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Adaptive response of Italian young adults with autism to the COVID-19 pandemic: A longitudinal study



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ABSTRACT

The COVID-19 pandemic has represented a hazardous situation for individuals with Autism Spectrum Disorder (ASD) and their families. The difficulties, following the COVID-19-derived lockdown, have involved working from home or loss of employment, and the demands of looking after their children without the daily support of specialists. The aim of this study was to evaluate the adaptive behaviour of young adult participants with ASD after the enforcement of lockdown measures in March 2020 in a specialised centre in central Italy, by administering the Italian form of the Vineland Adaptive Behaviour Scales Second Edition (VABS-II), at baseline as well as 6 months and 1 year after the lockdown. Participants with ASD who were not able to access their normal, in-person care – they were only followed at a distance (i.e. telehealth) – declined dramatically in their adaptive behaviour during the first months after the lockdown for some VABS-II dimensions such as the socialisation and daily living domains. The effects of the lockdown on adaptive behaviour remained after 1 year. Our results emphasise the need for immediate, continuous and personal support for people with ASD during and after the restrictions caused by the COVID-19 pandemic, in order to ensure at least partial recovery of adaptive functioning.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic has presented unprecedented global health, social, economic, and political challenges (Mazza et al., 2020; Siracusano et al., 2021). The levels of anxiety and stress linked to COVID-19 have affected the quality of life of the general population, but vulnerable populations such as individuals with psychiatric conditions are known to be overly influenced (Mutluer et al., 2020). Indeed, this pandemic has represented a hazardous situation for individuals with Autism Spectrum Disorder (ASD) and their families (Siracusano et al., 2021). In general, changes can produce more anxiety and stress for people with ASD, especially if the changes are consequences of negative events. Valenti et al. (2012) showed that individuals with ASD had decreased adaptive behaviours after exposure to the L'Aquila earthquake in 2009. Thus, catastrophes cause lifestyle changes in the autism population.

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In a systematic review, Panda et al. (2021) collected articles focused on psychological and behavioural complications in children and adolescents both with and without pre-existing behavioural problems and their caregivers related to COVID-19. Panda et al. (2021) concluded their systematic review explaining that children with pre-existing behavioural problems, such as ASD, have a high probability for worsening of their behavioural symptoms during the pandemic. In addition, the literature reports that the caregivers have more worry about the impaired behaviour and psychological symptoms seen in their children during COVID-19.

Considering that ASD involves social interaction impairment, restricted and repetitive behaviours, and the need for specific and personalised rehabilitation intervention, people with ASD have faced greater psychological, physiological, and social difficulties than those experienced by the general population (Mutluer et al., 2020). Moreover, the parents of individuals with ASD have faced a difficult challenge strictly related to the COVID-19 outbreak: the guidance and handling of their children. Indeed, during lockdown enforced by the Italian Government (9 March–5 May 2020), rehabilitation activities in centres were interrupted for individuals with ASD with good functioning or reduced to a minimum for individuals with ASD with low functioning. Telehealth interventions were implemented to ensure or to integrate minimal take-in-charge and family support. Naturally, the activity conducted in the rehabilitation centres for ASD after the lockdown reflected the limitations arising from changes in the specific setting; the lives of the families and caregivers of ASD; the overall precariousness of town services, including transport and social and family assistance; and the substantial decrease in economic activities that led to radical changes in average income and quality of life for most families.

In the gradual re-opening phase after the compulsory home confinement, high-functioning individuals with ASD were ensured telehealth and remote computer-driven active learning, while low-functioning individuals were readmitted to full activity in the centres. During the summer of 2020, the pressure of the COVID-19 pandemic was low in Italy. However, a strong second wave affected most Italian regions from October 2020 to February 2021, with consequent restriction of activities based on weekly local incidence rates.

