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Risk and protective factors of quality of life for children with autism spectrum disorder and their families during the COVID-19 lockdown. An Italian study

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ABSTRACT

Background: The lockdown due to the COVID-19 pandemic has been a difficult period for children with Autism Spectrum Disorder (ASD), and their families.
Aims: The aim of this study was to investigate the predictors of the quality of life (QoL) of children with ASD and their parents throughout the first lockdown, providing a snapshot of the impact of the pandemic on these families life.
Method and procedures: A cohort of 243 parents of children with ASD (2–15 years old) completed an original online survey regarding the modification of ASD cores symptoms during lockdown, the type of interventions they had done before and during lockdown and the activities performed by the child. Respondents filled the PedsQL for themselves and their children.
Outcome and results: The data obtained show a worsening of specific ASD core symptoms during lockdown and their role in predicting parents and children's QoL. Furthermore, protective factors for a better children's QoL as the Telehealth intervention, and some activities done at home during the lockdown as physical activity and play with parents are identified.
Conclusions: This study identifies the QoL's risk and protective factors for children with ASD and their families. Furthermore, reveals the fundamental role of the parents as children's QoL pro-

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tective factor, suggesting a higher collaboration between families and health care providers, whilst potentially improving families and children's QoL.

What this paper adds?

While there is a growing body of literature demonstrating that children with ASD faced numerous issues during lockdown, limited studies exist examining the QoL of children with ASD and their parents. This has been done creating an original survey regarding the daily life autism related issues during pandemic, and using a validated instrument for the QoL. Our findings show the protective and risk factors of children and parents' QoL during lockdown, providing information and concrete instruments for improving those families QoL and healthcare, now and when the pandemic will last.

1. Introduction

Coronavirus disease 2019 (COVID-19) developed into a global pandemic, and to prevent the spread of the virus, authorities imposed restrictive measures in many countries. Italy was the first European country to impose such measures (Government, 2020). Everyone was banned from leaving home except for approved reasons. This measure forced children to follow distance learning guidelines and forced parents to work remotely. Moreover, since most businesses were closed, many people lost their jobs or suffered a severe loss of income (Spinelli, Lionetti, Pastore, & Fasolo, 2020). In the family environment, the educational role of parents became much more crucial than it was before. All educational services were closed, babysitters and grandparents were not allowed to provide support, and contacts with peers were not allowed. Children could rely only on their parents, who then served as teachers, educators and playmates. Many parents also had to start working from home, and balance time and spaces while having to work with children nearby can be very challenging. Indeed, due to the absence of other educative and supportive figures, parents inherited the role of promoting positive development and new learning experiences for their children (Wang, 2020).

This plight was even more challenging for families and children with developmental disabilities (Di Renzo et al., 2020; Hume et al., 2020). One specific and broad subgroup of these families and children are children with autism spectrum disorder (ASD). The latest revision of DSM American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, 5th edition, (American Psychiatric Association, 2013) adopted the umbrella term "autism spectrum disorder" with two features: difficulties in social communication and social interaction and restricted and repetitive behaviour, interests or activities. Together with the core symptoms, cooccurring psychiatric or neurological disorders and intellectual disabilities are common in children with autism. These two sets of symptoms have a wide range of severity levels, which may be different for each child with ASD (Lord et al., 2020).

Recent studies on the impact of the lockdown on children with ASD and their parents showed high psychological distress in both populations caused by different factors related to the family and to the child, but none of those focused on the quality of life (QoL) of children with ASD and their parents during the first lockdown (from March to May 2020) (Di Renzo et al., 2020; Hume et al., 2020; Levante et al., 2021).

QoL is a multidimensional concept in which physical, psychological, and social components are influenced by personal characteristics and environmental variables (Cummins, 2005). Health-related quality of life (HRQOL) (World Health Organization, 1946), is more specific to the impact and characteristics of a particular illness, disorder, and medical treatment on the daily functioning and well-being of a patient (Dey, Landolt, & Mohler-Kuo, 2012).

What do we know about the QoL for children with ASD and their parents during the lockdown, and what may be the factors that predict better QoL in these populations?

The reason to explore these questions includes expanding limited research on QoL's protective factors and risk factors for parents and children with ASD during the lockdown. Another reason is to provide a snapshot of the impact of the pandemic on these people's lives to be able to suggest appropriate targets for services and interventions during the pandemic, as well as after it ends.

The present study aimed to contribute to the topic by also examining several potential risk factors and protective factors of QoL among the various aspects of parents' condition and children's functioning and adjustment modification during the first lockdown (from March to May 2020).

1.1. ASD symptoms and the COVID-19 lockdown

The literature reported that during the lockdown, there was a worsening of the ASD core symptoms. In fact, ASD symptomatology presented additional challenges for children to cope with during the COVID-19 pandemic. These challenges made it more difficult to practice physical distancing or to respect rules and habits that were not always understandable for them (i.e., disinfect your hands, do not touch your nose and eyes, and cover your mouth and nose with a mask). On the other hand, it led to an intensification of obsessional thinking and compulsive behaviour regarding contamination. Research showed that during this period, children with ASD had to face another major stressor: change in routines. Disruptions to routine brought about by COVID-19, led children to have higher levels of anxiety and emotion dysregulation (Amorim et al., 2020; Levante et al., 2021), more expression of fear and frustration through excessive rumination, an increase in agitation or irritability, changes in eating patterns and a decrease in self-care (Hume et al., 2020). In this context, not receiving school support was associated with more frequent and intense behavioural problems (Colizzi et al., 2020). Di Renzo et al. (2020) reported that during the first month of lockdown, there was an increase in restricted, repetitive behaviours, mannerisms, and stereotypes; there was also a worsening of sleep regulation, intensification of self- and other-directed aggressive behaviours, and there was an increase in sensory motor agitation and restlessness. On the other hand, this study suggested that children's existing prepandemic self-care skills were not lost, that the IQ score did not affect any changes in symptoms and that older age played a protective role with regard to emergency-induced intensification of behavioural problems. A recent study showed no significant worsening in adaptive functioning, and problematic behavior (Siracusano et al., 2021).

