



The impact of COVID-19 pandemic social restrictions on individuals with autism spectrum disorder and their caregivers in the State of Qatar: A cross-sectional study

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ABSTRACT

Introduction: Previous research has established an association between changes to the daily routine of individuals with Autism Spectrum Disorder (ASD) and increase in maladaptive behaviours. The relationship between maladaptive behaviours in autistic individuals and increase in care burden among their caregivers is also well established. However, no study has yet examined these associations in the context of the COVID-19 pandemic. The main aim of this study was to explore the impact of COVID-19 restrictions on autistic individuals and their caregivers.

Methods: A questionnaire-based cross-sectional study conducted with the caregivers of 58 autistic individuals across the mental health services at Hamad Medical Corporation, Doha, Qatar. The extent of care burden was measured using the Care Burden Interview, whereas changes in behaviour in autistic individuals was assessed using the Revised Overt Aggression Scale.

Results: A total of 58 caregivers participated in the study. Out of these, 24 (41 %) reported a clinically significant increase in their care burden. Among caregivers reporting an increase in care burden, two-third were caring for individuals whose behaviour either remained unchanged or improved during social restrictions. Nine autistic people (15.5 %) were reported to have no aggression prior to the implementation of COVID-19 social restrictions compared to 13 (22.4%) individuals during COVID-19 social restrictions. Minimal, mild and moderate aggression were reported in 27 (46.6 %), 21 (36.2 %), and 1 (1.7 %) patients respectively, before COVID-19 social restrictions compared to 29 (50 %), 15 (25.9), and 1 (1.7 %) during COVID-19 restrictions. Severe aggression was not reported in any patient either before or during COVID-19 social restrictions.

Conclusion: This study showed reduced levels of aggression in autistic individuals but an increase in care burden among their caregivers during the COVID-19 social restrictions highlighting the need of supporting patients and caregivers alike.

What this paper adds?

Burgeoning research evidence suggests that abrupt changes in the daily routine of individuals with autism spectrum disorder (ASD) can exacerbate challenging behavior particularly aggression; however, disruption in daily routine resulting from COVID-19 social

Abbreviations: ASD, autism spectrum disorder; ID, intellectual disability; W, World Health Organisation.

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restrictions has not been studied previously in terms of their impact on autistic individuals. Pandemic related changes in social life can potentially have implications for anyone including autistic individuals and their caregivers. This study expounds on behavioral disturbances in autistic individuals resulting from covid-19 social restrictions. Furthermore, it sheds light on perceived care burden among caregivers of these individuals. This study found a reduction in the level of behavioral disturbance in autistic individuals but an overall increase in care burden of their carers. The study thus highlights the need for healthcare services to mobilise additional resources to support caregivers thereby enabling them to look after themselves and their dependents with ASD.

1. Introduction

Autism Spectrum Disorder (hereafter referred to as ASD/autism/autistic) is a neurodevelopmental disorder characterised by persistent deficits in social communication and social interaction as well as restricted, repetitive, patterns of behaviours, interests or activities (Association, American Psychiatric, 2013). Deficits of this disorder commonly appear in the first few years of life and usually persist into adulthood (Al-Dewik et al., 2020). Autistic individuals tend to engage in repetitive behaviours that take the form of a fixed and rigid routine (Sigman, Arbelles, & Dissanayake, 1995). ASD affects approximately 1 % of the population (Baird et al., 2006; Mandy & Lai, 2016; Meyers, Presmanes Hill, Zuckerman, & Fombonne, 2018), with a male-to-female ratio closer to 3:1 (Loomes, Hull, & Mandy, 2017). The prevalence rate in Qatar (1.17 %) is comparable to that reported worldwide (Alshaban et al., 2019).

