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Functional Status of People with Autism Spectrum Disorder

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Abstract

Introduction: Austism spectrum disorder (ASD) heterogeneity requires these individuals to have functional heterogeneity. Compared to the general population, numerous studies have shown that people with ASD have a lower functional status in performing daily activities and most of them require assistive technology.

Methodology: We performed a comparative analysis of the collected data from 72 subjects with ASD and 75 neurotypical controls aged 3-24 years using the Rochester Health Status Survey IV (RHSS-IV) by conducting a structured individual interview to provide a comparative item for functional status and use of assistive technology in Macedonia.

Results: Children with ASD have a lower functional status in performing daily activities required for eating, dressing, showering and using the toilet ($p = 0.000$), as well as acquiring academic knowledge and skills ($p = 0.000$). Children with ASD use more assistive technology ($p = 0.032$) as opposed to neurotypical children and the most commonly used are alternative and aumentative devices ($p = 0.002$).

Conclusions: Most children with ASD have a lower functional status in performing the daily activities required for eating, dressing, showering and using the toilet, as well as acquiring academic knowledge and skills unlike their peers with neurotypical development. Also, children with ASD use alternative and augmentative devices, which is not the case with children in the control group. Accurate quantification is crucial for the progress and positive outcome of children with ASD.

Keywords: functional status, assistive technology, autistism spectrum disorder

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1. Introduction

Functional status is the ability of an individual to perform normal daily activities necessary to meet basic needs, fulfill normal roles, and maintain health and well-being (Leidy, 1994; Wilson & Cleary, 1995). These include activities and functional abilities to perform daily activities such as eating, dressing, going to the toilet, school activities, etc. Given the variability seen in the autism spectrum disorder (ASD), accurate quantification of functioning is vital to studying their outcome and quality of life. Numerous studies provide information on the impact of ASD on functioning in daily life. People with ASD often struggle to learn these and other functional skills (The Children's Hospital of Philadelphia, 2020).

Autism Spectrum Disorder (ASD) is a group of complex and heterogeneous developmental conditions characterised by decreased social interaction and communication, as well as a limited range of interests and / or stereotypical behavior (APA, 2013). New prevalence estimates made in the United States are 1 in 59 children with ASD (Baio J et. al., 2014). In addition to basic features, ASD is associated with changes in cognitive and emotional functioning (Levy, Mandell, & Schultz, 2009), social functioning, difficulty forming and maintaining relationships (Orsmond, Krauss, & Seltzer, 2004), and poor adaptive skills (Kanne et al., 2011), as well as lower rates of health-related quality of life (Kuhlthau et al., 2010; Travernor, Barron, Rodgers, & McConachie, 2012).

Studies also reveal significant interpersonal differences in outcomes and levels of functioning in people with ASD that result from interdependence of several factors. Intelligence and the level of language development is an important factor that affects the degree of functional status in ASD. The severity of symptomatology in ASD leads to impaired social, occupational, and other important areas of ongoing functioning (APA, 2013 & Baio J et. al., 2014). Another factor that affects functional status is health status. Compared to the general population, persons with ASD have changes in health conditions. According to our recent research we found predominance of oral ulcers, epilepsy, angina, sinusitis, constipation, inflammation of the intestines, permeable intestines, the presence of fungus Candida albicans, sleep problems, tics, eczema and allergic skin rash (Koceski and Trajkovski, 2021). People with more severe health conditions will have a lower level of functioning (Milosavljevic, 2015). These include psychiatric disorders that alter functional status (Mattila et al., 2010), with changes in psychological functioning including attention, executive functions, academic functioning, memory, emotions, and sensory information processing (Trajkovski, 2020). People with depression who have preserved intellectual abilities show reduced levels of functioning and regression in development (Magnuson & Constantino, 2011). Another large-scale study shows that children with epilepsy and ASD have shown significantly higher levels of cognitive impairment that affect their daily functioning. This includes reduced socialisation, communication, and motivation compared to people with ASD without epilepsy (Viscidi, 2014). Another important factor is the environment, ie the access to intervention programmes and the availability of support services that represent the largest part of the variability (Brundson & Happé, 2014; Levy & Perry, 2011). Most people with ASD and similar conditions live in low and middle-income countries or other low-resource environments, where functional implications may be significantly affected by available skills, resources, environmental support systems, and the presence of stigma (De Vries, 2016). There is also evidence that ASD is associated with certain gender differences (Bölte, Dukretis, Poustka & Holtmann, 2011; Halladay et al., 2015; Holtmann, Bölte, & Poustka, 2007) and strengths (Happé & Frith, 2009; Mottron, Dawson & Soulières, 2009) such as visual spatial, analytical, or savant skills that can positively affect an individual's level of functioning and quality of life to increase the individual's ability to achieve greater independence.