Taking these findings into account, it appears essential to investigate whether the modification of ASD symptoms had an impact on the QoL of children and parents during lockdown.

1.2. Interventions

The care of children with ASD is an important support for the child and for the family (Lai, Anagnostou, Wiznitzer, Allison, & Baron-Cohen, 2020), and it is even considered an important factor for a better QoL (Chiang & Wineman, 2014). Among the empirically validated treatments, clinician- or parent-delivered psychosocial interventions have been shown to improve some ASD core symptoms (French & Kennedy, 2018; Maglione, Gans, Das, Timbie, & Kasari, 2012). Psychosocial interventions vary in a continuum, ranging from highly structured Applied Behavioural Analysis (ABA) approaches to Naturalistic Developmental Behavioural Interventions (NDBI), developmental socio-pragmatic models (Ospina et al., 2008; Schreibman et al., 2015; Smith & Iadarola, 2015) and structured teaching models, such as the Treatment and Education of Autistic and Communication related Handicapped Children TEACCH (Mesibov, Shea, & Schopler, 2005). Additionally, many guidelines (World Health Organization, 2013 – National Institute for Health and Care Excellence), even in Italy (Fava et al., 2011; Strauss et al., 2012), recommend parent-mediated interventions (PMIs), especially for preschoolers with ASD (Valeri et al., 2020). In addition, most children with ASD receive other nonspecific interventions for autism, such as speech therapy (ST) and neuropsychomotricity (NP).

One of the major consequences of the lockdown was the suspension of psychological and rehabilitation services for the healthcare and educational needs of children with ASD (Schiariti, 2020, Thompson & Rasmussen, 2020), who often require intensive interventions (Giusti, Provenzi, & Montirosso, 2018; Järvikoski, Härkäpää, Martin, Vasari, & Autti-Rämö, 2015; Wilson, McKenzie, Quayle, & Murray, 2014). This absence was replaced by different types of telehealth interventions, a field that has been strongly implemented during lockdown (Johnsson, Kerslake, & Crook, 2019; Simacek, Elmquist, Dimian, & Reichle, 2020; Siracusano et al., 2021). Thus, we still do not know if the lack of interventions and the eventual replacement by telehealth interventions had an impact on the QoL of children with ASD and their parents.

1.3. Activities performed during lockdown

Focusing on the high vulnerability of children with ASD to routine disruption (Narzisi, Muratori, Calderoni, Fabbro, & Urgesi, 2013), parents reported difficulties in managing their children's daily activities, especially in terms of free and structured activities (Ameis, Lai, Mulsant, & Szatmari, 2020; Mumbardó-Adam, Barnet-López, & Balboni, 2021). Additionally, home confinement may lead to more time spent pursuing special interests. For example, many children with ASD used electronic devices (such as tablets, smartphones, and television) more often and for longer periods of the day, resulting in these devices becoming a source of deep interest, making it difficult to switch to other activities (ISS, O. N. A., 2020). Hence, considering the huge amount of time spent at home during lockdown and the difficulties in the organization of the time, the necessity to understand if the kind of activity and the amount of time spent on the activity had an impact on the QoL of the children with ASD and their parents emerged as a study aim. On the other hand, literature showed the beneficial effects of the parental presence at home, in particular of the time spent with their children (Burrell & Borrego, 2012; Siracusano et al., 2021) offering the opportunity to do more activities together to practice physical activity (Chen et al., 2020) and play together. Research in the field underline the importance of specific play activities, such as structured play activities (Freeman & Kasari, 2013). Therefore, we also aimed to evaluate if the time spent with the children in playing at the table, or doing physical activity could trigger underpinning mechanisms on children's ASD symptoms and QoL.

1.4. Parents of children with ASD

Parenting a child with ASD can be stressful (Bonis, 2016) due to the severity and chronicity of the condition, the comorbidities, the intensive interventions needed by the child, and the difficulty in obtaining services (Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). Caring for a child with ASD is associated with greater parenting stress when compared to any other disability, and Cidav (2011) revealed that families of children with ASD face a significant economic burden in the process. The family financial earnings of children with ASD, but in particular mothers' earnings, are less than those of children with another health limitation and less than those of children with no health limitation. Children with ASD are less likely to have both parents in employment. Given the substantial health care expenses associated with ASD, the economic impact of having lower income, in addition to these expenses, is significant. Moreover, the existing literature shows higher stress levels, more psychological distress and depressive signs, and increased rates of physical and mental health problems in caregivers of children with ASD (Totsika, Hastings, Emerson, Lancaster, & Berridge, 2011). Raising a child with ASD can generate stressful conditions that, in most cases, are associated even with adaptation to the child's routine, interference with health care systems and education, coordination of multidisciplinary caretakers, and limited availability of resources (Twoy, Connolly, & Novak, 2007).

This plight was aggravated during the strict lockdown that took place in the first wave of COVID-19. Research shows that the impact on families and carers was especially heightened because of the loss of the usual support of schools or day services.