Autistic individuals with/without Intellectual disability may exhibit several externalising behaviours collectively called “challenging behaviour”. They are defined as “culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities (Emerson & Bromley, 1995). Challenging behaviour is seen more frequently in autistic individuals compared to those without a diagnosis of ASD. (Holden & Gitlesen, 2006). Furthermore, it is estimated that the prevalence of challenging behaviour in people with Intellectual disability ranges between 15 % and 17.5 % (Koritsas, Iacono, Hamilton, & Leighton, 2008). The prevalence rates of challenging behaviour in individuals with ASD and concomitant intellectual disability (ID) are substantially higher than individuals with ID alone (Emerson et al., 2001).

Challenging behaviours often reported in autism include aggression towards people and objects and self-injury. ASD can be a “risk marker” for self-injury, aggression, and disruptions to the environment when compared to non-autistic individuals with developmental disabilities (McClintock, Hall, & Oliver, 2003). Previous studies have also reported high rates of aggression in autistic individuals towards both caregivers and non-caregivers (Farmer et al., 2015; Kanne & Mazurek, 2011).

1.1. Insistence on sameness, behavioural disturbance and changes in care burden

Research suggests that ‘insistence on sameness’ and ‘preference for routine’ seen in affected individuals are associated with varying degrees of anxiety (Rodgers, Glod, Connolly, & McConachie, 2012). Autistic individuals tend to get irritable and upset easily if changes are made to their daily routine (Autism Speaks, 2012) and it can occasionally result in significant behavioural disturbance. Any changes to the usual routine and structure in the typical day of an individual with ASD is therefore likely to have a significant impact on the family members caring for the affected individual (Norton & Drew, 1994).

The unique social and behavioural challenges of caring for someone with ASD often results in an increased level of stress for the caregiver (Barroso, Mendez, Graziano, & Bagner, 2018; Lee et al., 2012; Rivard, Terroux, Parent-Boursier, & Mercier, 2014). This physical, emotional, and mental strain is known as “caregiver burden.” The caregiver, typically the parent or guardian of the child, is someone who provides the most direct day-to-day care for the individual with ASD.

1.2. COVID-19 pandemic, autism spectrum disorder and care burden

The world witnessed an epidemic breaking out in Wuhan, Hubei province, China in December 2019 with hundreds of people infected on a daily basis initially. The causative organism was later identified as Severe Acute Respiratory Syndrome novel Coronavirus 2 (SARS – CoV-2) and the disease was named COVID-19. The World Health Organization (WHO) declared the outbreak a Public Health Emergency of International Concern in January 2020 and recognised it as a pandemic in March 2020. The disease has since spread to over 200 countries across the globe resulting in over a million people recorded as infected and more than one hundred thousand fatalities.

The first case of COVID-19 was reported in Qatar on 29th February 2020 prompting the government to take several precautionary measures, in line with most other nations as part of the international COVID-19 response. The measures imposed included, as in many other countries, closure of schools and universities, restriction on air travel, limiting access to public places and social distancing, thereby bringing routine life to a virtual halt.

Certain populations may be more vulnerable to the effects of social restrictions resulting from COVID-19. Individuals with neurodevelopmental disorders, particularly those with ASD, as described at the outset, may be especially vulnerable. The measures put in place to check the spread of the disease affected everyone including individuals with mental health illnesses and neurodevelopmental disorders.

While evaluating the health impact of a pandemic of such nature, special consideration must be given to individuals with neurodevelopmental disorders such as ASD. There is significant research evidence to suggest that natural disasters can have profound psychological consequences (Bryant, 2009; Fullerton & Ursano, 2005). Autistic individuals are particularly vulnerable to the effects of such disasters (Hoover, 2015). The COVID-19 pandemic constitutes a great global disaster with the potential to cause unprecedented

levels of stress in the general population. It is likely to have a significant impact on people with mental illness, particularly autistic individuals given the uncertainty and the unforeseen changes in daily life (Wigham, Rodgers, South, McConachie, & Freeston, 2015). It is recognised that autistic individuals are overwhelmingly likely to experience mental illness (Cvejic, Arnold, Foley, & Trollor, 2018; Hofvander et al., 2009; Lever & Geurts, 2016). ASD with co-occurring intellectual disability may render an individual even more vulnerable in this regard.