The International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) and the 5th Edition Diagnostic and Statistical Manual of Mental Disorders (DSM-5) provide accurate descriptions of diseases and conditions, but they remain limited in scope their ability to define and quantify functional abilities and disabilities in people with diagnosed disorders. Therefore, the International Classification of Functioning, Disability and Health (ICF) was developed by the World Health Organization (WHO) as a global and transdisciplinary handbook with the main aim of creating a "common language"

to enable the assessment of individual functioning using bio-psycho-social framework (De Vries & Bölte, 2016).

People with ASD often have difficulty performing activities on a daily basis, even with the help of another person. Activities in everyday life include personal needs such as mobility, eating, bathing, dressing and grooming and others. Due to the limited range of functionality in some people with ASD requires these people to use assistive technology (aids) most applicable in early childhood. Assistive technology means any product, part, equipment or system, whether used in its original form, modified or adapted, which is used to enhance, maintain or enhance functional capabilities. Assistive technology, ie aids, means movement aids, primarily wheelchairs, crutches, computers, custom keyboards, screens, mice, various programmes, books for the visually impaired, etc. It is important to emphasise, however, that any object that surrounds us can be used as an aid if its original or modified purpose allows the person who needs it to function better. As a consequence of assistive technology, people with disabilities have the opportunity for easier daily living, increased socialisation in society and a greater chance of reducing institutional costs without significantly increasing personal costs (Parant, Schiano-Lomoriello & Marchan, 2017; Ripat & Woodgate, 2012). However, despite the positive results from the use of assistive technology, many studies show relatively high rates of abandonment or non-use (25–33%) (Dijcks et al., 2006; Lauer, Longenecker Rust, & Smith, 2006; Federici & Borsci, 2011).

2. Material and methods

This study includes a total of 147 respondents living in Macedonia, of which 72 respondents with diagnosed ASD and 75 respodents with neurotipical development. The ages of the respondents are between 3 and 24 years. The research was conducted in the period from January to July 2019 in Macedonian language in following towns: Skopje, Bitola, Prilep, Veles, Tetovo, Ohrid, Struga, Stip, Kicevo, Kavadarci and the village of Krivogashtani.

We collected cross-sectional data using the Rochester Health Status Survey IV (RHSS-IV). RHSS-IV is a validated survey on the health and functional status of people with autism spectrum disorder (Fortuna et al., 2016) and intellectual or developmental disabilities (Davidson et al., 2008). The survey instrument has five sections: (1) demographics, (2) general health status health, (3) medical conditions, (4) functional status, and (5) health services utilisation. We used only the parts of demographics and functional status. Participants in the research are parents / guardians of children with ASD. The time required to collect data for one respondent is on average 5 minutes, and somewhere more. Functional ability was based on subjects' abilities to perform their activities of daily living (ADL). Each ADL was recorded as either: (1) independent, (2) requiring supervision or verbal prompt, (3) requiring physical assistance, or (4) totally dependent. We also examined the use of assistive technology in both groups. Because this study includes respondents from the pediatric population, there are activities that children with neurotypical development according to their calendar age could complete completely on their own, need supervision or verbal guidance, or should be verbally supported in how to perform the skill.

The contacts were provided through the Macedonian Scientific Association for Autism, through direct contact with the institutions for access to the target groups and through indirect telephone conversation with the respondent, ie parent, guardian or special educator and rehabilitator. The institutions in which the research was conducted are the following: special schools "Idnina" and "Zlatan Sremac" in Skopje, Daily Center for Autism in Skopje, non-governmental organisation "Open the windows" in Skopje, Center for Psycho-Physical Health, "Gaspar" in Skopje, Institute for Rehabilitation of Children with Impaired Hearing and Speech and Other Developmental Problems "Kocho Racin" in Bitola, PHI "Institute for Rehabilitation of Hearing, Speech and Voice" in Bitola, kindergarten "Our Future" in Prilep and in several primary schools within Bitola and Prilep. In other cities the data was taken by telephone. The respondents had a diagnosis meeting the DSM-5 criteria in the appropriate centers and institutions in Macedonia.

The data from this research were graphically processed and tabulated in the statistical software SSPS for Windows v.26.0. For comparison between the two groups, the Chi square-independence test was used. Therefore, the differences in the examined variables are analysed here, i.e., the results of the assessment of self-care skills on samples of persons

with ASD and a sample with neurotypical development. Statistical significance was determined at the level of $p<0.05$.

