10th International Conference: Research in Education and Rehabilitation Sciences



May 5 - 7, 2023 Zagreb, Croatia

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10th International Conference: Research in Education and Rehabilitation Sciences

ERFCON 2023

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Introduction

Welcome to the Conference Proceedings for the 10th International Conference: Research in Education and Rehabilitation Sciences - ERFCON2023, Volume 1. This milestone event brings together scholars, researchers, educators, and practitioners globally, facilitating profound discussions, the exchange of innovative ideas, and the presentation of groundbreaking research in the fields of education and rehabilitation sciences.

The themes of ERFCON2023 signify our dedication to exploring uncharted territories and pushing the boundaries of knowledge in special and inclusive education, rehabilitation, speech-language pathology, social pedagogy, and criminology. As we collectively explore new horizons, this conference provides a platform for intellectual exchange, fostering collaboration and inspiring transformative developments.

The Conference Proceedings underscore the importance of diverse perspectives and interdisciplinary collaboration in addressing the multifaceted challenges within education and rehabilitation sciences. By assembling experts with varying backgrounds, our aim is to weave a rich tapestry of insights contributing to the holistic advancement of these critical fields. Jasmina Troshanska from MK, University of Tetovo jasmina.troshanska@unite.edu.mk Teuta Ramadani Rasimi from MK, University of Tetovo teuta.rasimi@unite.edu.mk Natasha Chichevska Jovanova from MK, University Ss. Cyril and Methodius natasac@fzf.ukim.edu.mk Olivera Rashikj Canevska from MK, University Ss. Cyril and Methodius oliverarasic@fzf.ukim.edu.mk

Healthcare access barriers for individuals with autism: The awareness of medical professional

SUMMARY

Introduction: Autism spectrum disorder (ASD, autism) is a complex, life-long disorder characterised by two core symptoms, which range in severity: persistent deficits in social communication and social interaction, and restricted and repetitive patterns of behaviour. These behaviours are mainly unfamiliar to healthcare workers, hence the access to healthcare services for individuals with autism becomes challenging. This presentation aims to discuss results regarding the knowledge of autism among medical workers based on their experience and to highlight its importance as a possible barrier to accessing healthcare services.

Methodology: To examine the knowledge of autism, a survey was conducted involving 70 medical personnel. In addition, to gather more detailed information about specific experiences of the medical personnel, an interview was conducted with 6 medical doctors.

Results: All respondents said that they faced difficulties when working with children with autism - 43% had a problem communicating during the medical examination, while 41% found it difficult to administer medical therapy. In hospitals, individuals with autism are usually referred to one of the medical personnels in the department who is highly skilled in providing services. According to the information from the interviews, this highly skilled person usually has constant close contact with a person or child with autism in their family or friends circle.

Conclusion: Medical personnel agreed that they need additional education, informative material, materials for visual communication, and more time to perform a medical examination of patients with autism. Also, they stated that there was a lack of support for families and provision of resources in order for them to prepare children with autism before a doctor's visit.

Key words: autism, healthcare, medical personnel

Introduction

In recent decades, much research has focused on the diagnosis, different treatments, education, or inclusion of children with autism spectrum disorders. On the other hand, a minor part of the research focused on the quality of availability of the institutions and services where these children are treated or educated. Every visit to the medical facilities is stressful for every parent, but experiences show that visiting a doctor with a child with autism greatly stresses the parent and child. A child's communication and interaction problems, sensory needs, and behavioural challenges can significantly complicate a medical examination.

It remains unclear why this is happening when it is well known that according to the international documents for human rights, every person must have accessible health services for general healthcare needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness.

The reason for all this probably lies in the inaccessibility of sufficient information about people with autism during studies in medical staff, the inaccessibility of additional education that will follow the new inclusive trends of society or the insufficient awareness of the child's family with autism.

This research aims to discover the barriers faced by children with autism and their families when visiting medical facilities and awareness of autism among medical professionals. Assessing this problem can set the base for establishing more effective medical treatment and improving the quality of life for people with autism and their families. A total of 70 medical personnel participated in the research. Analyses of the survey responses verified the lack of education, informative material, materials for visual communication and more time for medical examination of patients with autism. The information evaluated here can be used for further research, raising awareness, improving the education of medical professionals, and supporting families.

