



International Journal of Autism

E-ISSN: 2710-3927
P-ISSN: 2710-3919
IJRSE 2022; 2(2): 26-29
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www.rehabilitationjournals.com
Received: 11-09-2022
Accepted: 15-10-2022

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Prevalence of difficulties in occupations among children with autism spectrum disorder in Jeddah and Makkah

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is characterized by difficulties in social participation, communication, and maladaptive behavior. Children who have been diagnosed with ASD exhibit impairments in several occupations, like self-care, leisure, and productivity. Such limitation may not only affect children's occupational performance and engagement, but affect the Quality of Life (QoL) and subsequently affect their parents' QoL. The purpose of this research is to measure the prevalence of difficulties in main occupations, which are self-care, productivity, and leisure among children with ASD in Makkah and Jeddah. The design is a descriptive cross-sectional study. Convenience sampling technique was used to recruit caregivers mothers to participate in the study. A developed questionnaire was used to collect data from 41 participants. Descriptive statistics were used to analyze demographic data and the response to questionnaire statements. The study found that ASD affects all types of occupations. The majority of children show difficulties in Self-care followed by productivity and leisure. An early identification of such deficits in those children's occupations would guide occupational therapists to select the appropriate methods and strategies for the early intervention, based on client's preference and needs. The Saudi occupational therapists would have to address the main occupational difficulties among those children in order to improve their independence in the activities of daily living to improve not only their QoL, but also to enhance their families QoL.

Keywords: Autism Spectrum Disorder (ASD), QoL, Makkah and Jeddah

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is characterized by difficulties in social participation, communication, and maladaptive behavior (Memari A *et al.* 2015) [12]. According to World Health Organization, the prevalence of ASD is a child out of 160 births (2019). However, there is limited information about the prevalence of children with ASD in Saudi Arabia.

Children who have been diagnosed with ASD demonstrated impairments in several occupations that are important in their daily life (Bal V *et al.* 2015; LaVesser P and Berg C 2010) [3, 9]. Occupation is defined by Occupational Therapy Practice Framework (OTPF) as various kinds of life activities in which individuals engage, including activities of daily living, instrumental activities of daily living, rest and sleep, education, play, leisure, and social participation (OTPF 3rd ed, 2014).

A study conducted in Saudi Arabia in 2017 to evaluate social participation of mothers of children with ASD showed that those mothers had difficulties engaging in social activities due to caring for their children. Mothers reported that 100% of children had difficulties with eating, meanwhile about 96% of them had issues with bathing, and 90% of them faced difficulties with toileting and dressing (Meny A *et al.* 2018) [13]. However, the study did not identify the children's difficulties in other occupations like leisure activities. Such difficulties in several areas would negatively affect not only children's Quality of Life (QoL), but it would also influence their families' QoL (Eapen V and Guan J 2016; Khanna R *et al.* 2011) [6, 8].

Studies that examined quality of life reported that children with ASD and their families have compromised QoL. One of the studies mentioned that the low QoL among families was due to the limited participation, lack of positive experience in exercising, frequent failure, emotional impairments, and low self-esteem.

Other studies also showed that the limited participation of parents in different occupations was mostly due to lack of resources and poor financial income (Lee LC *et al.* 2008, Memari A *et al.* 2015) ^[11, 12]. However, the QoL can be enhanced by assessing the issues that affect the QoL and planning accordingly for intervention to minimize such difficulties (Rogers SJ *et al.*, 2012) ^[16]. According to Estes A *et al.* (2015) ^[7] and Schaaf RC *et al.* (2014) ^[17] One of the rehabilitation interventions that can be provided for children with ASD to improve their activity of daily living is occupational therapy intervention. Occupational Therapist (OT) enables people to participate in the occupations that people want in order to enhance their occupational performance in activities of their daily living and instrumental activities of daily living (Schaaf RC *et al.* 2014) ^[17].

Due to the lack of studies about the prevalence of difficulties of all occupations among children with ASD, this study will address this issue by identifying the occupational difficulties, including self-care, productivity, and leisure in children with ASD in Saudi Arabia. Detecting the difficulties that children with ASD may face in everyday life will add knowledge to fill in the gap in the literature. Additionally, the finding would help the OT to tackle problems among those children. Subsequently, it would support the OT to plan appropriately for early intervention, which may lead to reduce the impairments in occupations among children. It would also help in improving their occupational participation as well as their independency and decrease dependency on their families (Case-Smith J and Arbesman M 2008 and Novak I *et al.* 2019) ^[5, 14].

Therefore, the purpose of this research is to measure the prevalence of difficulties in main occupations, which are self-care, productivity, and leisure among children with ASD in Makkah and Jeddah.

Methodology

Study design and technique

The study was conducted as a descriptive cross-sectional survey among caregivers

And mothers of children with ASD in Jeddah and Makkah. The sample technique for this study was convenience sampling.