3. Results

The results of a total of 147 respondents were analysed. Table 1 shows their demographic characteristics. The sample had more male (79%) than female respondents (21%), which is consistent with male dominance in ASD ($p = 0.00$). There was no significant difference in gender between the two groups ($p = 0.09$). There was no significant difference in terms of age between the two groups of respondents ($p = 0.801$), which will not affect changes in functional status. The mean age of subjects in the ASD sample was 10.53 years and in the control group it was 10.37 years. Also, there is no significant difference in terms of height ($p = 0.711$) and weight ($p = 0.209$) between the two groups of respondents.

Table 1
Demographic data

	ASD				Control group				
	Min	Max	M	σ	Min	Max	M	σ	p value
Age	3	24	10.53	4.07	3	20	10.37	3.68	p = 0.801
Height	76	180	142.60	26.06	98	181	144.08	22.23	p = 0.711
Weight	15	95	46.26	20.15	14	85	42.47	17.21	p = 0.208
Volume of half	23	128	63.46	20.13	24	98	63.60	15.42	p = 0.964

Table 2 presents the daily activities and functional abilities: eating, dressing, showering and using the toilet with varying degrees of independence. In all these activities there is a difference in functional status between the two examined others. People with neurotypical development (control group) have a better functional status $p = 0.000$ ($p <0.05$) compared to people with ASD.

People with ASD have the greatest independence in eating (61.1%) and using the toilet (52.8%), however, people with neurotypical development of identical calendar age are completely independent in these activities.

In terms of eating, people with ASD need physical assistance (22.2%) or complete dependence on physical assistance from another person with self-care skills (6.9%) unlike children from the control group where they do not need that assistance. In the control group 92% of them dress independently, unlike the people with ASD where only 38.9% get dressed independently, but most of them need physical assistance (33.3%), verbal guidance (19.4 %) and a smaller number are completely dependent on another person when dressing (8.3%), which is not the case with the control group. Most children in the control group, 90.7%, are completely independent when showering, unlike 23.6% of people with ASD and they need supervision while taking a shower (18.1%), physical assistance (38.9%) or complete dependence on physical assistance from another person in self-care skills (19.4%). Half of the respondents with ASD use the toilet independently (52.8%), while 96% of the control group are completely independent. Unlike people with neurotypical development, people with ASD need physical assistance (20.8%) in the functional ability to use the toilet, need supervision or an verbal guidance (13.9%) and some of them (12.5%) use nappies or are completely dependent on others.

Table 2
Functional status of children with ASD

Activities in everyday life	ASD f(%)	Control group f(%)
Eating		
Independent	44 (61.1)	74 (98.7)
Supervision or oral prompting	7 (9.7)	1 (1.3)
Need physical help	16 (22.2)	/
Completely dependent on another person	5 (6.9)	/
Dressing		
Independent	28 (38.9)	69 (92)
Supervision or oral prompting	14 (19.4)	4 (5.3)
Need physical help	24 (33.3)	2 (2.7)
Completely dependent on another person	6 (8.3)	/
Showering		
Independent	17 (23.6)	68 (90.7)
Supervision or oral prompting	13 (18.1)	1 (1.3)
Need physical help	28 (38.9)	5 (6.7)
Completely dependent on another person	14 (19.4)	1 (1.3)
Toilet use		
Independent	38 (52.8)	72 (96)
Supervision or oral prompting	10 (13.9)	/
Need physical help	15 (20.8)	2 (2.7)
Completely dependent on another person	9 (12.5)	1 (1.3)
	p = 0.000	

In addition to the above problems, in Table 3, children with ASD have problems in learning, i.e. with the functional abilities that are needed to acquire academic knowledge and skills. There are differences in the functional abilities required to acquire academic knowledge and skills between the two groups, i.e. people with ASD had less functional abilities needed to acquire academic knowledge and skills compared to children with neurotypical development with $p = 0.000$ ($p < 0.05$). In fact, 29 participants (40.3%) with ASD had problems with academic knowledge and skills, and only 4 (5.3%) of the control group.

Table 3
Problems in academic knowledge and skills

			ASD	Control group	Total
	no	Count (Expected Count)	43 (55.8)	71 (58.2)	114
	yes	Count (Expected Count)	29 (16.2)	4 (16.8)	33
Total		Count (Expected Count)	72	75	147
				p = 0.000	

For some with ASD, using assistive technology in their daily routines and activities is important to them. In relation to Table 4, the subjects with ASD use more assistive technology than the subjects with

neurotypical development with p = 0.032 (p<0.05). Therefore, the use of assistive technology depends on whether the respondent has ASD. Sixteen of the participants (22.2%) with ASD use assistive technology, and 7 (9.3%) of the control group. The rest, with a higher frequency than the total number of respondents, use assistive technology, namely 56 respondents (77.8%) with ASD and 68 (90.7%) from the control group.