Objective

Autism spectrum disorder (ASD) is a neurological and developmental disorder affecting how people interact, communicate, learn, and behave. Although scientists can diagnose autism at any age, it is described as a "developmental disorder" because symptoms generally appear in the first two years of life (National Institute of Mental Health, 2023). To meet diagnostic criteria for ASD according to DSM-5, a child must have persistent deficits in social communication and interaction. This means a child has deficits in social-emotional reciprocity, nonverbal communicative behaviours used for social interaction, and deficits in developing, maintaining, and understanding relationships. Also crucial for diagnosis is that the child manifests restricted, repetitive patterns of behaviour, interests, or activities, inflexible adherence to rou-

tines, or ritualized patterns of verbal or nonverbal behaviour, sensory issues, or unusual interest in sensory aspects of the environment. All these symptoms must be present in the early developmental period. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay (Center for Disease Control and Prevention, 2022). According to the CDC, around 1% of the world's population has autism spectrum disorder – over 75,000,000 people. In 2022, 1 in every 100 children are diagnosed with autism spectrum disorder and in 2023, the CDC reported that around 1 in 36 children in the U.S. is diagnosed with autism. Autism prevalence has increased 178% since 2000. The country with the highest rate of diagnosed autism in the world is Qatar, and the country with the lowest rate is France. Also, statistics showed that medical expenditures for children and adolescents with autism were 4.1 to 6.2 times greater than those without autism (Zauderer, 2022).

Due to the diagnostic process of children with autism, but also due to the presence of medical comorbidities such as epilepsy, bowel disorders, cranial abnormalities, diabetes mellitus, sleep disorder or muscular dystrophy, adolescents with ASD often visit medical institutions (Kohane, McMurry, & al., 2012).

According to WHO: "People with autism require accessible health services for general healthcare needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness. Nevertheless, people with autism have higher rates of unmet healthcare needs than the general population. They are also more vulnerable during humanitarian emergencies. A common barrier is created by healthcare providers' inadequate knowledge and understanding of autism" (World Health Organization, 2023). EU reports that professionals need better knowledge: "Professional understanding of risks for poor health conditions and behaviours in autistic adults is uneven across health areas" (ASDEU, 2020). Studies show that people with autism die 12 years earlier than the general population, and one reason is poor access to health services (Simpson, 2020).

Because of the specific characteristics, children and youth with ASD adjust to new environments more efficiently with a structured routine (National Institute of Mental Health, 2023). Also, a hospital setting is incredibly challenging for them, considering the sensory input, social demands, and disrupted routine. Some of the children can have challenging behaviour while visiting medical institutions. Negative interactions with the healthcare system and concerns about the quality of care provided to this population have been reported by individuals with ASD, their families, and healthcare providers (Feil, 2014). Patients need to be treated as individuals, and healthcare professionals need to take the time to learn more about people with autism and Asperger syndrome, for example, what makes them anxious and their preferred communication method (Aylott, 2010). In Macedonia and the region where the health system is at a lower level, there is a lack of regulations for adequate health care for people with autism spectrum disorders. Therefore, it is necessary to conduct research in this area and raise awareness about autism in medical institutions. Although the results are part of a small sample, they will provide a base for further research and improvement of health services by implementing project activities in the field.

Research Problems and Hypotheses

The only official document in the RN Macedonia where we can find data about the healthcare system and autism is "Official Gazette of the Republic of Macedonia", which states that "Measures to be taken to improve the situation": 1) training of health professionals working in prevention teams for autism recognition; 2) introduction of M-chat as mandatory screening of all children aged from 18 to 24 months old in mandatory systematic examinations of preschool children" (Ministerstvo za zdravstvo, 2018).

Our experience shows that in the diagnostic process, when parents are concerned about the child's development, sometimes, medical professionals are not informed enough to meet the problem of the child and parents. As a result of insufficient knowledge of the problem, the diagnosis of children with autism is late. Also, medical students have neither theoretical nor practical experiences with specific tools for recognizing early signs of autism. In our country, many families receive advice from medical professionals on using alternative treatments and methods which are unproven and uncertain. This practice shows us a lack of information about autism and the use of information from the Internet that, although helpful, can sometimes be confusing, inappropriate and inaccurate.

Despite this information, around Europe and the world, organizations work on improving awareness of medical professionals and improving medical services by creating and producing materials and training for medical institutions and families (SANTE BD, 2023).

This research aims to discover challenges in medical treatment by medical staff and awareness of autism in medical professionals. Assessing this problem can set the base for establishing more effective medical treatment and improving the quality of life for people with autism and their families. Based on the goal, we raised two research questions:

1. Do medical professionals embrace basic knowledge of ASD?

2. What are the challenges of medical treatment of children and adults with autism based on medical professionals' perceptions?

