How to Cite:
Mohamed, M., Elhariri, H. M., Elsheikh, M. S., Atti, M. A., Belawo, H. M., & Adel, A. (2022). Effect of COVID-19 quarantine on caregivers of Egyptian children with autistic spectrum disorder. *International Journal of Health Sciences*, *6*(S4), 1000–1007.
https://doi.org/10.53730/ijhs.v6nS4.5901

Effect of COVID-19 quarantine on caregivers of Egyptian children with autistic spectrum disorder

Mostafa Mohamed
Assistant Researcher in Department of Research of Children with Special Needs, Medical Research and Clinical Studies Institute, National Research center, Cairo, Egypt

Hazem Mohamed Elhariri
Researcher in Community Medicine department, Medical Research and Clinical Studies Institute, National Research center, Cairo, Egypt

Mai S. Elsheikh
Researcher in Complementary Medicine Department, Medical Research and Clinical Studies Institute, National Research center, Cairo, Cairo, Egypt

Mohamed Abdel Atti
Resreacher in Department of child health Medical Research and Clinical Studies Institute, National Research center, Cairo, Egypt

Hanan Mohamed Belawo
Lecturer in Department of Emotional and Behavioral Disorders, Faculty of special education, Misr University for Science and Technology, Egypt

Ahmed Adel
Resreacher in Department of child health Medical Research and Clinical Studies Institute, National Research center, Cairo, Egypt

***Abstract*---**The urgent requirement for adaptation of Children with autism spectrum disorder (ASD) during COVID-19 pandemic has brought major problems to families and caregivers. Aim: To explore and observe the role of caregiver either mother or father or both regarding outcome behavior of children with ASD during the social isolation of COVID-19 outbreak period. Method: The web based questionnaire was applied on families of 110 children diagnosed with ASD. It took about 20 minutes to be filled by parents of affected children. These children was diagnosed in outpatient clinic of department of research on children with special needs according to

International Journal of Health Sciences ISSN 2550-6978 E-ISSN 2550-696X © 2022.
***Corresponding author**: Mohamed, M.; Email: mostafa_gaballah2000@yahoo.com*
Manuscript submitted: 27 Feb 2022, Manuscript revised: 18 March 2022, Accepted for publication: 09 April 2022

criteria of DSM5.The survey was designed to study the effect of COVID-19 Quarantine on children with ASD and to record changes observed by their caregivers on their attitude and behavior during this period. Results showed a potential important psychological outcome impact of the COVID-19 pandemic in relation to the role of main caregiver. In conclusion: In terms of the influence of the COVID-19 pandemic on mental health, clinicians should be aware of warning symptoms shown not just by risk groups, but also by all families, and we must all be prepared for post-pandemic monitoring of mental problems.

***Keywords*---**autism spectrum disorder, COVID-19 Quarantine, caregivers survey, social and sleep disturbances.

Introduction

To reduce or halt the spread of the virus, the coronavirus (COVID-19) epidemic kept parents and children at home and away from each other. Many of our daily habits have been altered as a result. Introducing new routines might be difficult for children with autism spectrum disorder (ASD). Because of this, families of children with COVID-19 may have faced considerable difficulties during the pandemic [1]. Because of this, they may need more assistance in order to comprehend what is occurring around them and what is required of them in certain scenarios.

However, ASD is a long-term developmental condition that affects social interaction, communication, and repetitive, stereotyped behavior. [2] An autistic child's difficulties connecting to people and their acute sensitivity to environmental changes were first identified by Leo Kanner in 1943 [3]. ASD's prevalence has progressively grown, despite the fact that it was formerly thought to be an uncommon condition [3,4]. So, families and parents' well-being are harmed by the changes that happen. People with ASD and their families also face a lot of stress, financial burden, strain on family relationships, structure, changes in family roles, and activities, feelings of guilt and blame about the diagnosis, and the social stigma of having a child with ASD, according to a lot of research [2].

Because some patients may not be able to follow the recommendations, physical distance and frequent hand washing may be difficult to achieve in these types of inpatient or residential settings. Caregiver stress, sadness, anxiety, limitations in duties and activities, marital conflict, and deteriorated physical health are only a few of the issues carers of autistic children face, according to various studies [5, 6]. As far as we know, no previous research has looked at how parents and caregivers of children with ASD communicate their worries and anxieties.