The association between changes in daily routine and maladaptive behaviours (aggression, self-injury and severe tantrums) in autistic individuals is well established. Such maladaptive behaviors and lack of functional independence in autistic individuals can increase care burden in caregivers thereby impacting their quality of life (Kheir et al., 2012; Lin, 2011). Previous research also suggests maladaptive behaviours displayed by autistic individuals can cause more stress to caregivers and families than the core symptoms of the condition (Hastings et al., 2005; Lecavalier, Leone, & Wiltz, 2006). However, to the best of our knowledge, such associations have not been explored in the context of a pandemic before. Although most unwelcome, this pandemic provided a rare opportunity to evaluate its impact on the lives of autistic individuals and their caregivers.

1.3. The current study

This study aimed to explore the perceived impact of COVID-19 restrictions on autistic individuals and the associated care burden as reported by their caregivers. In particular, we were interested to know whether caregivers reported any changes in the behavior of autistic individuals and their own perceived care burden. We were further interested to see whether any differences existed in the severity of behavioural disturbance and associated care burden in individuals with co-occurring diagnoses of ID and ASD compared to their counterparts with ASD alone as reported by their caregivers. Another point of interest was to explore whether the level of perceived care burden varied with the gender of the individual with ASD.

2. METHOD

2.1. Design and participants

This was a questionnaire-based, cross-sectional study conducted within the Child and Adolescent Mental Health Service (CAMHS) and Adult Psychiatry Service, Hamad Medical Corporation, Qatar.

The primary caregivers of all individuals with a confirmed diagnosis of ASD under the care of the Mental Health Service, Hamad Medical Corporation, were included in the study. The list of participants was obtained through individual caseloads of clinicians and further corroborated by the data monitoring team in the main psychiatry department at Hamad Medical Corporation. The presence of a formal diagnosis of a mental disorder in the caregivers was considered an exclusion criterion.

A total of 99 participants, of whom 76 known to the Child and Adolescent mental health service and the remaining 23 to the Adult Psychiatry Service, were therefore assessed for eligibility. No parent or caregiver reported an established history or diagnosis of a mental disorder and therefore the size of the final sample remained 99 after applying the exclusion criteria. However, 41 participants could not be included as they either refused to participate or were unreachable, reducing the final sample size to 58.

Data were collected between 14th May 2020 and 30th June 2020. There was no change in the level of social restrictions during this period in the state of Qatar.

2.2. Ethical considerations

The study was reviewed and approved by the Medical Research Center (MRC-05-027) and the Institutional Review Board (IRB) at Hamad Medical Corporation, Qatar. Phone calls were made to all caregivers included in the sample to invite them to the study. All information relevant to the study including its purpose, impact on clinical care and confidentiality safeguards were provided. This process was completed using an invitation form with a standard script that was developed specifically for this study, in both English and Arabic languages.

Consent of the participating caregivers and their dependents (individuals with ASD), where applicable, was recorded on the respective invitation forms. Responses were not tagged to any personally identifiable information. All data was anonymised after collection.

2.3. Measures

We used the following two instruments based on previously validated questionnaires:

2.3.1. Revised overt aggression scale (ROAS)

The ROAS was adapted from the Modified Overt Aggression Scale (MOAS) (Sorgi, Ratey, Knoedler, Markert, & Reichman, 1991), itself a modified version of the Overt Aggression Scale (OAS) (Yudofsky, Silver, Jackson, Endicott, & Williams, 1986), that was originally developed to measure the change in levels of aggression among people with mental disorders.

