASD, the greater the repertoire of their coping strategies. Stress coping strategies are a predictor of the autonomy level.

Final remarks

The issue of autonomy of persons with ASD and their strategies of coping with stress addressed in the article is infrequently discussed in the literature. The analyses carried out here help prove that the relational or habitual sociability of persons with ASD is particularly important for empowering their autonomy. The individuals with ASD who participated in the study showed increased autistic behaviours and traits, but it is the females who displayed their greater severity. Previous research on ASD that targeted boys and males revealed that procedures for diagnosing ASD may overlook females with less severe autistic traits. Women on the autism spectrum who are able to camouflage the difficulties they experience may go unnoticed, even when they need and ask for help.

The presented research has been inspired by the author's long clinical work with children and adolescents with ASD. The author believes that the research results obtained here should translate into improved practice. Individuals taking part in the research participated in various types of therapies. Research has shown that these had no effect on the level of autonomy. It is worth noting, however, that people who are now adults with ASD had limited access to early diagnosis and therapy in childhood or adolescence. Social development takes place to the greatest extent in the first five years of life (Eliot, 2003:397-447). Responsive developmental support models for individuals with ASD, such as the ESDM model, have a scientifically proven impact on the social development of young children with ASD. As shown by the research results discussed here, they are essential for the development of autonomy.

However, ESDM is not the only model focusing on the child's social initiative and engagement. Similar approaches include DIR (Developmental, Individual difference, Relationship-based model) and Floortime, RDI (Relationship Developmental Intervention) (Gutstein, 2012) and SCERTS (Social Communication, Emotional Regulation, Transactional Support) (Siemiątkowska-Sujka, 2019:247-254).

Obviously enough, childhood is not the only time for building interactions. For adolescents on the autism spectrum, the so-called two-hit model of autism (e.g., Knudson, two-hit model) cannot be ignored (Picci, Scherf, 2015:349-371). It is known that adolescence for individuals on the autism spectrum is associated with feelings of loneliness. Peer volunteering may be of much help in this respect. The idea of peer volunteering is a hundred years old. It was invented in the United States as a method of preventing social exclusion of children from poor, incomplete or dysfunctional families (Płatos, Wojaczek, Zawistny, 2015:109-132). The core part of the project consists of regular meetings of people matched in pairs, held for at least 10 months. The pairs are free to decide on where and when they meet, and what they do. Peer volunteering successfully addresses the developmental and socialisation needs of people with ASD (Prokopiak, Siedlecka, 2020).

For past decades, behavioural methods prevailed in work with people on the autism spectrum, focused on teaching skills through rewards and punishments. These methods are still quite popular and well-grounded in scientific research. The research reported in this article pinpoints potential benefits of a modified therapeutic trajectory, based on seeking the child's initiative, interaction and relationship-building skills. Efforts are needed to promote a model of working with people on the autism spectrum that supports their spontaneity, initiative to approach and interact with others, and their ability to make contact.

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