Additionally, due to the stay-at-home order, centre-based and home-based rehabilitative and therapeutic services were not accessible to children with ASD. This disruption compelled parents to provide 24-h care that was usually shared with paid carers or external family support (i.e., grandparents) (Courtenay & Perera, 2020). With the reduction of professional support, parents of children with ASD faced an increased frequency and severity of challenging behaviour in their children and, at the same time, faced personal challenges, such as loss of employment and working from home. Parents of children with ASD reported higher stress, depression, and anxiety for the following: the absence of services, stoppage of work due to the emergency (Manning, Billian, Matson, Allen, & Soares, 2020; Wang, 2020), educational responsibility, maintenance of routines, dealing with children's behaviour, keeping children occupied, and social isolation (Amorim et al., 2020; Mumbardó-Adam et al., 2021). In fact, parents of children with ASD already felt socially isolated before the pandemic; social distancing during this pandemic aggravated the sense of loneliness (Lim, Tan, Aishworiya, & Kang, 2020). Nonetheless, parents had to struggle with the use of online platforms for education or telehealth care (or other services) (Provenzi, Grumi, & Borgatti, 2020). This was more difficult for children with ASD with high support needs, where communication and cognitive factors were critical barriers to engagement (Johansson, Gulliksen, & Gustavsson, 2020). Online education also relied on digital access and the caregiver's ability in the home to support the student, placing constraints on the caregivers' work (Cidav, Marcus, & Mandell, 2012). Hence, the lockdown amplified academic challenges, socioeconomic difficulties, and parental burden for many children with ASD and their caregivers (Ameis et al., 2020). From the analysis of the literature, the high distress experienced by parents of children with ASD before and during lockdown appears evident, but no studies to date have considered whether these factors had an impact on their QoL.

1.5. The present study

As is evident from the analysis of the available literature, recent studies examining the impact of the lockdown on children with ASD and their parents showed high psychological distress in the whole family worsened by different factors related to the family and to the child.

The present study aimed to examine the protective factors and risk factors associated with the QoL of children with ASD and their parents during the first COVID-19 lockdown in Italy.

Considering the literature on the possible predictors of the QoL of the parents and of the children, we first tested whether endogenous factors, such as ASD symptom severity at diagnosis, exogenous factors such as sociodemographic condition of the families, and the modification of the ASD core symptoms during lockdown were possible predictors of the QoL of parents during lockdown. Second, we tested whether ASD symptom severity at diagnosis, the type of interventions performed pre- and during lockdown, and the type and amount of time the child spent in different activities could be predictors or mediator of the QoL of children during lockdown. To our knowledge, this is the first study to approach this subject while encompassing the QoL of children with ASD and their parents using a standardized instrument, based on the Italian population from all over the country.

2. Methods

2.1. Participants

The survey population was composed by 243 parents of children with ASD between 2 and 15 years old, of both sexes: 86 % (209) males, mean age was 7 (*SD* = 3.3). Mothers' mean age was 38.4 (*SD* = 6.6) and fathers' mean age was 42.4 (*SD* = 7.5). The sample was equally distributed throughout the Italian peninsula. In particular, 70 participants (28.8 %) were living in the North area, 95 (39.1 %) in the Center, and 76 (31.3 %) in the South. Two hundred twenty-three (91.8 %) of the respondents were mothers. Considering the average family income, 27 (11.1 %) less than 1000 euro, 70 participants (28.8 %) declared to earn between 1000 and 1500 euro, 38 (15.6 %) declared to earn between 1500 and 2200, 70 participants (28.8 %) more than 2200 euro, and 38 (15.6 %) participants did not answer to the question. Parents' education is reported in Table 1.

In respect to the child's ASD diagnosis, 69 (28.4 %) children presented a high symptoms severity, 108 (44.5 %) medium and 66 (27.1 %) low. Also, 56 (23 %) of children had no language, 46 (19 %) produced single words, 92 (37.8 %) produced short sentences, and 49 (20.2 %) produced complex sentences. At last, regarding the cognitive functioning, 79 (32.5 %) of children had a high cognitive

Table 1
Parents education.

	Mothers		Fathers	
	N	%	N	%
Education				
Elementary school	3	1.2	2	0.8
Middle school	26	10.7	64	26.3
High school	118	48.6	114	46.9
Bachelor degree	22	9.1	12	4.9
Master degree	40	16.5	25	10.3
Post graduate formation	32	13.2	20	8.2
Missing data	2		6	

functioning, 115 (47.3 %) medium and 49 (20.2 %) low.

2.2. Procedure

Parents involved in the study filled out an anonymous online Qualtrics Survey, after reading the written consent form and explicitly agreeing to take part to the study. The survey was shared via social media for a limited time window during the first wave lockdown (from May 15th to 30th, 2020). Families of children with ASD were identifies through inherent pages or groups on Facebook. In case of multiple children with ASD, the parent was asked to report on one child only and filled another survey for the other children. There was no monetary compensation for participating.

2.3. Materials

For the purpose of the study, the entire survey was reviewed and edited by a team of expert developmental psychologists, developmental neuropsychiatrists and statisticians (Levante et al., 2021; Manning et al., 2020; Spinelli et al., 2020). The survey consisted of four areas and is preceded by a small introduction. The four areas are detailed below:

2.3.1. Sociodemographic characteristics

The first area (questions 1–11) investigated the sociodemographic characteristics of the child's family: age of mother and father, level of education, family earning, region of residence.

2.3.2. ASD diagnosis

The second area (questions 12–17) concerned the child's ASD diagnosis – specifically, parents reported the severity level of the autistic symptoms that the child was assigned when last seen by a Neuropsychiatrist. Diagnosis included ASD symptoms severity (high, medium and low), language competences (from no language to complex sentences) and cognitive functioning (high, medium and low).