The MOAS divides aggression of the subject over the past week into four categories: (1) verbal aggression; (2) physical aggression against objects; (3) physical aggression against self; and (4) physical aggression against others. Each type of aggression is given a rating of 0 when that aggression is absent. When present, it may be rated at any one of the four levels of severity. The score in each category is

multiplied by its allocated weight factor and then summed to yield a total aggression score. The range of total score on the MOAS can therefore range from 0 to 40 depending on the severity of aggressive behaviour: no aggression = 0, minimal aggression = 1–10, mild aggression = 11–20, moderate aggression = 21–30, and severe aggression = 31–40.

The MOAS has been used in studies involving individuals with intellectual disability and autism for almost three decades now. The inter-rater reliability of the MOAS is very high with a mean of 0.93 (range 0.85–0.98) and an overall weighted kappa of 0.58 or moderate reliability (Altman & Bland, 1991; Kho, Sensky, Mortimer, & Corcos, 1998).

The ROAS (Appendix 1) is a purposely designed version of the MOAS devised by the investigators of this study to assess any changes in aggressive behaviour (extent of behavioural disturbance) specifically in the context of a global stressor such as a pandemic. No changes were made to the content of the original MOAS and the only adaptation made was to enable its use for comparing the severity of aggression between two different time periods i.e. before and during the pandemic's social restrictions rather than measuring it at a specific time only. The Arabic version of MOAS used for the study had previously been used reliably in previous studies (Assaf, Abd El-Hay, Eissa, & Abohammar, 2018; Elzahr, 2004; Sehlo, Youssef, Hussein, & Elgohary, 2015).

2.3.2. Caregiver burden interview (CBI)

This scale was adapted by the investigators from the 22-item version of the Zarit Burden Interview (ZBI-22; Zarit, Orr, & Zarit, 1985) to assess the change in care burden experienced by caregivers. The ZBI-22 is the reduced form of the original 29-item Zarit burden interview developed in 1980 (Zarit, Reever, & Bach-Peterson, 1980). The Zarit Burden Interview scale is the instrument most consistently used in research to measure care burden among caregivers of autistic individuals, dementia and intellectual disability (Bédard et al., 2001; Oshodi, Umeh, Afolabi Lesi, Eigbiki-Aideyan, & Adeyemi, 2014; Pandey & Sharma, 2018). Moreover, it has been used to measure a change in the level of care burden over time (Bédard, Molloy, Pedlar, Lever, & Stones, 1997) and to differentiate between study participants (Molloy, Lever, Bédard, Guyatt, & Butt, 1996). The Arabic version used in the study was adapted from the ZBI-A, the validity of which has been established previously (Bachner, 2013).

The scale used in this study (CBI) consisted of 12 items derived from ZBI-22 that were considered most relevant to the context i.e. tailored to measure the difference between levels of care burden among caregivers of autistic individuals before and during the social restrictions imposed to control the COVID-19 pandemic. The items reflect how a caregiver feels when they are taking care of their dependents with significant care needs. The likert scale was amended to make it suitable for caregivers to rate care burden changes before and during the pandemic appropriately (Appendix 2). The responders were expected to specify their level of agreement to each of the 12 items comparing their level of stress between the two time periods, by choosing the most suitable point out of the 5 points on the likert scale: 0) Strongly disagree; 1) Disagree; 2) Neither agree nor disagree 3) Agree; 4) Strongly Agree. The range of score per item was 0–4, with a total score range of 0–48. A score of 25 or more is considered clinically significant given a score of 2 on each item means no change.

These instruments (ROAS & CBI) were administered by healthcare professionals, proficient in both English and Arabic languages comprising two senior psychiatric nurses with a background in Child and Adolescent Mental Health and General Adult Psychiatry services were given a two-hour training in administering the tools which included practice sessions aimed at enhancing inter-rater reliability. These sessions were provided by two of the study's authors.

The original text in previously standardised Arabic versions of both the questionnaires was retained to ensure the meaning remained unchanged. Furthermore, a pilot was conducted on the first five respondents to ensure standardisation.