Eshraghi et al. (2020) underlined that the difficulties faced by parents of individuals with ASD increased with the pandemic. These difficulties involve working from home or loss of employment and the demands of looking after their children without the daily support of specialists. Asbury et al. (2020) declared that during COVID-19, parents of individuals with ASD have reported increased anxiety and fear, accompanied by increased distress, stress, and low mood. Amorim et al. (2020) conducted an observational, cross-sectional, and analytical study to explore how children with ASD and their parents experienced the social isolation during COVID-19. Specifically, Amorim et al. (2020) applied an anonymous questionnaire that included children's demographic and clinical characteristics, along with the impact of the COVID-19 outbreak in different aspects of the family's daily life. The majority of parents of ASD children reported a negative impact in emotion management. Additionally, caregivers reported higher mean scores of anxiety levels in themselves and in their children. Thus, the results of Amorim et al.' (2020) study show a potentially important psychological impact of the COVID-19 pandemic not only in children with neurodevelopmental disorders but in their caregivers as well.

To confirm this evidence, Cusinato et al. (2020) showed that changes in daily routine during COVID-19 negatively affect parents' psychological dimensions, thus exposing children to a significant risk to their well-being. Specifically, in their study, Cusinato et al. (2020) detected some risk factors for psychological maladjustments of children, such as parental stress, changes in working conditions, and parental psychological problems. Another study conducted on the parents of individuals with ASD during the COVID-19 pandemic revealed increased difficulties in managing daily activities, including free time and structured activities, and more frequent behavioural problems in their children (Colizzi et al., 2020). These difficulties led to a worsening of ASD clinical features, with special regard to the ones concerning behaviour, after the lockdown (Eshraghi et al., 2020; Siracusano et al., 2021). The lockdown due to COVID-19 required isolation and quarantine and interfered with family norms and routine, inducing widespread anxiety and psychological problems in individuals with ASD. The symptomatology of people with ASD has worsened after the pandemic: increased stereotypies, aggression, hypersensitivity, behavioural problems, and sleep and appetite alterations have occurred (Mutluer et al., 2020).

In our study, we evaluate the adaptive behaviour in ASD during the COVID-19 pandemic through the Vineland Adaptive Behaviour Scale (VABS-II). Adaptive behaviour is defined by the extent to which a person is capable of being self-sufficient in real-life situations, including the functional use of communication, socialisation, daily living, and motor skills (Sparrow et al., 1984, 2005a, 2005b). In addition, adaptive behaviour is the collection of conceptual, social, and practical skills that have been learned and are performed by people to function in their everyday lives (Del Cole et al., 2017; Schalock et al., 2010). According to Mouga et al. (2016), adaptive behaviour in autism is positively correlated with intellectual profile, especially in the communication domain. The literature agrees in defining an adaptive functioning profile for people with ASD. Previous adaptive behaviour findings in children, adolescents, and young adults with ASD showed significant deficits in the socialisation domain compared to a relative ability in the daily living skills and communication domains (Pugliese et al., 2015; Szatmari et al., 2003; Volkmar et al., 1987). Thus, the adaptive functioning in ASD would be described in terms of "strongest to weakest domains": the stronger domain is daily living, whereas the weakest domain is socialisation (Del Cole et al., 2017).

1.1. Objective

The purpose of this study was to evaluate the intermediate- and long-term adaptive behaviour of young adult participants with ASD for 1 year after their exposure to the general COVID-19 lockdown enforced in Italy beginning in March 2020.

The a priori hypothesis of this study was those people with ASD exposed to the lockdown show a clear decline in adaptive functioning over time with respect to before COVID-19 pandemic.