Table 4
Using assistive technology

		ASD	Control group
	no	f(%) 16 (22.2)	7 (9.3)
	yes	f(%) 56 (77.8)	68 (90.7)
Total		f(%) 72 (100)	75 (100)
		p = 0.032	

Assistive technology for upper and lower limbs, hearing aids, lenses, walkers, wheelchairs, customised equipment and mechanical lifts are not used by any of the respondents. Table 5 presents the types of assistive technology. Alternative and augmentative devices are not used at all by the respondents from the neurotypical group, and from the group with ASD they are used by 12.5% (p = 0.002). For corrective glasses there is no difference between the groups: 9.7% (7 participants) of the respondents with ASD and 7 (9.3%) from the neurotypical group. Two participants with ASD (2.7%) use a corset to support a crooked spine.

Table 5
Types of assistive technology

			ASD	Control group
Alternative and augmentative aids	no	f(%)	63 (87.5)	/
	yes	f(%)	9 (12.5)	/
			p = 0,002	
Corrective glasses	no	f(%)	65 (90.3)	68 (90.7)
	yes	f(%)	7 (9.7)	7 (9.3)
Corset to support a crooked spine	no	f(%)	70 (97.2)	/
	yes	f(%)	2 (2.8)	/

4. Discussion

This study examined the functional status and use of assistive technology from participants aged 3-24 years in people with ASD compared with neurotypes (control group). In this study, the analysis of the results of the functional status i.e. activities and functional abilities: eating, dressing, showering and using the toilet depends on whether the child has ASD, i.e. people with ASD have a lower functional status in performing daily activities compared to the control group (p = 0.000). According to Bal et al. (2015) ASD respondents aged 2 to 21 years showed a slower development of daily life skills than the general population, which is likely to reflect more impaired nonverbal cognition; even in young people with ASD who have a successful prognosis, daily life skills were below age expectations. Another study found that life tasks for children and adolescents with ASD were more strongly related to their functional skills for daily activities than to IQ or the severity of ASD symptoms (Kao et al., 2015). Numerous studies show that altered health reflects on functional status. Most often, psychiatric disorders lead to significantly lower levels of functioning (Mattila et al., 2010 & Simonoff et al., 2008). Then

there are neurological diseases/conditions, among which epilepsy is associated with lower daily functioning (Viscidi et al., 2014 & Ko et al., 2016).
Regarding the differential activities included in this study, 61.1% of people with ASD are independent when eating, while 22.2% of respondents need physical assistance in performing the functional skill of eating. No studies have been found to indicate difficulty eating as a functional ability, but a number of studies have been reported in the literature that show behavioural eating problems, such as sensory food selection, eating endolonic food, and so on. (Gray et al., 2018; Maskey et al., 2013; Margari et al., 2020). The dressing skills of children with ASD are important for their social environment, selective skills and improving quality of life. It is among the self-care skills needed for people with ASD to function independently. Unlike the control group which is independent (92%) when dressing, in this study children and adolescents with ASD need physical assistance (33.3%) or supervision (19.4%). Studies in the literature have shown that the skill of undressing is easier than the skill of dressing for these children. They also also show that unbuttoning is relatively easier than fastening. Therefore, both undressing and dressing skills must be taught in parallel (Varol, 2011). Interviews with families indicate that teaching children the functional skill need to dress/undress is of primary importance to them (Farlow, & Snell, 2003). The results of another study showed that encouraging this skill was effective in the teaching process (Cetrez-Iscan, Nurcin, & Fazlioglu, 2016). It is also important that children with ASD are taught how to manage personal hygiene without additional assistance. In this study, a smaller proportion of people with ASD can take a shower on their own (23.6%) as opposed to the control group (90.7%). Many people with ASD need physical assistance when taking a shower (38.9%), supervision or verbal prompting (18.1%), but some of them (1.4%) are completely dependent on another person. Some young people with ASD have an increased sense of smell or touch which may make some aspects of personal hygiene unpleasant. The feeling of water from the shower, the smell of certain soaps or shampoos and the texture of some towels can have an impact (Baranek, 2005). The process of developing a toilet routine may take longer in children with ASD compared to neurotypical children and may involve its own special challenges. In our study, half of the patients with ASD (52.8%) used the toilet independently, unlike the control group, which is almost completely independent (96%). In this study, people with ASD need supervision or verbal prompting when using the toilet (13.9%), need physical assistance (20.8%), and some of them have not developed functional abilities to use the toilet (12.5%) and most often use nappies. Amongst other things, the lack of independence in personal hygiene skills increases the burden on the caregiver and makes children with ASD more dependent (Flynn & Healy, 2012). Therefore, it is important to develop tools to help people with ASD increase their ability to perform these basic life activities, which will lead to savings that can be invested in other critical areas of need. In the research of Piccin S. et al. (2017) an effective tool for learning hygiene items in people with ASD is the presentation of the skill through video animation. For young children with ASD, the acquisition of urinary control can be facilitated by the use of animated toilet video in combination with operational editing strategies (Keen, Brannigan, & Cuskelly, 2007).
In addition to personal hygiene skills, people with ASD have problems acquiring academic knowledge and skills. The research showed that 40.3% of children with ASD versus 5.3% of the control group have such problems ($p = 0.000$). Children with allergies and learning difficulties, hyperactivity, increased fatigue, incoordination and irritability; when treating allergies there is a significant improvement in learning ability, a reduction in hyperactivity and inappropriate behaviour, and an improvement in intellectual performance (Sheri Marino, 2014 & Mostafa, 2012). In practice, it should not be the case that children with ASD face academic problems because there are special education programmes for these children. In this study, the large percentage of children with problems acquiring academic knowledge and skills is due to insufficient knowledge of how to best teach them in order to take advantage of the potential opportunities in the child.
Due to the difficulties they face, people with ASD use assistive technology in order to compensate for the inhibited spheres of this spectrum. Compared to the general population, the analysis in this study showed that the use of assistive technology depends on whether the child has ASD, ie people with ASD use more systemic technology than the general