2.3.3. Original survey

The third area consisted of an original questionnaire named "Survey on the functioning and adjustments of children with Autism Spectrum Disorder and their families during lockdown". All the questions in this area referred to the past 1 month (April 2020). The instrument was created considering the existing literature and the daily issues experienced by the families during the lockdown.

Here, the first set of questions (questions 18–26) collected information regarding the family's living, working, and home conditions during lockdown as, number of house rooms, external help, parents working condition.

The second set of questions (questions 27–34) regarded the kind and the intensity of interventions the child was doing before and during the lockdown. Three categories of specific interventions for autism were included: ABA intervention, NDBI, Parent Training (PT) and PMI (PT/PMI). Furthermore, non-specific interventions for autism such as ST and NP (ST/NP) were included. Parents could select more than one intervention.

The third set of questions (questions 35 & 36) investigated the eventual ASD core symptoms modification during lockdown. Parents reported values on a 3 point Likert scale, (improved, same, worsened) modification in: language and communication, emotional regulation, social interaction, stereotypies, behavioral problems, restricted interests, autonomies and ASD symptomatology overall. The last item referred to a global evaluation of all the symptoms of the two areas of the ASD symptomatology. Reliability analysis was carried out on these 8 items. Cronbach's alpha reached acceptable reliability, $\alpha = 0.88$.

The fourth part (question 37) collected information about the time spent by the child in different activities at home during lockdown. Parents were asked to rate how much time (never - 0 h, short time – less than 2 h, and a lot of time – more or equal to 2 h) (American Academy of Pediatrics, 2001) the child was spending with the following activities as: playing with parents / by themselves / with siblings, reading a book, doing physical activity, playing video-games, talking to friends online, using social networks, and watching television.

2.4. Quality of life measurement

The fourth area of the survey referred to the QoL of the children with ASD and parents during the lockdown. To measure QoL in children with psychiatric disorders and their parents, we used the Pediatric Quality of Life InventoryTM PedsQL version 4.0 (Varni, Seid, & Kurtin, 2001). Its generic part encompasses the core health dimensions formulated by the World Health Organization (1948), it is well validated, and has proven its usefulness for measuring QoL of children with different diseases. In particular, the PedsQL is considered a "gold standard instrument" to measure the HRQOL in children and youth with ASD (Ikeda, Hinckson, & Krägeloh, 2014). The PedsQL Generic Core Scales parent proxy-report formats was used for investigate the child's QoL. On the other hand, for the QoL of the parents the PedsQL 2.0 - Parent Family Impact Module 2.0 (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004) was used. In both modules, the instructions ask how much of a problem each item has been during the past 1 month. The items are scored on a five-point Likert-scale, ranging from 1 = *"never a problem"* to 5 = *"almost always a problem"*. A higher PedsQL scores indicate better QoL (Fairclough, 2010).

2.5. Data analysis

The data were analyzed with Pycharm (Python language). For the questionnaire the missing values and the overall non-response rate was lower than 5%. Thus, the choice to drop the non-responses, instead of implementing an imputation method, was mostly driven by the low impact of missing values (Agresti, 2012). First descriptive and correlation statistics were computed on the original survey data and on PedsQL Family Impact Module and PedsQL Generic Core Scale. The possible risk or protective factors of QoL, as socio-demographic condition of the family, ASD severity symptoms at the diagnosis, ASD core symptoms modifications, the interventions and the activities performed during lockdown, were considered. Then regression analysis were conducted.

The regression analysis focused on two main areas: the predictors of PedsQL Family Impact Module as ASD symptoms modifications and ASD severity symptoms at the diagnosis, controlling for environmental factors such as the sociodemographic conditions of the family; the predictors of PedsQL Generic Core Scale as the ASD severity symptoms at the diagnosis, ASD symptoms modifications, the interventions and the activities performed during lockdown. The regression analysis was adopted to disentangle the effect that the different variables related to parents and children condition during lockdown have on PedsQL. Afterward, we estimated a multivariate mediation model with the types of activities, such as playing at table with the parents and doing physical activity, predicting PedsQL Generic Core, through the mediating role of ASD symptoms modification.

To perform the regression analysis a data transformation was required: PedsQL scores have been normalized using the min-max normalization; the variables expressed on a Likert scale were analyzed with a dual approach: on one hand the answers were transformed into two dichotomous variable in order to first depict the sign of the occurred phenomena (e.g. the effect of any improvements or worsen of child’s symptomatology); secondly the strength of the effect was analyzed, with modest results in term of significance level; the hours spent in the activities done during lockdown, were reparametrized as percentage of time spent in a specific activity over the total time spent in all activities. We leveraged linear regression models, Durbin -Watsnot test to check for autocorrelation of the residuals and Breusch-Pagan test to determine if heteroskedasticity is present.

3. Results

3.1. Descriptive and correlational statistics

3.1.1. Quality of life measurement

From 243 respondent, 211 answered only to PedsQL parent Family Impact Module, and 194 answered to PedsQL parent Family Impact Module and PedsQL Generic Core Scale. The mean of the PedsQL- Parent Family Impact was 52 ($SD = 19.2$) and the mean of the PedsQL Generic Core Scale was 61.1 ($SD = 16.8$).

3.1.2. Sociodemographic condition

Concerning this variables, work and home conditions, almost half of the mothers were unemployed, while half of the fathers went to work. Furthermore, the mean average of hours worked per week is 5.6 for mothers ($SD = 3.2$) compared to 7.8 ($SD = 3.2$) for fathers. Almost all the sample had Wi-Fi at home, and half of the parents did not have any kind of external help in managing the children during the lockdown (Table 2).