Study and methodology

The survey included 100 children diagnosed as autistic spectrum disorder (ASD) according to the criteria of DSM5 manual who attended to the outpatient clinic of the learning disabilities -National Research Centre. The study included children

between 4-12 years old of both sex with no apparent genetic disease and after exclusion of any neurological comorbidities.

This survey was done by a web based questionnaire conducted in Arabic language. It took about 20 minutes to be filled by parents of affected children. The questionnaire was designed to study the effect of COVID 19 Quarantine on children with ASD and to record changes observed by their caregivers on their attitude and behavior during this period.

All information was gathered using a Google form and an online application. The questionnaire has two primary sections. The first is concerned with sociodemographic data such as age, place of residence, and gender. The second was interested on behavioral data such as eating, sleep patterns, and social interactions during this time period in comparison to those children's past patterns. The study was approved by the National Research Centre's (NRC) Medical Research Ethical Committee (Registration no.20088).

Statistical methods

The data was coded, tabulated, and statistically analyzed using IBM SPSS statistics (Statistical Package for Social Sciences), version 22.0, IBM Corp., Chicago, USA, 2013, and Microsoft Office Excel 2007. Quantitative data, such as counts and percentages, were subjected to descriptive statistics. The Chi square test and Fisher's Exact test were employed for inferential analyses, as well as the post hoc Bonferroni test for variables with tiny anticipated numbers. In order to be deemed significant, P values have to be less than 0.050.

Results

Among the studied 110 cases, the main care giver was the mother in 85 (77.3%), father in 12 (10.9%) and both in 13 (11.8%).

Table 1
Demographic characteristics among the studied cases and comparison according to main care giver

Variables		All cases (N=110)	Main care giver responsibility			P-value
			Mother (N=85)	Father (N=12)	Both (N=13)	
1- consanguinity		25 (22.7%)	18 (21.2%)a	7 (58.3%)b	0 (0.0%)a	§0.010*
2- number of children in family	1–2	76 (69.1%)	70 (82.4%)a	4 (33.3%)b	2 (15.4%)b	§<0.001*
	≥3	34 (30.9%)	15 (17.6%)a	8 (66.7%)b	11 (84.6%)b	
3- similar family condition		16 (14.5%)	8 (9.4%)a	1 (8.3%)a	7 (53.8%)b	§0.001*
4- father education	Moderate	19 (17.3%)	14 (16.5%)	2 (16.7%)	3 (23.1%)	§0.828
	High	91 (82.7%)	71 (83.5%)	10 (83.3%)	10 (76.9%)	
5- father job	Govern.	27 (24.5%)	21 (24.7%)	3 (25.0%)	3 (23.1%)	§0.364
	Private	77 (70.0%)	61 (71.8%)	8 (66.7%)b	8 (61.5%)	
	None	6 (5.5%)	3 (3.5%)	1 (8.3%)	2 (15.4%)	
6- mother education	Moderate	16 (14.5%)	13 (15.3%)	1 (8.3%)	2 (15.4%)	§1.000
	High	94 (85.5%)	72 (84.7%)	11 (91.7%)	11 (84.6%)	
7- mother job	Govern.	20 (18.2%)	14 (16.5%)	1 (8.3%)	5 (38.5%)	§0.235
	Private	15 (13.6%)	13 (15.3%)	2 (16.7%)	0 (0.0%)	
	None	75 (68.2%)	58 (68.2%)	9 (75.0%)	8 (61.5%)	
8- residence	Urban	102 (92.7%)	82 (96.5%)a	7 (58.3%)b	13 (100.0%)a	§0.001*
	Rural	8 (7.3%)	3 (3.5%)	5 (41.7%)	0 (0.0%)	
9- child age	<6 years	62 (56.4%)	51 (60.0%)a	2 (16.7%)b	9 (69.2%)a	#0.011*
	≥6 years	48 (43.6%)	34 (40.0%)a	10 (83.3%)b	4 (30.8%)a	
10-pt education	Centers	37 (33.6%)	27 (31.8%)	6 (50.0%)	4 (30.8%)	§0.424
	Sessions	39 (35.5%)	29 (34.1%)	3 (25.0%)	7 (53.8%)	
	School	34 (30.9%)	29 (34.1%)	3 (25.0%)	2 (15.4%)	

*Significant (<0.050), #Chi square test, §Fishers Exact test. Based on post hoc Bonferroni test, homogenous groups took the same symbol (a,b)

Table 2
Care-given activities among the studied cases and comparison according to main care giver