2. Method

We conducted a longitudinal study comparing the scores obtained on the Vineland Adaptive Behaviour Scales Second Edition (VABS-II) of participants with ASD for three different times: at baseline (T0), after 6 months (T1), and after 1 years (T2) from the lockdown due to the COVID-19 pandemic. A group of 44 young adults with ASD (14 females, 30 males; age range 18–35 years), all diagnosed and followed up before the pandemic in the context of the rehabilitation programme established at the Regional Reference Centre for Autism in L'Aquila, Italy (Valenti et al., 2019), participated in this longitudinal study. The diagnosis was made by experienced clinicians, according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5) (American Psychiatric Association (APA), 2013) and using the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) (Lord et al., 2012), and the Childhood Autism Rating Scale Second Edition - Standard Version (CARS 2-ST) (Schopler et al., 2010) for ASD individuals with communication difficulties and intellectual disability. All ASD participants were classified as level 1, level 2, or level 3 according to the DSM-5 criteria. Because intellectual disability can significantly impact the prognosis of individuals with ASD, intelligence quotient (IQ) was assessed with the Wechsler Adult Intelligence Scale – Fourth Edition, Italian version (WAIS-IV) (Wechsler, 2008a, 2008b), and the Leiter International Performance Scale – Third Edition (Leiter-3) (Roid, Miller, & Koch, 2013), according to language abilities of ASD participants. Psychometric testing identified 19 out of 44 participants with ASD (43 %) as having an intellectual disability data are showed in Table 1.

2.1. Procedure

Before the lockdown enforcement, participants with ASD were attending semi-residential rehabilitation centres for autism and underwent adaptive behaviour assessment with the VABS-II (T0) in person. In the period of September–October 2020, all participants with ASD underwent an intermediate (T1) adaptive behaviour evaluation, and in the period of March–April 2021, all ASD participants underwent a final adaptive behaviour evaluation (T2). For T1 and T2, the adaptive behaviour evaluation was conducted in telematic mode.

All participants or their legal tutors (parents or other), when necessary, gave informed consent to participate in the study. The study was conducted in accordance with the Declaration of Helsinki and the rules of good clinical practice and ethics in public mental health service and was officially approved and authorised by the local ethical committee.

2.2. Clinical measures

2.2.1. Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012)

The ADOS-2 (Lord et al., 2012) is a semi-structured and standardised test used for the diagnosis of ASD. It consists of five modules that are administered according to the age and level of expressive language of the individual. In our study, modules 3 and 4, which can be used for adolescents and adults with fluent language, were used. An expert performs specified activities with the examinee, coding items for the appropriate module. Each item of the test can be coded as 0 when there is no evidence of abnormal behaviour, 1 when it is slightly abnormal, and 2 when the behaviour is markedly abnormal. Each coded item passes through an algorithm to obtain a social affect (SA) score and a restricted and repetitive behaviour (RRB) score that can be summed to obtain a total score. Diagnosis of ASD is made based on the results of these measures, using cut-off points.

2.2.2. Childhood Autism Rating Scale Second Edition - Standard Version (CARS 2-ST; Schopler et al., 2010)

The CARS 2 (Schopler et al., 2010) is the recent form of the CARS (Schopler et al., 1980), which investigates 15 areas of behaviour in the identification of individuals with ASD. It is based on direct observation of the behaviour and on the parameters of frequency, intensity, specificity, and duration that characterise it. The scores for each of the 15 items range from 1 to 4. A score of 1 indicates that the subject's behaviour is within the normal range concerning age, and a score of 4 indicates that the behaviour is severely abnormal. In addition to the four scores, it is possible to use intermediate scores (1.5, 2.5, 3.5). A total score is determined by summing the ratings

participants.	
	MEAN (SD)
Chronological age	21.95 (5.78)
Gender (F; M)	14; 30
ADOS-2	
SA	13.2 (4.14)
RRB	2 (2.4)
TOTAL	13.7 (3.8)
CARS 2-ST	
TOTAL	35.5 (4.26)
IQ TOTAL	
WAIS-IV	82.5 (7.23)
LEITER-3	63.71 (14.26)

Table	1							
Mean	score	of	clinical	and	cognitive	data	of	ASD

on all 15 items. The CARS 2 total scores range from a minimum of 15 (within normal limits on all items) to a maximum of 60 (severely abnormal on all items). This new version comprises three modules: CARS2- Standard Version (CARS 2-ST), High-Functioning Version (CARS2-HF), and a Questionnaire for Parents or Caregivers (CARS 2-QPC). In our study, the CARS 2-ST module was used, because it can be administered in subjects of all ages with communication difficulties or an IQ estimated to be below average (< 79).