3.1.3. How are the sociodemographic variables related to parents’ QoL?

Spearman correlation coefficient between PedsQL Family Impact Module and socioeconomic conditions of the family was computed (Table 3). Economic conditions did not significantly correlated with PedsQL Family Impact Module variability.

3.1.4. Interventions

Regarding the interventions that the children were doing before the lockdown, data showed that 109 children did ABA intervention, 43 NDBI, 39 PT/PMI, and 150 ST/NP. Focusing on the Telehealth interventions that the children were doing during lockdown, data showed that only the 27.5 % (67 children) of children did telehealth. Forty-three children did ABA, 8 NDBI, 10 PT/PMI, 36 ST/NP.

Table 2
Sociodemographic condition during lockdown.

	Mothers			Fathers	
	N	%		N	%
Unemployed	99	40.7	Unemployed	26	10.7
Fired	5	2.1	Fired	4	1.6
On vacation	7	2.9	On vacation	5	2.1
Layoffs	15	6.2	Layoffs	15	6.2
Telework	36	14.8	Telework	39	16.0
Go to work	55	22.6	Go to work	117	48.2
Not answered	26	10.7	Not answered	37	15.2

Table 3
Spearman correlation coefficient for selected metrics on sociodemographic characteristics.

	1	2	3	4	5	6	7	8	9	10
1 PedsQL Generic Core Scale										
2 PedsQL Family Impact Module	.54***									
3 Mother's age	−.06	.05								
4 Father's age	−.06	.07	.74***							
5 Maternal schooling	.02	−.08	.13*	.06						
6 Family income	.0	−.05	.19**	.04	.43***					
7 Paternal Schooling	.06	.04	.11	.08	.45***	.41***				
8 Mather's job	.04	.05	.08	−.08	.32***	.32***	.17*			
9 Father's job	−.02	−.00	−.05	−.06	.16*	.18*	−.04	−.10		
10 Nr. of house rooms	.05	.04	.04	.06	.09	.26***	.06	.14*	.07	

Note: (*p < .05; **p < .01; ***p < .001).

3.1.5. *ASD symptoms*

Next, regarding the exploration of changes if any in the ASD symptoms during data showed that parents reported that language and communication competencies, emotional regulation, autonomies and social interaction improved during the lockdown, stereotypies, behavioral problems and restricted interests worsened. Looking at ASD symptomatology overall question, data did not show substantial difference between improvements and worsening (Table 4).

3.1.6. *Activities performed during lockdown*

The data regarding activities suggested that children spent more time playing with parents, playing by themselves, watching tv and playing video-games. In contrast, the most uncommon activities were playing with siblings, reading books, doing physical activity, talking to friends online and using social networks (Table 5).

3.1.7. *Is there any relation between interventions before and during lockdown and ASD diagnosis?*

The relation between ASD severity symptoms at the diagnosis and interventions performed were analyzed leveraging chi square test statistics in order to understand if any correlation between the different categories emerged. The diagnosis and the interventions done pre-lockdown were significantly related. In particular, interventions such as ABA and NDBI were significantly related to the ASD severity symptoms at the diagnosis. However, the interventions performed during lockdown were independent from the diagnosis of the child (Table 6).

Table 4
ASD symptoms modification during lockdown.

Core symptoms	Missing	Improved		Equal		Worsened	
		N	%	N	%	N	%
Language and communication	3	151	61.9	57	23.4	32	13
Emotional regulation	6	96	39.4	76	31.1	65	26.6
Social interaction	8	87	35.7	70	28.7	78	32
Stereotypes	4	54	22.2	102	41.8	83	34
Behavioral problems	5	62	25.4	95	38.9	81	33.2
Restricted interests	5	75	30.7	81	33.2	82	33.7
Autonomies	7	126	51.7	78	32	32	13
ASD symptomatology overall	2	101	41.5	43	17.6	97	39.7

Table 5
Time spent on different activities during lockdown.

	Missing	Never		Short time		A lot of time	
		N	%	N	%	N	%
Play at table with parents		32	13.2	197	81.1	14	5.8
TV		17	7	153	63	73	30
Video-games		58	23.9	118	48.6	67	27.6
Online friends		171	70.4	51	20.9	3	1.2
Missing	18						
Social network		180	74.1	47	19.3	16	6.6
Play with friends		22	9.1	126	51.9	95	39.1
Play with siblings		116	47.7	94	38.7	33	13.6
Read books		131	53.9	107	44	5	2.1
Missing	5						
Play alone		32	13.2	137	56.4	74	30.5
Physical activity		121	49.8	113	46.5	9	3.7

Table 6
Chi square stats between ASD severity symptoms at the diagnosis and the interventions done pre and during lockdown (telehealth).

Interventions	Chi stat	df	p
ABA	7.96	2	.018
NDBI	7.29	2	.026
PT/PMT	4.98	2	.083
ST/NP	.67	2	.71
ABA telehealth	3.09	2	.21
NDBI telehealth	2.13	2	.34
PT/PMT telehealth	.41	2	.81
ST/NP telehealth	.89	2	.64

3.2. Regression analyses

3.2.1. What counts for the QoL of parents?

Then, to access the effect of ASD severity symptoms at the diagnosis and ASD core symptoms modification on PedsQL Family, regression analysis was performed, dividing the sample in preschool children (age range 2–5 years) and schoolchildren (age range 6–15 years). Table 7 shows that the worsening of ASD symptomatology overall during the lockdown and the chronic low cognitive functioning of the child had a negative impact on PedsQL Family Impact Module, especially for the families with preschool children. The results were robust and significant and they explain the 15 % of PedsQL Family Impact Module sample variability (*R-squared* = 0.15, *Adj. R-squared* = 0.14, *Df. Model* = 4, *Breusch-Pagan test : Lagrange multiplier statistics* = 6.56, *p* = .16).