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Based on the research question, we yielded several hypotheses. The first one: 1. Medical pro-

fessionals often encounter patients with autism, from whom more children than adults; 2. Medical professionals have basic knowledge of autism and can recognize the characteristics of children with autism, 3. The following hypothesis was that medical professionals had attended training to recognize early signs of autism, and the last one 4. Medical Professionals face difficulties in the medical treatment of patients with autism.

Methods

The study aimed to survey participants who work in the hospital (secondary healthcare), which covers the Polog region in RS Macedonia, with a population of 251 552 citizens (Wikipedia, 2023). The participants work in the hospital as medical doctors with different profiles. After analyzing the literature and existing information in Macedonia, we created a questionnaire for this research. We were using the Knowledge About Childhood Autism Among Health Workers (KCAHW) questionnaire (Baker et al., 2008) to guide survey creation for this research, and the terms used in the survey adapted to the local language, which did not identically translate the terms. After piloting, a survey was used for the research. Surveys were distributed to the potential participants using the link by Google Forms and were available from June 1st to July 2nd, 2022. The survey had 18 questions, and the first five questions collected demographic information from the participants about gender, age, nationality, current working area, and years of service as doctors. The remaining questions targeted their awareness of autism spectrum disorders. When the survey ended, row data was moved to Excel, and the frequencies were counted for the number of responses in each category. Due to the small sample, the data were analyzed through descriptive statistical procedures. Seventy medical doctors participated in the study, of which 39 were women, and 31 were men. The youngest respondent was 32 years old, and the oldest was 63. The arithmetic mean of the age was 49.34. Doctors with different working profiles and experiences (Table 1).

Table 1 Socio-demographic and working experience profile (n=70)

Socio – demographic and working experience profile	Parameters	Frequency	Percentage
Cander	Female	39	56.7 %
Gender	Male	31	43.3 %
Nationality	Macedonian	18	25.7 %
	Albanian	52	74.3 %
	General practitioner	12	17.1 %
	Pediatric Medical	13	18.6 %
	Internal medicine	7	10 %
	Surgery	10	14.2 %
	Intensive care	4	5.8 %
Current working area	Cardiology	6	8.6 %
	Orthopedy	7	10 %
	Psychiatry	2	2.8 %
	Anesthesiology	6	8.6 %
	Immunology	2	2.8 %
	Otorhinolaryngology	1	1.4 %
Years of experience as doctor	Less than 10 years	12	17.1 %
	From 10 to 20 years	29	41.4 %
	From 20 to 30 years	23	32.9%
	More than 30 years	6	8.57 %

In order to get more in-depth information about doctors' experiences, six interviews were conducted with doctors working in hospitals from other cities in Macedonia. Doctors were between 45 and 52 age old; 5 were women and one man. One of the doctors was also the mother of a child with autism. The questions in the interview were open-ended to allow the doctors to express all the challenges they face when contacting patients with autism, their experiences and readiness to work with these patients, and also what they can do to improve conditions. Interviews were conducted online on Zoom from June 1st to July 12th, 2022. To analyse the Interviews, we used Atlas software, with transcribed data divided into categories, encoded and data grouped in 4 themes.

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Results and discussion

Results of the survey processing

Regarding the first hypothesis, "Medical professionals often encounter patients with autism, from whom more children than adults", starting with the question that doctors responded, "How many patients with autism have they met in the last six months?". To this question, 7% of the doctors answered that in the last six months, they did not have a patient with autism, 74% of the doctors answered that they had 1-5 patients with autism, 19% of the patients met 6-9 patients with autism, and none of the doctors met more than ten patients with autism (Figure 1). Furthermore, in the next question, "The age of autistic patients that visit the doctor more often is 2-3 years old, 15% of them declare that it is the age group over six years old (Figure 2). Based on the results, we can conclude that the first hypothesis is confirmed.

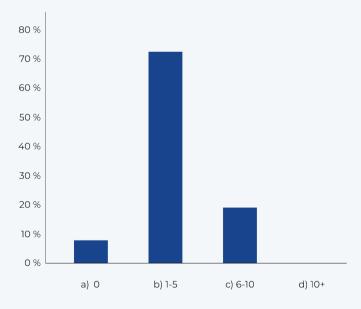


Figure 1 Percentage of the doctors meeting children with autism in the last six months

The second hypothesis is "Medical professionals have basic knowledge of autism" they can recognize the characteristics of children with autism. We will refer to several questions of the instrument to answer it, and we will refer to the survey question: "Do you know what autism is? "All respondents, 100% of doctors, said that "yes" they knew about autism. Furthermore, table 1 presents seven questions that are signs of recognizing autism early on and concerning awareness of autism and its recognition by medical professionals. It can be noted that

the highest percentage of doctors (88.6%) notice the child's behaviour as deaf. Furthermore, autism is associated with epilepsy (62.8%), absence of speech (61.4%), eye contact disorder (60%) and stereotypical behaviour (54.2%). It is characteristic that many of them (68.6%) stated that the absence of social smiles is not a sign of autism, and 64.2% said that autism is not associated with abnormal eating habits.