2.4. Statistical analysis

Demographic variables and scores on both scales were presented using means and frequencies. A paired *t*-test was used to compare results in overt aggression scores before and after COVID-19. A chi-square test was used to compare the categorised variables. A linear regression test was used to predict overt aggression from the care burden. The analysis was conducted using the Statistical Product and Service Solutions (SPSS) version 22. A *p*-value of ≤ 0.05 was considered statistically significant.

Table 1
Clinical and demographic information of patients with ASD.

	Number (n)	Percentage (%)
Age		
<18 years	43	74.1
18 years or more	15	25.9
Gender		
Male	48	82.8
Female	10	17.2
Diagnosis		
ASD	26	44.8
ASD & ID	32	55.2

3. Results

3.1. Sample characteristics

A total of 58 caregivers, all parents of autistic individuals, participated in the study with a response rate of 57 %. The age-range of autistic individuals studied was 6–28 years (mean = 14.8 years) with 48 being males and 10 females. A total of 26 individuals had a diagnosis of ASD alone whereas 32 had a diagnosis of intellectual disability in addition to having a diagnosis of ASD (Table 1).

Majority of the participants of the study (43/58) were caregivers of children and young people aged 0–18 years with 16 autistic individuals having a diagnosis of ASD only and 27 with combined ASD and Intellectual disability. The remaining 15 participants out of the total 58 were caregivers for adults with 10 individuals having ASD only and the remaining 5 with combined ASD and Intellectual disability.

3.2. Care burden scores

Among the study sample, 24 caregivers (41.4 %) reported a clinically significant increase in the extent of care burden compared to before COVID-19-related restrictions were enforced. This increase in the extent of care burden was seen more commonly in caregivers of adult autistic individuals (9/15 = 60 %) compared to those caring for children or young people under the age of 18 (15/43 = 34.8 %). Taken separately, the proportion of caregivers who reported an increase in the level of care burden was higher in the ASD alone group (46.2 %) compared to the ASD and ID combined group (37.5 %). See Table 2.

3.3. Overt aggression scores

A total of 9 (15.5 %) autistic individuals were reported to have no aggression prior to enforcement of COVID-19 restrictions compared to 13 (22.4 %) during COVID-19 restrictions. Minimal, mild and moderate aggression was reported in 27 (46.6 %), 21 (36.2 %), and 1 (1.7 %) autistic individuals, respectively, before COVID-19 restrictions compared to 29 (50 %), 15 (25.9), and 1 (1.7 %) during the restrictions. Severe aggression was not reported in any individual either before or during COVID-19 social restrictions.

As seen in Table 3, the number of autistic individuals with no aggression increased by 4 (6.9 %). Overall, there was a reduction in aggression scores during the restrictions. Only 9 (15.5 %) autistic individuals were reported to have a worsening in their behaviour during social restrictions compared to before their implementation, 22 (38.9 %) were reported to have reduced aggression and the remaining 27 (45.6 %) were reported to have no change in their level of aggression. The mean and standard deviation of OAS scores before and during COVID-19 restrictions can be seen in Figs. 1 and 2, respectively. The difference between these scores was found not to be statistically significant ($p = 0.30$).

It is interesting to note the addition of 4 autistic individuals reporting no aggression during restrictions belonged to the combined group i.e. ASD and ID. Likewise, the only patient in the moderate aggression group before COVID-19 belonged to the combined group but moved to a category with lower aggression during COVID-19. On the contrary, there were no individuals with moderate aggression before COVID-19, but one during COVID-19 in the ASD only group.

3.4. Association between change in aggression levels and extent of care burden

A linear regression analysis was used to test if care burden predicted overt aggression before COVID 19. The results showed that the predictor explained 14.8 % of the variance ($R^2 = 0.148$, $F(1,56) = 9.717$, $p = .003$). As for after COVID 19, the results showed that the predictor explained 29.6 % of the variance ($R^2 = 0.296$, $F(1,56) = 32.497$, $p = .000$).