2.3. Adaptive behaviour measure

2.3.1. Vineland Adaptive Behaviour Scales Second Edition (VABS-II)

The Italian form of the VABS-II (Sparrow et al., 2005a, 2005b, 2008) was used to assess the adaptive functioning of the participants. Three VABS II skill domains were used in this study: communication (receptive, expressive and written language skills), daily living (personal self-care, domestic living skills and community living skills) and socialisation (interpersonal skills, play and leisure and coping skills). To ensure greater reliability, the VABS II-II was administered to each participant's parent by the same professional at the three scheduled times.

The VABS II provides standard scores (M = 100, SD = 15), and higher scores indicate better functioning. VABS II scores can range from four *SDs* below the mean to more than two *SDs* above the mean in individuals with autism with and without co-morbid mental retardation (Klin et al., 2007; MacLean et al., 1999). The importance of adaptive behaviour variability in autism is underscored by its strong contribution to prognosis (Gillham et al., 2003). Identifying sources of variability in adaptive behaviour is critical to obtain a more complete picture of development in autism and to identify treatment targets (Mazefsky et al., 2008). All forms of the VABS-II can be used to measure the effectiveness of intervention strategies. The VABS II is sufficiently sensitive to test the effects of a treatment on several aspects of autism. The VABS-II norms used for comparison with the sample where those for individuals with disabilities. For the purposes of our study, the Survey Interview Form was administered.

2.4. Data analysis

Differences in VABS-II scores for the three measure times (T0 vs T1 vs T2) were assessed by performing repeated measures analysis of variance (ANOVA). Effect sizes were evaluated through partial eta squared (partial η^2). Sphericity was assessed by Mauchly's test; a violation was corrected through the Greenhouse–Geisser correction. Any significant results were further explored by post hoc comparisons. The alpha level was set at 5 %. As a subsequent analysis, we considered age, gender and IQ as covariates in order to adjust outcomes for possible significant interactions.

3. Results

3.1. VABS-II communication domain

There were no significant differences in this dimension among the three measure times.

3.2. VABS-II socialisation domain

The repeated measures ANOVA with a Greenhouse–Geisser correction showed that mean interpersonal relationships scores differed significantly between time points, F(2,40) = 5.82, p = .016, partial $\eta^2 = .225$. The post hoc test revealed that it did not change significantly between T0 (M = 50.57, SD = 8.68) and T1 (M = 48.00, SD = 5.08); however a significant difference was found between T0 and T2 (M = 37.05, SD = 21.27; $M_{dif} = 13.52$, SE = 5.17, p = .017) and between T1 and T2 ($M_{dif} = 10.95$, SE = 4.54, p = .026), indicating an overall reduction in this measure at T2.

Table 2

Mean scores and comparison of Vineland sub-	scales measured at each time points.
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Vineland subscale	Mean (SD) at each time point			F (2,40)	р	Post-hoc comparison
	Т0	T1	T2			
Reception	31.95 (4.17)	33.88 (2.13)	33.00 (1.89)	2.45 ^a	0.121	-
Expression	85.14 (12.52)	81.38 (10.77)	82.81 (20.38)	0.58	0.561	-
Writing	35.57 (4.35)	35.50 (1.87)	38.24 (6.24)	2.95	0.064	-
Interpersonal Relationships	50.57 (8.68)	48.00 (5.08)	37.05 (21.27)	5.82 ^a	.016*	T0 > T2
Play and Leisure	45.38 (7.61)	41.75 (7.90)	46.38 (3.11)	3.01	0.082	-
Social Rules	33.52 (10.71)	25.88(12.40)	34.38 (12.50)	1.39	0.281	_
Personal	71.19 (4.98)	66.75 (3.92)	64.33 (7.15)	8.49	0.001*	T0 > T1&T2
Domestic	34.48 (9.34)	31.50 (4.78)	24.71 (7.79)	11.44 ^a	.001*	T0&T1 > T2
Community	49.48 (10.56)	47.25 (4.46)	44.62 (7.73)	2.04	0.143	-

^a Denotes Greenhouse-Geisser correction.

