

**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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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, which included the closure of shops and the shutdown of all schools and universities across the country (Government, 2020). Everyone was banned from leaving home except for proven 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 et al., 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 et al., 2020).

This plight was even more challenging for families and children with developmental disabilities. 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, (APA, 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. Furthermore, almost 50% of people with ASD have intellectual disability. Together with the core symptoms, cooccurring psychiatric or neurological disorders 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).

The World Health Organization defines QoL as “individuals’ perceptions of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards and concerns” (The WHO Quality of Life assessment, 1995). This definition is, therefore, a subjective appraisal of how the individual relates to the world in the context they currently experience. QoL is a multidimensional concept in which physical, psychological, and social components are influenced by personal characteristics and environmental variables (Schalock, 2004; Cummins, 2005). This concept is related to health, which is, “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (p.1315) (WHO, 1946). Health-related quality of life (HRQOL) 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, et al., 2012; Drotar, 2004; Limbers et al., 2009).

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).

### **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 (Yhaya & Khawaja, 2020). 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), 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.

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.

### **Interventions**

The care of children with ASD is an important support for the child and for the family (Lai et al., 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 et al., 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 et al., 2006). Additionally, many guidelines (WHO 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 (Schariti, 2020; Thompson & Rasmussen, 2020), who often require intensive interventions (Giusti et al., 2018; Järvikoski et al., 2015; Wilson et al., 2014). This absence was replaced by different types of telehealth interventions, a field that has been strongly implemented during lockdown (Johnsson et al., 2019; Simacek et al., 2020). 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.

### **Activities performed during lockdown**

Focusing on the high vulnerability of children with ASD to routine disruption (Narzisi et al., 2013), parents reported difficulties in managing their children's daily activities, especially in terms of free and structured activities (Ameis et al., 2020). 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 (Istituto Superiore di Sanità [ISS], 2020). On the other hand, children spent more time with their parents and their siblings, offering the opportunity to do more activities together to practice physical activity (Chen et al., 2020) and play together. 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.

### **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 et al., 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 psychological well-being of parents of a child with ASD is significantly influenced by their child's disorder. 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 et al., 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 (Troy et al., 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 et al. 2020; Wang et al., 2020), educational responsibility, maintenance of routines, dealing with children's behaviour, keeping children occupied, and social isolation (Amorim et al. 2020). 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 et al., 2020). Other risk factors for increased stress include: having more than one child with disability, children with severe ASD who required constant supervision and assistance for activities of daily living, and children with disrupted sleep (Catalano et al., 2018). Nonetheless, parents had to struggle with the use of online platforms for education or telehealth care



(or other services) (Provenzi et al., 2020). This was more difficult for children with ASD with high support needs, where communication and cognitive factors were critical barriers to engagement (Johansson et al., 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 et al., 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.

### **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 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.

## 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 et al., 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 et al., 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 et al., 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 et al., 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 et al., 2011; Kousha et al., 2016).

Focusing on other variables, a fundamental consideration must be made regarding ASD symptom modification during lockdown. The results showed 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 et al., 2020). 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 et al., 2014; Olsson & Hwang, 2011; 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).

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 et al. (2014) 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 (Kok et al., 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. 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), obesity and overweight problems (Dickinson & Place, 2014), time executing tasks (Oriol et al., 2011), cognitive functioning (Bremer et al., 2016), behavioural problems (Sorensen & Zarrett, 2014), aggressive behaviours (Neely et al., 2015), socioemotional functioning (Bremer et al., 2016), and stress levels (Hillier et al., 2011). Physical exercise also produces gains in health-related QoL (Tilford et al., 2012), even in individual programs (Toscano et al., 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 (Block & Obruniskova, 2007; Garcia et al., 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 et al., 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. 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.

### **Conclusion**

The lockdown due to the COVID-19 pandemic was a plight for everyone, but even more so for children with ASD and their families. By better understanding the risk factors and protective factors of children with ASD and their families' QoL, we aim to provide new approaches to minimize the difficulties and improve QOL during this difficult period. In this study, parents provided information regarding the lockdown period about their living condition, the child's daily activities, ASD severity symptoms at diagnosis, ASD symptom modification, and interventions

before and during the lockdown. Furthermore, they filled out the PedsQL about themselves and their child. As demonstrated by the study, children's and parents' QoL was low and was predicted by some factors. Regarding the parents, some factors were endogenous, such as children's ASD severity symptoms at diagnosis; however, others were exogenous, since the symptomatology worsened during lockdown. The latter appeared to be a risk factor, even for children's QoL. On the other hand, children's protective factors were the type of activities performed by the child and the telehealth intervention. 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. This study may help to identify the needs of the population and design new methods and procedures to best serve children with ASD and develop collaborations between families and all health care providers. 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.



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