Behaviour either remained the same or improved in 49 individuals (84.4 %) during COVID 19 restrictions. Among the caregivers of these 49 autistic individuals, 16 belonged to the 24 reporting a clinically significant increase in care burden. Thus two-third of the caregivers with increased perceived care burden reported no change or improvement in behavior of their dependents. However, the remaining eight caregivers with increased perceived care burden reported a worsening in aggressive behavior of their dependents.

3.5. Gender variations

The proportion of caregivers reporting care burden increase was higher for male autistic individuals (43.7 %) compared to females (30 %). The remaining 56.3 % of males and 70 % of females scored below 25 on the CBI. Similarly, a reduction in aggression scores was reported more in the female group (Table 4).

Table 2

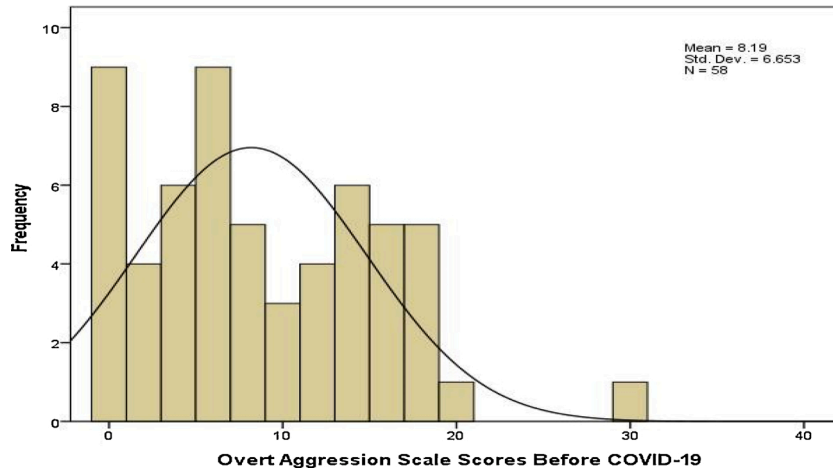
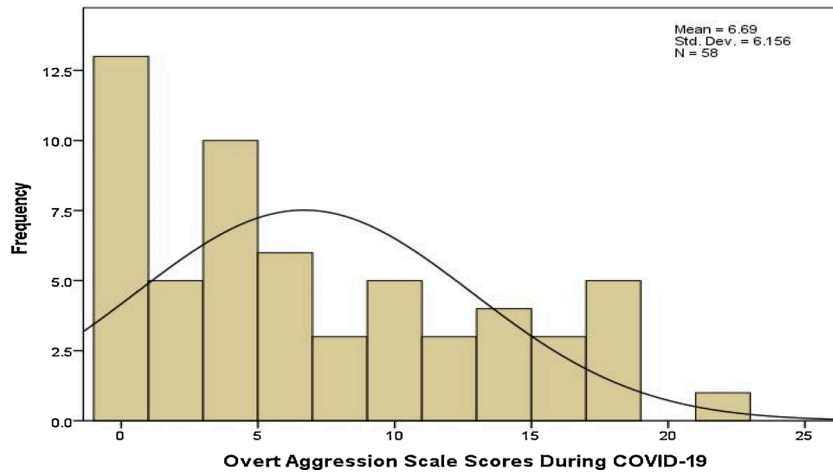
CBI scores in ASD alone compared to ASD and ID.

CBI Score	Group		P-value
	Autism with ID n (%)	Autism no ID n (%)	
Score less than 25	20 (62.5%)	14 (53.8 %)	0.506
A score of 25 or more	12 (37.5 %)	12 (46.2 %)	

Table 3

Severity of aggression before and after COVID19 social restrictions.