Denotes p < .05

3.3. VABS-II daily living domain

A significant difference was also found for the domestic score after applying the Greenhouse–Geisser correction: F(2,40) = 11.44, p = .001, partial $\eta^2 = .364$. The *post-hoc* tests revealed a lower score at T2 (M = 24.71, SD = 7.79) compared with T0 (M = 34.48, SD = 9.34; $M_{dif} = 9.76$, SE = 2.37, p = .001) and T1 (M = 31.50, SD = 4.78; $M_{dif} = 6.78$, SE = 1.38, p < .001). Finally, we found a significant difference between time points regarding the personal score: F(2,40) = 8.49, p = .001, partial $\eta^2 = .298$. Adjusting the model, we detected a significant interaction between age and time regarding personal score (F[2,80] = 16.25, p < .001, partial $\eta^2 = .489$). This feature indicates that personal score is affected over time according to age; however, the adjustment still maintained the effect of time as significant (F[2,80] = 6.59, p = .002, partial $\eta^2 = .279$). The *post-hoc* tests revealed significantly higher scores at T0 (M = 71.19, SD = 4.98) compared with T1 (M = 66.75, SD = 3.92; $M_{dif} = 4.44$, SE = 1.72, p = .018) and T2 (M = 64.33, SD = 7.15; $M_{dif} = 6.85$, SE = 1.96, p = .002). Table 2 shows the VABS scores at baseline and six months and one year after the COVID-19 lockdown.

4. Discussion

This study shows the adaptive response of young adults with autism due to the dramatic experience of a pandemic. Consistently with Valenti et al. (2012), we decided to focus our attention on adaptive behaviour rather than symptoms by using the VABS-II, a well-recognised instrument with demonstrable reliability and validity in both typically developing individuals and those with disabilities. It is also the prominent measure for assessing adaptive functioning in children with autism (Newsom & Hovanitz, 1997). Previous research has found that children with autism present a characteristic pattern of adaptive behaviour, as measured by the VABS (deficits in the socialisation domain, relative deficits in the communication domain and relative strengths in the daily living domain; Fenton et al., 2003; Valenti et al., 2010, 2012). The COVID-19 pandemic has forced individuals with ASD and their families to work in smart-working mode, also putting a strain on operators who had to revise the rehabilitation programmes and the objectives.

Our results suggest that this mode of intervention has led to negative changes in the adaptive behaviour of the ASD participants in the study, especially in the domains investigating socialisation and daily living. Regarding daily living, the score of domestic and personal domains decreased significantly after one year. The domestic score investigates abilities such as housework the subject performs, whereas the personal score evaluates how the subject eats, dresses, and maintains his or her personal hygiene. Contrary to our hypothesis, these skills were decreased probably because young adults with ASD became more dependent on their parents who were at home. In addition, parents, more stressed and tired than before the pandemic, showed a greater tendency to take care of their son/daughter's hygiene as well as feed and perform other actions rather than work patiently on these activities. Regarding socialisation, the disruptive effects of the lockdown emerged most clearly when interpersonal relationship scores were examined. Our results demonstrate that the lockdown negatively affected the performance of ASD participants in their ability to interact with others. The lower scores in the VABS-II than in the past were statistically and clinically significant in most of the dimensions examined (i.e., daily living and socialisation domains). These results clearly reflect the dramatic life changes that the participants and their families faced: since March 2020, they have experienced uncertainty about their work, health services, environment, and social relationships.