Variables		All cases (N=110)	Main care giver responsibility			P-value
			Mother (N=85)	Father (N=12)	Both (N=13)	
11- medication	Yes	40 (36.4%)	28 (32.9%)	6 (50.0%)	6 (46.2%)	§0.563
	No	46 (41.8%)	36 (42.4%)	4 (33.3%)	6 (46.2%)	
	Sometimes	24 (21.8%)	21 (24.7%)	2 (16.7%)	1 (7.7%)	
12- medical care	Yes	24 (21.8%)	15 (17.6%)	4 (33.3%)	5 (38.5%)	§0.379
	No	58 (52.7%)	47 (55.3%)	5 (41.7%)	6 (46.2%)	
	Sometimes	28 (25.5%)	23 (27.1%)	3 (25.0%)	2 (15.4%)	
13-social support	Yes	52 (47.3%)	43 (50.6%)	6 (50.0%)	3 (23.1%)	§0.294
	No	28 (25.5%)	22 (25.9%)	2 (16.7%)	4 (30.8%)	
	Sometimes	30 (27.3%)	20 (23.5%)	4 (33.3%)	6 (46.2%)	
14- vacancy period		99 (90.0%)	81 (95.3%)a	9 (75.0%)b	9 (69.2%)b	§0.003*
15- shower frequency		53 (48.2%)	41 (48.2%)	6 (50.0%)	6 (46.2%)	#0.981

*Significant (<0.050), #Chi square test, §Fishers Exact test. Based on post hoc Bonferroni test, homogenous groups took the same symbol (a,b)

Discussion

The lockdown that was enforced by governments as part of the endeavor to control the COVID-19 pandemic involved severe measures, such as house confinement and the closing down of special education systems. Our purpose was to examine the influence of mother, father or both as care provider on the result behavior for children with autism throughout this important life difficulty. Among the studied 110 cases, the main care giver was the mother in 85 (77.3%), father in 12 (10.9%) and both in 13 (11.8%).we had observed significant result regarding positive history of consanguinity and family history of similar condition, in addition to families with more than 3 children(0.010*,0.001*,0.001 respectively).
On March 11, 2020, the World Health Organization (WHO) declared the new coronavirus (COVID-19) outbreak a global pandemic. On March 13, students were instructed to stay at home due to a lockout at their local schools. Students started to get tasks from their lecturers on a regular basis, while others attended classes through video chat. In addition, the Portuguese government began airing classes on television [8]. [8] Egypt, too, had taken this step. The lack of special education meant that certain children were disadvantaged despite attempts to ensure that all children had equal access to school. Because the healthcare system is flexible, children with neurodevelopmental disorders like autism spectrum disorder (ASD) have their treatment interrupted.

In order to assist families in coping with stress, a number of organizations, including WHO and UNICEF, have provided guidance [9]. Parents and guardians of children with ASD are advised by Narzisi et al. [10] to 'explain to your child what COVID-19 is,"structure daily life activities,' 'implement and share special

interests with parents,' and 'keep contact with the school' as ways to adapt this condition during the COVID- 19'stay at home period.'

It is vital that both parents complement one another in their roles as raising their children. Both parents have an important part in helping children grow into healthy, well-rounded individuals, despite the fact that their duties are quite different. Within a family, the roles of mother, father, and children are all unique from one another. They are shaped by the mother's, father's, and child's personalities in general, as well as the quality of the surroundings [11]. The duties of the father and mother are distinct. Parents, both father and mother, are equally important for a child's successful growth [12].

In keeping with this, Baker et al. [13] found that families react differently to the diagnosis, with some becoming closer and others growing apart. Finding out more about the elements that impact family dynamics, such the level of care needed for children, socioeconomic position of families and parents, or marital status of parents, is vital. The study also found that siblings may play a significant role in the care of an autistic child, according to the findings. A study of sibling dynamics, including how gender and age impact sibling dynamics and how siblings cope with having a sibling with autism, is also a viable option.

In this case, it is globally known that the mother plays the most essential part in the lives of children during the prenatal time, with the father's and mother's responsibilities progressively balancing out afterwards. On the other hand, it is incorrect to state that one parent is more vital than the other, since both roles are unique in that a father, despite his best efforts, is unable to supply what a mother requires, and vice versa. Each of them has distinct traits.