	OAS scores before COVID-19			OAS scores during COVID-19		
	ASD and ID	ASD alone	P-value	ASD and ID	ASD alone	P-value
No aggression (0)	1 (3.1 %)	8 (30.8 %)	0.018	5 (15.6 %)	8 (30.8 %)	0.195
Minimal (1–10)	15 (46.9 %)	12 (46.2 %)		16 (50.0 %)	13 (50 %)	
Mild (11–20)	15 (46.9 %)	6 (23.1 %)		11 (34.4 %)	4 (15.4 %)	
Moderate (21–30)	1 (3.1 %)	0 (0 %)		0 (0 %)	1 (3.8 %)	

**Fig. 1.** Overt Aggression Scale Scores Before COVID-19 Social Restrictions.**Fig. 2.** Overt Aggression Scale Scores During Covid-19 Social Restrictions.**Table 4**

Care burden and Gender distribution.

Severity	OAS scores before COVID-19 social restrictions			OAS scores during COVID-19 social restrictions		
	Gender n (%)		P-value	Gender n (%)		P-value
	Male	Female		Male	Female	
No aggression	7 (14.6)	2 (20)	0.914	10 (20)	3 (30)	0.878
Minimal aggression	23 (47.9)	4 (40)		24 (50)	5 (50)	
Mild aggression	17 (35.4)	4 (40)		13 (27.1)	2 (20)	
Moderate aggression	1 (2.1)	0 (0)		1 (2.1)	0 (0)	

4. Discussion

The current findings showed positive outcomes for autistic individuals in terms of levels of aggression during the pandemic-related social restrictions. There was a reduction seen in the proportion of autistic individuals with aggressive behaviour during the restrictions compared to when these restrictions were not in place. This is an interesting finding given the observation that changes in routine or environment of an individual with ASD can lead to behavioural disturbance with symptoms of anxiety, irritability and aggression (Kanner, 1943; Volkmar & Cohen, 1994). This finding is not consistent with the general impression that disruption in daily routine caused by COVID-19 social restrictions might result in emergence or exacerbation of behavioral disturbance in autistic individuals.

More autistic individuals were found to be in the 'no-aggression' group during the pandemic than before. Likewise, there was a clear reduction in the number of individuals in the moderate and severe aggression categories with an accompanying increase in the number of individuals in the lower aggression categories. The overall trend was quite clear in that a large number (88.4 %) of autistic individuals were reported by their caregivers to have either a reduction or no change in their level of aggression during COVID-19 restrictions. The reason behind this curious reduction or no change in aggression levels could be twofold. Firstly, since many autistic individuals prefer a routine, it is possible that their routine is eventually maintained more by staying at home rather than venturing out. During the pandemic, mandatory restrictions on movement meant most people stayed indoors most of the time. This could have in fact helped individuals to remain unperturbed in their routine. Previous studies examining the hypothesis that social behaviour and self-regulation of children is improved during outdoor activities compared to indoor ones have concluded different outcomes (Chang & Chang, 2010; Von Kampen, 2011). Our study concluded that the behaviour of individuals with ASD or/and Intellectual disability improved when they stayed homebound for longer periods.

There is, however, a second reason which appears more plausible to put forward. Previous studies have demonstrated that factors such as family functioning (Baker, Seltzer, & Greenberg, 2011) and quality of family life (Ng et al., 2015) help family members to cope with challenges. Family cohesion, one dimension of family functioning, refers to the emotional bonding that family members have towards one another, which includes the amount of time family members spend together and their involvement in each other's activities (Ekas et al., 2016). The fact that during COVID-19 social restrictions, most families remained housebound must have resulted in caregivers spending more time with their dependents. This may have provided most autistic individuals an anticipated and consistent routine in addition to more effective management of their needs resulting in a reduction in the severity of maladaptive behaviour. This higher level of personal care, however, must have come at the expense of the psychological well-being of the caregivers. Most individuals with ASD and other developmental disabilities usually have access to specialist services for daily support, which was likely disrupted by the COVID-19 pandemic, compelling the caregivers to take up additional roles and responsibilities in addition to basic care provision. Caregivers were probably compelled to compensate, to different extents, for care previously provided by different professionals looking after the individual: specialist education teachers, occupational therapist and speech, language therapists, and so forth.