Life changes following the pandemic affected the general population, but as shown by Mutluer et al. (2020), people with clinical conditions were more vulnerable. Mutluer et al. (2020) investigated on how 87 individuals with ASD and a mean age of 13 years responded to COVID-19 in terms of comprehension and adherence to implemented measures, changes in their behavioural problems, and how their caregivers' anxiety levels relate with these behavioural changes. Their results showed that the ASD individuals had problems understanding what COVID-19 is and the measures it requires; they also had challenges in implementing social distance and hygiene-related regulations of the pandemic. In addition, most ASD participants in the study by Mutluer et al. (2020) stopped receiving special education during the pandemic. In the study, Mutluer et al. (2020) observed a COVID-19-related clinical presentation that resembled post-traumatic stress disorder in ASD individuals in terms of increased stereotypies, aggression, hypersensitivity, behavioural problems, and sleep and appetite alterations.

We support the idea that the deterioration in the various domains of life of people with autism and their families may be, in part, a direct consequence of the pandemic. However, we think there are indirect effects of the pandemic that may have influenced the deterioration of some abilities of ASD individuals, such as the unexpected interruption of rehabilitation treatments and their daily activities outside the home. Complicating the picture could be that people with ASD did not understand the reason for these changes, which caused them more stress.

Contrary to our results, Sergi et al. (2021), showed that the children in lockdown experienced improvements in communication, socialisation, and personal autonomy. Specifically, Sergi et al. (2021) evaluated the effects of the lockdown during the COVID-19 pandemic, followed by quarantine provisions and during the three months after the resumption of activities. Their study was conducted on a group of 88 children with a mean age of 23 months, staking part on an applied behaviour analysis-based intervention. In addition, Sergi et al. (2021), describe how parent training was significant in avoiding delays in the generalisation of socially significant behaviours. However, we believe that this the study of Sergi et al. (2021) has two important limitations: 1) there was a lack of follow-up (T2), and 2) only level 1 was considered and not levels 2 and 3, which may have a greater impact on parents' stress levels.

Of course, our study has some limitations. The first is the relatively small sample size, although it should be kept in mind that the fewer factors included in a design, the more power it will have to detect significant effects. A notable weakness of our study is that it fails to describe the lockdown's impact on caregivers and interventionists, especially for low-functioning individuals. We know that the response of people with ASD to traumatic events is mediated by caregivers and significant others in the person's life, so our findings may represent an artefact of impaired caregiver functioning. Moreover, during lockdown the caregivers could have been more constantly observing their son/daughter's functioning than prior to lockdown or when lockdown had only just commenced. It is

important that future research assess this possibility. A further potential limitation of the study lies in the use of parental responses to assess the participants' adaptive behavioural changes. Since both parents and professionals contributed to the intervention, both are prone to bias (in either direction).

In addition, our results suggest that after a partial throwback to relatively stable life conditions and immediate, intensive interventions after the lockdown, adults with autism have not shown a tendency to recover their adaptive functioning, and a complete recovery likely will take a longer time.

In conclusion, our study indirectly demonstrates that resiliency and the recovery of pre-pandemic functioning in young adults with autism would depend largely on their immediate inclusion in routine, intensive rehabilitation programmes and the steadying, as much as possible, of daily life routines. Public health services may consider collaborating with community partners, families and health services providers to improve post-pandemic coping in people with ASD (Eisenman et al., 2009). Overall, while considering our findings as preliminary, we strongly recommend further research in this understudied area of interest.

What this paper adds?

- This research evaluates adaptive behaviour of young adults with Autism Spectrum Disorder for one year after the general COVID-19 lockdown.
- Results indicates a worsening of adaptive behaviour skills due to lockdown restrictions.
- The recovering seems a long-term process thus urgent action is needed.

CRediT authorship contribution statement

MV and MM designed the research. MCP, ILD, and MA collected the data. RV, MCP, and ST analysed the data. All authors contributed to writing the manuscript.

Declaration of Competing Interest

The authors declare that there is no conflict of interest.

Data Availability

Data will be made available on request.

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