According to the findings, a higher level of involvement by fathers was linked to a lower incidence of maladaptive behavior in children; additionally, the effect of maternal depression on child problem behaviors varied according to the degree of involvement by fathers who were actively involved in the parenting of the children [14]. As a result, the likelihood of child problem behaviors and development is reduced. Only a few studies have compared the experience of caring for children with ASD in LMICs and non-Western nations with that of high-income countries, to our knowledge at least [15,16].

Limitations, Implications and Future Directions

As a cautionary note, it is crucial to point up the study's shortcomings, such as the fact that all data was collected by parents rather than directly by children. It was also not taken into consideration that children with high functioning autism were grouped with children with other subtypes, which may have affected the efficiency of adaptation approaches because of the inequalities in cognitive and social functioning between these two groups. Furthermore, caregivers in this research were recruited from a single geographic location; hence, recruiting from a diverse geographic region might assist offer a diverse variety of mother and father experiences. More study extending to a variety of ages, such as teenagers and adults with ASD, would be good to give additional experiences from various age groups.

For the public mental health, it is important for physicians to be aware of the warning signs of the COVID-19 pandemic's impact on mental health, and we must all be prepared for postpandemic surveillance of mental disease.

References

1. Congress of the United States House of Representatives Committee on Oversight and Reform Subcommittee Staff. Preliminary findings of the subcommittee's coronavirus antibody testing investigation.2020. PARR J.: Autism. Am. Fam. Physician., Sep. 15, 78 (6): 758-60, 2008 0r APA 2013
2. CDC. Centers for Disease Control and Prevention. CDC estimates 1 in 68 children has been identified with autism spectrum disorder. 2014. Website: https://www.cdc.gov/ media/releases/2014/p0327autism-spectrumdisorder.html.
3. ZAROFF C. and UHM S.: Prevalence of autism spectrum disorders and influence of country of measurement and ethnicity. Social Psychiatry & Psychiatric Epidemiology, 47 (3): 395-8, 2012.
4. Holmes N, Carr J: The pattern of care in families of adults with a mental handicap: a comparison between families of autistic adults and Down syndrome adults. J Autism Dev Disord 1991, 21:159– 176.
5. Shu BC: Quality of life of family caregivers of children with autism: the mother's perspective. Autism 2009, 13:81–91.
6. WHO Director-General's opening remarks at the media briefing on COVID19 –March 2020. URL: https://www.who. int/dg/speeches/detail/ who-director-general-s-opening-remarksatthe-media-briefing-on-covid-19 -- 11-may-2020.[18.06.2020]. 8. República Portuguesa. Comunicação enviada às escolas sobre a suspensão das atividades com alunos nas escolas de 16 de março a 13 de abril.
7. Pan A, Liu L, Wang C et al (2020) Association of Public Health Interventions with the epidemiology of the COVID-19 Outbreak in Wuhan, China. JAMA 323(19):1915–1923
8. Narzisi A. Handle the autism spectrum condition during the coronavirus (COVID-19) stay at home period: ten tips for helping parents and caregivers of young children. Brain Sci 2020; 10: 207.
9. IŠŇOVSKÝ, Ľ. et al. *Základy rodinnej výchovy.* Banská Bystrica: UMB, 2007.
10. Gežová K C, Father's and Mother's Roles and Their Particularities in Raising Children. Acta Technologica Dubnicae , 2015 (5), issue 1 DOI: 10.1515/atd-2015-0032 45
11. Baker, Jeffrey P. 2013. "Autism at 70 – Redrawing the Boundaries." *The New England Journal of Medicine* 369(12):10891091.
12. Chang JJ, Halpern CT, Kaufman JS. Maternal depressive symptoms, father's involvement, and the trajectories of child problem behaviors in a US national sample. *Arch Pediatr Adolesc Med.* 2007;161(7):697–703
13. Ilias, Kartini, Jeanette Liaw, Kim Cornish, Miriam Sang-Ah Park, and Karen Golden. 2017. Wellbeing of mothers of children with "A-U-T-I-S-M" in Malaysia: An interpretative phenomenological analysis study. Journal of Intellectual & Developmental Disability 42: 74–89.

14. Blake, Jasmine, Eric Rubenstein, Peng-Chou Tsai, Hafizur Rahman, Sarah Rieth, Hasmot Ali, and Li-Ching Lee. 2017. Lessons learned while developing, adapting and implementing a pilot parentmediated behavioural intervention for children with autism spectrum disorder in rural Bangladesh. Autism 21: 611–21.