	Answers		
Questions regarding awareness of autism spectrum disorders	Yes	No	l don't know
Disturbance of eye contact, facial expression, and body movement during social interaction	42 (60%)	12 (17.1%)	16 (22.8%)
Child can appear as if deaf	62 (88.6%)	8 (11.4%)	0
Delay or total lack of development of spoken language	43 (61.4%)	20 (28.5%)	7 (10%)
Social smile is usually absent in a child with Autism	20 (28.5%)	48 (68.6%)	2 (2.9%)
Stereotype and repetitive movement	37 (54.2%)	21 (30%)	12 (17.1%)
Autism is related to abnormal eating habit	10 (14.2)	45 (64.2%)	15 (21.4%)
Autism could be associated with Epilepsy	44 (62.8%)	12 (17.14%)	14 (20%)

Table 2 Doctors' awareness of autism spectrum disorders

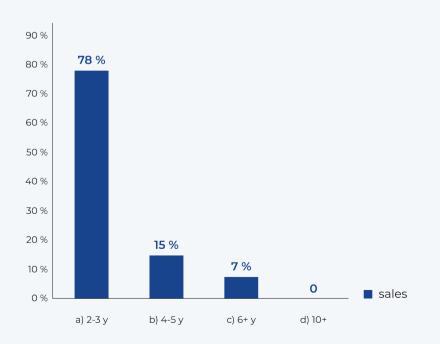
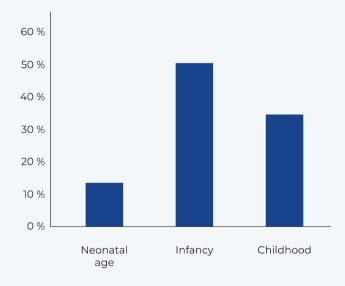


Figure 2 Percentage of the children that visit doctors based on age

In addition, when asked about the onset of autism, 50% answered that it is in infancy, and only 14% answered that autism onset is in neonatal age (Figure 3). Based on the results regarding the second hypothesis, we can conclude that it is confirmed.

The third hypothesis, "Medical professionals had attended training for recognition of early signs of autism", we can see in Figure 4 that according to the results, 55% of the medical staff of the hospital say that they sometimes participate in the training developed on the diagnosis of autism, 30% of them always participate, and 15% of them have never participated, which leads to refuse the third hypothesis.





The last hypothesis, "Medical Professionals who face difficulties in the medical treatment of patients with autism", was assessed with the question, "Do they face difficulties in treating patients with autism? All responded 100% with yes, and the second question, "What is their biggest challenge in working with an autism patient?" most often pointed to communication with the child (43%), then giving therapy (41%), and the child's behaviour (16%). This issue also had the opportunity to list something else, but no respondent sought another challenge (Figure 5), which concluded that the last hypothesis was confirmed.

Results of the interview processing

When processing interviews, the answers were grouped into four categories: education, procedures for treating autism in health institutions, autism awareness and availability of training. In each category, data were grouped into two themes presented in Table 3.

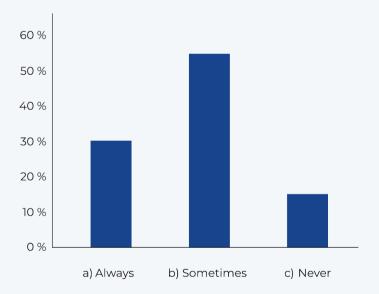
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Category	Theme	Statements
Education	Education during studies	"During the studies, autism was not covered as a condition or problem in our subjects."
	Education in the framework of professional development in the workplace	"I did not attend training, I did not have experience, I did not have a chance to see another doctor treating autism."
Procedures for the treatment of autism	Doctor's decisions	"I approach them friendly; I let them sit in my chair and relax I do not send them into a lab where it is crowded; instead, I call a nurse to take their blood in my office where they have already been adapted to the environment."
	Parents' decisions	"To draw blood out from children with autism in their homes, be- cause the child finds it difficult to experience the moment going to hospital".
Autism awareness	Personal experiences	"My child has disabilities, so if a patient with autism appears at the hospital, other doctors and nurses send him/her to me".
	Experiences from the environment	"We have a child with autism in the neighbourhood; therefore, it is easier for me to work with them. I can cope with the situation."
Availability of training materials	Materials for doctors	<i>"I think there is a lack of training for doctors and material to work with the child with autism, something to show. We only have medical materials, toys, strips, etc."</i>
	Materials for parents and children	"Parents need to prepare their children properly for the most basic examinations, at least, that occur more often, such as taking blood, going to the dentist, family doctor, etc."