Our study confirmed that COVID-19 restrictions resulted in an increase in the care burden for many caregivers. This finding is consistent with the explanation that improvement in maladaptive behaviours may come at the expense of more care burden. This is corroborated by our finding that behavior either remained the same or improved in most autistic individuals whose caregiver reported an increase in care burden. A point worthy of mention here is that more than half (58.6 %) caregivers reported no change or reduction in their care burden. All these caregivers looked after autistic individuals in whom behavior remained the same or improved except one whose behavior worsened. This does contrast with our previous impression that COVID-19 restrictions resulted in reduced challenging behaviour in autistic individuals at the expense of an increase in the level of care burden in their caregivers.

These competing findings can further be explained by the fact that ASD, by definition, is a dimensional disorder with different individuals with the condition, having their unique set of challenges and needs. Sensory features in autistic individuals are prevalent and highly heterogeneous (Ausderau et al., 2014; O'Donnell, Deitz, Kartin, Nalty, & Dawson, 2012). Individuals with ASD and coexisting significant sensory needs may prefer to stay indoors to be able to cope with their sensory deficits and may therefore not exhibit any change when staying indoors despite disruption to their normal life routine. Then there are individuals who may have a strong preference for routine and may therefore display challenging behaviour when the structure to their typical day of living is disrupted. Another group is the one that responds positively to stimulating activities in their usual places of learning and may therefore become disturbed in behaviour when compelled to stay indoors.

Having a diagnosis of intellectual disability in addition to ASD appeared more favourable for behaviour compared to the group with ASD only; however, a relatively small sample size may have influenced this inference. As discussed previously, we also found that the proportion of caregivers who reported an increase in the level of care burden was higher in the ASD alone group (46.2 %) compared to the ASD and ID combined group (37.5 %). Activities of daily living can become challenging for individuals with ID and contribute to emotional dysregulation (Noel, 2018). Therefore, the relatively more favorable outcome for the combined group (ASD and ID) could be due to the fact that social restrictions made navigating through daily life challenges simpler and more predictable.

4.1. Limitations and future directions

The study was conducted a few months after COVID-19 restrictions were implemented which could have allowed autistic individuals some time to adapt to their new routine. Thus, it is possible that behavioral disturbance occurring during the first few days or weeks may have improved over the next few weeks or months. The relatively small size of the study sample may also be considered a limitation. However, since similar restrictions were implemented worldwide, it is possible that similar outcomes are seen elsewhere

thus making the findings of this study generalisable.

Qatar is fortunate to be among the few countries with its own National Autism Strategy. This has not only set the direction for improving care for autistic individuals but has enhanced awareness among caregivers and the general public. In order to ensure that autistic individuals as well as their carers receive the best care and support in Qatar as well as the broader region, this study offers practical recommendations for healthcare professionals and policy makers and highlights the need for adding a range of specialist mental health services for both autistic individuals and their caregivers. The study strongly points toward the need for inclusive services in the region e.g. appropriate supported accommodation and/or respite care services. Since Qatar has a diverse population, one study cannot capture caregivers' view fully. Further research is needed to explore the specific needs of autistic individuals and their families in order to improve their well-being and quality of life.

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Author contribution

Yasser Saeed Khan: Corresponding author (ykhan5@hamad.qa). Conceptualisation, methodology, project administration, investigation, writing-original draft, writing-review and editing, visualisation.

Abdul Waheed Khan: Conceptualisation, methodology, project administration, investigation, writing-original draft, writing-review and editing, visualisation.

Mohamed El Tahir: Conceptualisation, methodology, writing-review and editing.

Samer Hammoudeh: Formal analysis, writing-review and editing.

Mahmoud Shamlawi: investigation, writing-review and editing.

Majid Alabdulla: Conceptualisation, methodology, project administration, writing-review and editing, supervision

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Declaration of Competing Interest

The authors declare that there is no conflict of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.ridd.2021.104090>.

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