population ($p = 0.032$). Positive experiences from the use of assistive technology in people with ASD are known in the literature (Sean et al, 2019), but there are also studies where people with ASD abandon the use of assistive technology (Dijcks et al., 2006; Lauer, Longenecker Rust, & Smith, 2006; Federici & Borsci, 2016). In this study, assistive technology for upper and lower extremities, hearing aids, lenses, walkers, wheelchairs, customised equipment, and mechanical lifts are not used by any of the respondents. 22.2% of the children with ASD use alternative and augmentative technology, which is not used by those in the control group ($p = 0.002$). This is confirmed in the study by Costantino and Bonati (2014) and their findings of positive effects of alternative and augmentative technology for people with speech difficulties. They help children to convey their needs and desires in appropriate and positive ways, which improves the understanding between the interlocutor and the person with ASD, and thus reduces stress levels. Although alternative and augmentative technology do not appear to interfere with speech production and may result in increased speech production, modest observed results require realistic expectations (Schlosser & Wendt, 2008). A recent study showed that the use of alternative and augmentative technology in people with ASD did not show significant results in expressive speech (Rose et al., 2020).

5. Limitations and contributions for future research

The limitations in this research include collecting information directly from the medical records, because through structured individual interviewing a certain subjectivity or distortion of the results is possible.

This research reveals the direction of new research around functional activities for everyday life because they contribute to the the independence of the person. Consider the use of alternative and augmentative technology and the types of assistive technology are generally used by people with ASD and their positive effect on improving the functional status of these people by improving daily life and improving the outcome of this condition.

The research with its findings and conclusions acknowledges the contributions of special educators and rehabilitators, medical staff, speech therapists, psychologists and parents.

6. Conclusion

Although ASD is well described in the pediatric literature, this is the first study from the Balkan region examining functional status in children and adolescents with ASD. We found that functional status in ASD was substantially lower in our cohort. Persons with ASD have lower functionality in the daily activities of: eating, dressing, showering and using the toilet. These skills are easily acquired through everyday life situations for the neurotypical population, but for persons with ASD, learning the skills is a more complex process that can take longer. Acquiring functional skills results in favourable outcomes, including increased opportunities for community interaction and a better overall quality of life for people with ASD. Therefore, functional skills should be included in the individual educational programmes of these children and practised on a daily basis. Acquired functional skills provide greater choices in life and reduce the need for intensive support and the use of assistive technology.

Students with ASD are also more likely to experience changes in learning to differentiate themselves from other children in the control group. Learning functional skills is crucial for people with ASD and helps alleviate some maladaptive behaviours (e.g. self-harm, aggression) by encouraging the individual to choose the appropriate replacement skill. For example, teaching a child to make choices and to show what he wants gives him a way to express his desires. This can reduce frustration and the likelihood of engaging in maladaptive behaviours. Greater advocacy and awareness is needed to ensure that children and adolescents with ASD are treated properly.

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Conflicts of interest

The authors declare no conflict of interest.

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