3.2.2. What counts for the QoL of children?

To access the effect of ASD severity symptoms at the diagnosis, ASD core symptoms modification variables, activities performed during lockdown and telehealth on PedsQL Generic Core Scale, the relevant variables were firstly selected leveraging backward

Table 7
OLS Regression Results. Different factors and PedsQL Family Impact.

	Coef	Std. err	t	p
Const	.49	.05	10.21	.001
Preschool children	−.05	.03	−1.89	.060
Low cognitive functioning	−.08	.03	−2.52	.012
Improvement Social interactions	.02	.00	2.42	.016
Worsening ASD symptomatology	−.08	.03	−2.59	.010

elimination algorithm. By dividing the sample in preschool and school children, no significant differences emerged. In Table 8 the results of the model are presented. The result depicts the negative and significant effect of worsening of child ASD symptomatology overall modification during lockdown on PedsQL Generic Core Scale. The effect was partially smoothed when telehealth intervention was performed during lockdown ($R\text{-}squared = 0.30$, $Adj.\ R\text{-}squared = 0.27$, $Df.\ model = 7$, $AIC = -153.6$, $BIC = -127.5$, $Breusch\text{-}Pagan\ test : Lagrange\ multiplier\ statistics = 11.67$, $p = 0.11$)

3.2.3. Mediation analysis

Furthermore we performed the mediation analysis in order to depict the mediation effect of the modification of the ASD symptomatology overall on the activities performed during lockdown. Moving the mediator on the regression analysis we get an $AIC = -139.0$ and $BIC = -126.0$.

The analysis was conducted on the activities performed during lockdown showing a significant effect on PedsQL Generic Core. The analysis aims at disentangling the effect of activities performed on PedsQL, that could have been mediated by a modification in ASD symptomatology. The result of mediator model is shown in Table 9 were a negative and significant effect of *Play at table with parents* was depicted. The target model results are then shown in Table 10.

We estimated the direct and indirect effects of activities on PedsQL Generic Core. The results are summarized in Table 11 and Fig. 1, and indicates that the more time parents spent playing at table with their children, the worsening of ASD symptomatology overall decreases, having a mediator effect on the children’s QoL.

4. Discussion

The aim of this study was to show how and what influenced the QoL of children with ASD and their parents during the first Italian lockdown in response to the COVID-19 pandemic. It is important to point out that this research was conducted at the end of the first lockdown; thus, parents reported what they and their children with ASD experienced in the long previous period. The results from these parents’ surveys indicate that the QoL of parents and children was low during the lockdown. In particular, as already shown in previous studies, the QoL of parents was lower than that of their children (Huang et al., 2009; Shipman, Sheldrick, & Perrin, 2011).

To understand the possible predictors of the two QoL, we looked at various aspects of parents’ condition and children’s functioning and adjustment modification during lockdown.

In contrast with other studies (Eurofound, 2020; Keshky, El Sayed, Basyouni, & Al Sabban, 2020), we found that the socioeconomic condition of the family did not predict the QoL of the parents during lockdown. This is perhaps because the socioeconomic conditions of the families of children with ASD did not change during the lockdown differently from the other populations (Eurofound, 2020; Martin, Markhvida, Hallegatte, & Walsh, 2020). Furthermore, mothers of our sample, as primary caregivers of children with ASD, are more likely to be unemployed than fathers, even if they were educated to a higher level. This condition is confirmed in the literature (Zhou, Liu, Xiong, & Xu, 2019) and demonstrates the strong social impact of those syndromes and the consequent disability of the families. Maternal unemployment and the chronic disability of the child contribute to an increased risk of anxiety and depressive symptoms in mothers of children with ASD compared to the risk in mothers of children without ASD (Estes et al., 2009; Ingersoll, Meyer, & Becker, 2011).

Focusing on other variables, a fundamental consideration must be made regarding ASD symptom modification during lockdown. Parents reported a worsening of some core symptoms in the “restricted, repetitive patterns of behaviour, interests, or activities” cluster and an improvement in various core symptoms of the “social communication and social interaction” cluster. As previous research showed, (i.e., Colizzi et al., 2020; Di Renzo et al., 2020) children’s ASD core symptoms changed over the lockdown period. The worsening in the aforementioned areas can be interpreted as a signal of the children’s need to latch themselves to a known pattern of behaviour, which could help them when the daily routines were disrupted. Children had to adapt abruptly to a new adjustment, both external as social isolation and full-time coexistence with parents and internal as managing emotions (Di Renzo et al., 2020). Furthermore, the lost support from school could have intensified the symptoms in these areas of ASD (Colizzi et al., 2020), and the increased worry of parents further exacerbated children’s psychological well-being and increased their behavioural problems (Zhang et al., 2020). Another consideration could be that, considering that pandemic life changes could be classified as a trauma-like condition, these clinical reactions in individuals with ASD are likely to have shared characteristics with post-traumatic stress disorder (Mutluer, Doenyas, & Genc, 2020). This factors appear to have a stronger impact on the QoL of parents of preschool children. This is maybe due to the less autonomous behaviour achieved by the younger children, and the higher need of support provided only by the

Table 8
OLS regression. Different factors and PedsQL Generic Core.

	Coef	Std. err	t	p
Const	.56	.03	17.24	.001
Worsening social interaction	−.06	.02	−2.52	.012
Improve Language and communication	.04	.02	1.72	.086
Improve behavioral problems	−.08	.02	−2.88	.004
Play at table with parents	.36	.17	2.02	.044
Physical activity	.48	.18	2.71	.007
Worsening ASD symptomatology	−.11	.02	−4.09	.001
Telehealth	.04	.02	1.76	.080

Table 9
OLS regression. Different activities and ADS symptomatology.