Sitting

The study was conducted at Future Pioneer Center in Makkah and the Saudi Society for Autism in Jeddah. Permissions were taken from two centers.

Tool

The questionnaire which was used in this study was developed by the authors of the study. The validity and reliability were tested by doing pilot study and making some adjustments on the questionnaire according to the participants' feedback. The aim of the instrument is to measure the prevalence of difficulties in occupations among children with ASD. The parents were informed about the purpose of the study, their eligibility, and ensured anonymity if they chose to participate. The questionnaire consists of four parts and 54 structured statements in Likert scale.

Demographic data

Child information which includes age, gender, severity of

the autism, previous intervention, and type of intervention that the child received. The name of the patients and ID were not collected. Additionally, Family information which includes the level of education and employment status for parents.

- **Self-care:** it has 37 statements that are divided into five sub-categories which are eating, dressing, grooming, bathing, and toileting.
- **Productivity:** it has seven statements.
- **Leisure:** it has ten statements.

Participants

The inclusion criteria for the participants were:

- Children with ASD between 4-12 years old.
- Children with mild, moderate, and severe ASD.

The exclusion criteria for participants

Any child is diagnosed with ASD and associated with other physical or mental impairment like epilepsy or cerebral palsy as these issues may increase the limitation of occupational performance as participation, which may affect the finding of the study. The questionnaires were collected only from 52 parents, but only 41 that met the inclusion criteria. The participants were excluded because they were under the required age and because some questionnaires were not completed. All participants signed a consent sheet before data collection.

Data analysis

Data analyzed by using SPSS (Statistical Package for Social Sciences) version 20. For Descriptive statistics, qualitative variables were presented as frequency and percentage while quantitative variables were presented as mean and standard deviation. The difficulty of each occupation was found by measuring the mean. The lowest mean indicates the most difficult occupation.

Results

The total number of participants were 52, but only 41 who met the inclusion criteria, and 26 of them were male. Most participants 14 were in the age group (10-12). Moreover, 11 of children have received occupational therapy intervention, 18 of children received behavioral therapy intervention, and 12 receive other types of interventions. The highest education level for parents is bachelor's degree, while the lowest education level was the middle school degree.

Table 1: Socio-demography of participants

	Variable (N=41)	Frequency	%
Gender	Male	26	63.42
	Female	15	34.15
Age	3-6 Years	11	26.82
	7-9 Years	16	39.02
	10-12 Years	14	34.15

The first and fifth questions were about the ability to use a spoon, and most of the mothers answer strongly agreed, which means the child could use the spoon independently with no assistance. The second question was about if the child with autism could complete the feeding session by himself, and most of the mothers answered strongly agree, which means the child could feed himself independently. The next question was about the ability to use the fork, and most of the mothers' answers strongly agree, which means

the child could use the fork independently. In question 4, we ask the mother if the child can use a knife during feeding sessions, and they answered with neutral, which means some of children are not able to use the knife by themselves during feeding. In questions 6,7,8, and 9, we asked the mothers if the child could drink and hold the cup by himself, and they answered strongly agree, which means the child can hold and drink from the cup by himself. Moreover, in questions 10, 11, 14, 15, and 16, we asked the mothers if the child can put the shirts, pants, shoes, and socks on and off, and the mothers answered with strongly agree, which means the child could put the shirt, pants, shoes, and socks on and off. On the other hand, questions 12 and 13 were about if the child can button himself, and the mothers answered with strongly disagreed, which means the child cannot button himself and needs maximum assistance. Additionally, in question 17 we asked the mothers if the child can lace his shoes by himself, and they answered strongly disagree, which means the child could not lacing shoes independently and need maximum assistance. However, in questions 18,19, and 20 we asked the mothers if the child were able to hold and use toothbrush and toothpaste to brush teeth by himself, and the mothers answered with disagreeing, which means the child could not brush himself independently and needs more assistance in brushing teeth. In question 21, we asked the mothers if the child could brush hair by himself, and the mothers answered with neutral, which means some of them could, and the others could not brush hair independently. In questions 22, 23, and 24, we asked the mothers if the child can wash hands and dry them, and the mothers answered with strongly agree, which means the child could wash hands independently. In questions 25, 26, and 27, we asked the mothers if the child can bath, wash his face, and dry himself independently, the mothers split into two groups, some of them answered disagree, which means the child could not bath and wash face independently, and the others answered neutral, which means the child could