Discussion

The findings of our study clearly show that medical doctors in the Polog region have a knowledge about autism even though they have no education about autism. It was remarkable that autism is not part of the subjects during medical studies, and some doctors never had the opportunity to see practice on how someone treats a child with autism when entering a medical ordination. In the study of Altay, from Edirne, Turkey, two-thirds of family physicians with a mean professional experience of 16.9 ± 8.8 years were not trained in ASD (MA, 2019). Perhaps shortcomings also exist in secondary medical schools, which we did not anticipate in our research. Eseigbe et al. state that the same data was presented publicly in Ghana at a conference in 2014 (Eseigbe et al., 2015). There is still no official epidemiological data on autism in Macedonia, so autism services are challenging to plan and predict. The first epidemiological study on autism began in 2000 (Trajkovski et al., & M, 2005) as a part of the project.

This gap has been in the media in the last 20 years. Parents' awareness is also more splendid and more common than before. Most doctors in the Polog region met children between the ages of 2 to 4 years old (78%). Young children usually visit general practitioners and pediatric medical doctors. In our case, the total number of these specialists is 25, which shows that this result is not because of the sample of the type of doctors but because children visit medical institutions more often than adults with autism. The medical trend of looking at autism during early development still prevails; 74% of the doctors had 1-5 patients with autism in the last six months of the research period. After diagnosis, most parents visit different specialities, seeking a "cure" for their child in the form of alternative treatments and supplements. These "treatments" sometimes can be life-threatening (Tochi, 2015). Due to the lack of treatments and specialists provided by state health, parents often pay for services in private clinics, which affects their family's quality of life (Troshanska et al., 2018).





Regarding the awareness of signs of autism, our respondents showed good knowledge; that is, they usually recognize the children so that they look like deaf children due to lack of speech and stereotypical movements. They do not consider an eating problem as an early sign, as well as a lack of a social smile and 50% of them stated that autism onset in infancy. Furthermore, the lack of additional education and monitoring of new diagnostic procedures, the region's traditional beliefs, and the country's weak health system led to inadequate treatment of children and persons with autism in any clinic. Procedures for treating autism depend on the doctor's personality, and our interviews showed that the child with autism, for any intervention, is often sent to the doctor who has the most empathy due to personal or family reasons. In addition to the lack of training for the medical staff, there is also a lack of materials that will serve both doctors and parents to better communicate with children with autism. Often, children with autism come unprepared for interventions. The doctors stated they have a big problem with communication, behaviour and applying appropriate therapy.

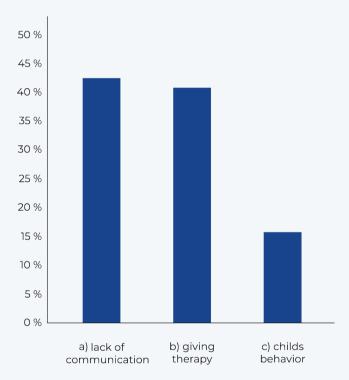


Figure 5 Challenges during treatment of autistic patients by medical professionals

Limitations: This study was limited to medical doctors from one region in the Western part of Macedonia. Also, the sample was small. The impact of selection bias can result from sampling, and the number of questions was limited to not extend the time for answering the questions in the survey or interview. This study is a preliminary study made to prove the need for applying a project to assess the knowledge and needs of the medical staff and conduct more extensive research that will cover the entire territory of the country.

Conclusion

Our study indicated a lack of systematic education of medical doctors about autism. Nevertheless, even with this fact, medical doctors have good knowledge about autism. Early intervention is medical, mainly in the first years of life, before or after diagnosis, and parents often search for a "medical cure" for autism. A big challenge for doctors is communicating with autistic patients and their behaviour and problems when administering therapy. Because of this, they require education, training, and materials to support communication. Autistic patients should be prepared and familiar with the procedures during the examination through appropriate materials. However, it is also necessary for doctors to prepare for a meeting with an autistic patient. In that way, the health treatment of children and people with autism will be better, and the family's quality of life will also be improved.

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