	Coef	Std. err	t	p
Const	.58	.06	8.98	.000
Play at table with parents	−1.34	.52	−2.57	.011
Physical activity	−.80	.54	−1.48	.140

Note: (R-squared = 0.04, Adj. R-squared = 0.03, Df. Model = 2).

Table 10
OLS regression. Different activities and ADS symptomatology on PedsQL Generic Core.

	Coef	Std. err	t	p
Const	.57	.02	21.61	.000
Play at table with parents	.42	.18	2.30	.022
Physical activity	.48	.19	2.56	.011
Worsening of ADS symptomatology	−.14	.02	−5.62	.000

Note: (R-squared = 0.21, Adj. R-squared = 0.20, Df. Model = 3).

Table 11
Mediation analysis.

Predictor	Total effect	ADE	ACME
Play at table with parents	.61***	.42**	.19**
Physical activity	.59***	.48*	.11

Note: (*p < .05; **p < .01; ***p < .001).

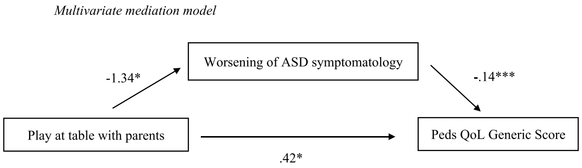

Fig. 1. Multivariate mediation model.
Note: (*p < .05; **p < .01; ***p < .001).

parents during lockdown (Levante et al., 2021). However, future studies should deepen this focus. On the other hand, the improvements in the "social communication and social interaction area" may be justified because those skills acquired before the lockdown period, when supported by the parents, were not lost (Di Renzo et al., 2020), or we can speculate that during continuous and perpetual cohabitation, attunement improved between parents and children, leading to a better perception of those competencies by parents. Indeed, parents were always there, so children had more direct stimulation from more stable and even more emotionally positive reference figures. Furthermore, the lockdown condition could have been an ideal condition for some of those children with autism, leading to an exaltation of their symptomatology.

Our results showed that ASD symptomatology modification during lockdown played a role as a parent's QoL predictor factors. In particular, the parent's perception of the child's social interaction improvements during lockdown appeared to be a protective factor of the parent's QoL. It is necessary to consider that impairment of social interactions is an essential area for the diagnosis of ASD and therefore of parental concerns and children's wellbeing. On the other hand, the worsening of ASD symptomatology overall and the child's low cognitive functioning seemed to be risk factors for the parent's QoL. In fact, the literature shows that a chronic condition, such as a child's intellectual disability, has a strong impact on the parent's QoL (Chiang & Wineman, 2014; Pisula & Porębowicz-Dörsmann, 2017). The QoL of parents of children with ASD was therefore highly influenced by exogenous and endogenous factors related to ASD. This plight could have been aggravated by the absence during the lockdown of interventions and supports for the families and for the children even more with high severity ASD symptoms, leading to higher impact of children's disability to parent's life.

Hence, the ASD symptomatology modification during lockdown emerged to be a predictor of children's QoL as well. Specifically, the worsening of social interaction and the worsening of the symptomatology overall during lockdown seemed to be risk factors. Previous studies have shown that the PedsQL was significantly correlated with ASD-related measures of symptoms and functional impairments (Kuhlthau et al., 2010; Varni et al., 2012). Those

Conversely, one of the protective factors of children's QoL seemed to be telehealth intervention. This was an expected and revealing result, mostly because of the low percentage of children who utilized telehealth during the lockdown. In fact, there is an increasing number of studies supporting the usefulness of telehealth for intervention (Johnsson et al., 2019; Simacek et al., 2020), even before the outbreak of the COVID-19 pandemic. However, we showed that despite this stressful, unexpected and particular condition, in less than 3 months, telehealth intervention, regardless of the type, appeared to have a positive impact on children's quality of life. Indeed, our data showed that the types of interventions that children were doing before the COVID-19 outbreak were highly correlated with ASD severity symptoms at diagnosis. This trend was not confirmed for the telehealth interventions, perhaps because children were doing only the available telehealth interventions at the time. A potential hypothesis is that because children with ASD needed their parents during the telehealth intervention, caregivers were trained to interact with children with ASD without therapists assuming the knowledge of caregivers, regardless of the type of telehealth intervention (Walker & Riley, 2001). Russa, Matthews, and Owen-DeSchryver (2015)) showed that ASD interventions are interdependent on caregivers and that active engagement of caregivers is key to positive outcomes. Considering the unique period of lockdown, which was without any kind of external support and intervention, we can suppose that the engagement of the parents in the telehealth intervention was very high. Furthermore, parents and children were spending the all of their time together, in the most naturalistic setting, their own house, letting them practice the therapist's directions continuously and in everyday activity. This was shown to be an important factor for the improvement of ASD core symptoms (Valeri et al., 2020). In fact, in such circumstances, when children with ASD cannot perform in person interventions and spend more time at home with parents, any type of telehealth intervention becomes a "kind of parent-mediated intervention", which can have a deep impact on the whole family and can be easily delivered online. Parents and caregivers know their child best, and their involvement in interventions is important. They help professionals understand a child's unique areas of strength and challenges and can ensure consistent implementation of therapeutic techniques in the home and community settings (Solomon & Soares, 2020).