bath and wash with assistance. In questions 28 to 35, we asked the mothers if the child could do the whole toileting process, and the mothers answered with strongly disagree, which means the child could not use the toilet independently, but most of the mothers mentioned that their child asks them to go to the toilet. In question 36, we asked the mothers about their reading skills, and the mothers answered strongly disagreed, which means the child could not read and did not have any reading skills. In questions 37 and 38, we asked the mothers if the child could hold the pen and write independently, and the mothers answered agree to use the pen which means the child could use the pen independently, but disagree with writing, which means the child could not write independently. In questions 39, 40, 41, we asked the mothers if the child could go to school and finish his homework with extra classes, and the mother strongly agreed with these questions. In question 42, we asked the mothers if the child could do home duties and help with chores, and the mothers agreed with the question. In questions 43,44,45, and 46, we asked the mothers if the child could play and interact with the other kids appropriately, and the mothers split into two groups: some of them says their child could do that, and the other said they don't. In questions 47 and 48, we asked the mothers if the child could draw and complete the shapes by himself and most of the mother's response was neutral. In questions 49 and 50, we asked the mothers if the child could share toys and play with other kids, and they were disagreed. In questions 51 and 52, we asked the mothers if the child could watch the TV and use the tablets and smart devices appropriately, and they strongly agreed, which means they can use the smart device and watch T.V. appropriately. When comparing the means of the three different categories, the result showed that children with ASD have most difficulties in self-care followed by productivity followed by leisure as presented in Figure-1.

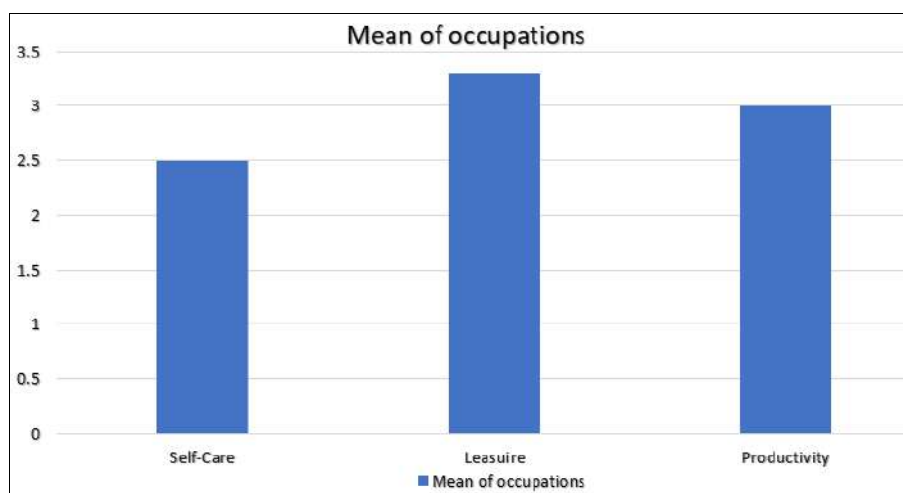


Fig 1: This column showing mean of difficulty in Occupations. The lowest mean indicates the most difficult occupation

Discussion

The aim of this research was to identify the prevalence of difficulties in occupations for children with ASD. One of the main focus of occupational therapist's interventions are occupations training, such as ADL and IADL. These interventions are concerned with teaching the child using several strategies on feeding, dressing, playing, and writing by himself to be more independent and to increase the

quality of life of children and families. This study demonstrated the most difficult occupations at self-care were toileting, lacing shoes, and buttoning, while productivity were reading and writing meaningful sentences. However, in the leisure part the most difficult occupations were sharing toys and playing with peers. Not surprisingly, these issues reflect the cure impairment usually seen in children with ASD.

There are three studies had similar results and demonstrate difficulties in self-care, playing, and reading and writing with children with ASD. The first study, According to Meny A *et al.* (2018) [13] the result from the current study indicates that self-care was the most affected occupation among children with ASD aged between 4 to 12. In another study, as reported from parents needs one of the main leisure and playing goals at M-COPM assessment were sharing and playing with peers (Rogers SJ *et al.*, 2012) [16]. Moreover, according to Bauminger-Zviely, N. (2013) [4] children with ASD demonstrate educational challenges including reading and writing.

Conclusion

Strength and Limitations

This study demonstrates that the occupations of children with ASD were negatively affected. Self-care was the most affected occupation followed by productivity, and leisure. Difficulties in such occupations would negatively affect children's and parent's occupational performance and their QoL. In order to improve those children's abilities to be more productive and independent occupational therapy intervention should be provided for them.

This study is unique as it is the first study that was conducted in Saudi Arabia to explore the difficulties of children with ASD in daily life occupations. However, several limitations in this study need to be acknowledged. First, this study is limited by relatively small sample size due to Corona pandemic and the limited number of autism centers in western region of Saudi Arabia. Second, most parents were not collaborative due to the lack of awareness of research importance for better outcome.

Recommendation

A recommendation for future studies would be to collect a larger sample size for comprehensive outcome. Also, this study could be duplicated in different settings in other regions in Saudi Arabia.

Compliance with ethical standards

Ethical consideration

There is no conflict of interest to disclose, and the authors receive no specific funding for this work. Also, IRB approval was obtained before conducting data, and consent forms were obtained from each participants before the questionnaire.

Acknowledgement

We would like to thank Dr. Mohamed Eldigire for helping us with the analyzed data.

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