During lockdown, the disruption of everyday routines and the organization of free time and structured activities at home have been shown to be a strong challenge for parents and children (Ameis et al., 2020). In this respect, our data showed that some activities have protective factors on children's QoL. One of these is the structured play at a table, which is a kind of activity that children with ASD are often already used to doing during intervention or when they play by themselves or with other people; this play is familiar because of their tendency to have very limited play, with only a few toys, or in a repetitive way. Structured play activity usually gives children clear guidelines about what to do and when, creating a lower-stress environment (Freeman & Kasari, 2013; Kok, Kong, & Bernard-Opitz, 2002), which is even more important during a lockdown that involves the disruption of daily routines. This kind of activity conducted with the parents appears to be a strong protective factor of the children's QoL. To support this view, the study shows that more time spent playing at a table with parents led to a decrease in the worsening of the symptomatology and then to a better children's QoL. Through the structured play, parents might had more time and possibilities to play with their children following their interests, understanding their level of current performance and supported the child's effort by structuring and guiding the child's play. Greater time in joint engagement with people and objects is important for the development of play which has a key role in the ASD symptomatology improvements. Furthermore, parents-child interaction and relationship is characterized by sensitivity, warmth, contingent responsiveness, nurturance, predictability and appropriate level of stimulation, which is related to more positive outcomes for children with ASD (Freeman & Kasari, 2013). In turn, this kind of activity might lead to a better children's QoL. This finding highlights the importance of coaching parents in activities suited for children with ASD. They can become therapeutic allies most of all during those times of restrictions, when in person interventions are forbidden, but coaching through telehealth is becoming very common (Simacek et al., 2020).

Another activity that played a role as QoL's protective factor is physical exercise; this type of activity was uncommon in our sample, which may be because the sedentary nature of life at home contributed to a decrease in the children's physical activity (Chen et al., 2020). Therefore, the literature shows that physical exercise exerts a positive influence on different symptoms, such as physical motor deficits (Batey et al., 2014), cognitive functioning (Bremer, Crozier, & Lloyd, 2016), behavioural problems (Sorensen & Zarrett, 2014), socioemotional functioning (Bremer et al., 2016), and stress levels (Hillier, Murphy, & Ferrara, 2011). Physical exercise also produces gains in health-related QoL (Tilford et al., 2012), even in individual programs (Toscano, Carvalho, & Ferreira, 2018). During the lockdown period, engaging in physical exercise in a safe home environment could have been an opportunity to create a new routine and participate in a different activity with the family (Garcia, Lawrence, Brazendale, Leahy, & Fukuda, 2020). This is an important strategy for healthy life during the COVID-19 crisis (Chen et al., 2020).

Finally, screen time is one of the most prevalent activities for children during lockdown. Even if these activities, such as playing video games and watching television, do not play a role as predictive factors of QoL, it is necessary to emphasize that they are extremely attractive for children with ASD (Fineberg et al., 2018), even because most of these children are less engaged in social and physical activities and may prefer screen use over other leisure activities (Jones et al., 2017). During lockdown, difficult behaviours presented by children with ASD may also lead their parents to use more screen time as a means of regulating their children (Thompson & Christakis, 2005) for its calming effect and as a respite from the challenges for them (Nally, Houlton, & Ralph, 2000). In addition, the social withdrawal hypothesis proposes that increased screen time may limit social interactions with family members (Varni et al., 2011), and these interactions are crucial for language, communication, and socioemotional skills. Further research should deepen this focus, which requires special monitoring during the pandemic, as well as after it ends.

Autism is a chronic condition that presents a complex medical and psychological pattern that involves the children and their family (Kemper & Bauman, 1998). During the COVID-19 pandemic, those families had to deal with the pandemic itself and the relative restrictions, and they had to maintain their own lives and address a disability as substantial as autism can be. Assessing QoL, as a multidimensional concept of physical, mental, psychological, and social wellbeing and not merely the absence of the disease, led us to provide risk factors and protective factors for good QoL during lockdown to implement new approaches and help families with special monitoring during this challenging period. This study may helped in the identification of their needs as the difficult socioeconomic conditions, the lack of the telehealth interventions or any kind of guidance and assistance during lockdown; on the other hand helped in the recognition of the protective role played by the parents even as therapeutic allies, advising a more constructive coaching for them.Indeed, even if restrictions are lifted and school will reopen, the psychological impact of the pandemic will last. Increased awareness of the risk factors for good QoL in this population in this unprecedented event is needed to prevent them in the short and long terms. This study has potential limitations, such as the limited sample of children with ASD and their parents, the different numbers of PedsQL Generic Scores and PedsQL Family Impact Modules obtained, and the proxy report form of the survey. Despite these limits, this study has important strengths, such as the use of a standardized instrument (the PedsQL), the inclusion of the Italian population all over the country, and the collection of information regarding the whole period of the first Italian lockdown. The use of this information can provide care and alleviate some of the challenges experienced by children with ASD and their families while potentially improving their QoL and health care. Future research should thoroughly study the protective factors and risk factors for QoL of children with ASD and their families during these times of restrictions to provide more elements for the recovery and wellbeing of this specific population.

Author’s contributions

Maria Grazia Logrieco: conceptualization, investigation, writing original draft; **Laura Casula**: conceptualization, resources, methodology; **Giuseppe Niccolò Ciuffreda**: formal analysis, software, writing original draft; **Roberta Lucia Novello**: validation, data curation; **Maria Spinelli**: writing- review & editing, resources; **Francesca Lionetti**: methodology, writing- review & editing, resources; **Ilaria Nicolì**: visualization, data curation; **Mirco Fasolo**: conceptualization, supervision, project administration; **Giovanni Valeri**: conceptualization, supervision, project administration; **Stefano Vicari**: conceptualization, supervision, project administration.

Declaration of Competing Interest

None.

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