Psychological impact of the SARS-CoV-2 pandemic in children with neurodevelopmental disorders and their families: evaluation before and during covid-19 outbreak among an Italian sample

Impatto psicologico della pandemia da SARS-CoV-2 nei bambini con disturbi del neurosviluppo e nelle loro famiglie: valutazione prima e durante l'emergenza covid-19 su un campione italiano

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SUMMARY. Background. The SARS-CoV-2 pandemic forced parents and children to modify their habits with a radical change in the family routine and consequent increase in psychological stress. Children with a neurodevelopmental disorder (NDDs) are particularly vulnerable to new and unexpected situations; moreover, the parents of these children generally show high levels of psychological stress due to the greater commitment that this condition imposes on them. The aim of this study is to evaluate the disease status of NDDs children before and during SARS-CoV-2 pandemic and to evaluate the psychological effects related to measures of social distancing on these children and their families. **Materials and methods.** Seventy-one children with NDDs, were enrolled in this study and followed up at the Child Neuropsychiatry Unit of the University Hospital Consortium Corporation Polyclinic of Bari (Italy) along with their parents. Parents were evaluated before national lockdown (baseline) and recontacted during the SARS-CoV-2 emergency almost after a year. The changes in emotional/behavioral problems of children and parenting stress before and during the SARS-CoV-2 pandemic were assessed with Child Behaviour CheckList (CBCL) and Parent Stress Index - short form (PSI). **Results.** The analysis of the emotional and behavioral problems of children with NDDs did not show statistically significant differences between the before and during the SARS-CoV-2 pandemic period. The evaluations conducted on parents highlights an increase in parental stress during the pandemic. Significant differences ($p<0.05$) were found in three subscales: Parenting Distress (PD) scale, Dysfunctional Interaction Parent-Child (P-CDI) scale and Defensive responding scale (DF). **Conclusions.** This study highlights the increase in parental stress and a more difficult parent-child interaction with NDDs in the period of lockdown due to the pandemic; identification of these risk targets can be useful for interventions in similar situations. Therefore, it is necessary to provide caregivers information to manage and overcome challenges experienced during a pandemic and providing psychological support for caregivers of children with NDDs.

KEY WORDS: covid-19, lockdown, social isolation, neurodevelopment, children well-being, parenting stress, stress managements, mental health prevention.

RIASSUNTO. Introduzione. La pandemia di SARS-CoV-2 ha costretto genitori e figli a modificare le proprie abitudini con un cambiamento radicale della routine familiare e conseguente aumento dello stress psicologico. I bambini con disturbi del neurosviluppo (NDD) sono particolarmente vulnerabili a situazioni nuove e inaspettate; inoltre, i genitori di questi bambini mostrano generalmente alti livelli di stress psicologico a causa del maggior impegno che questa condizione impone loro. Lo scopo di questo studio è valutare lo stato di malattia dei bambini affetti da NDD prima e durante la pandemia di SARS-CoV-2 e valutare gli effetti psicologici relativi alle misure di distanziamento sociale su questi bambini e le loro famiglie. **Materiali e metodi.** Settantuno bambini con NDD sono stati reclutati in questo studio e seguiti presso l'Unità di Neuropsichiatria Infantile dell'Azienda Ospedaliero-Universitaria Policlinico di Bari (Italia) insieme ai loro genitori. I genitori sono stati valutati prima del lockdown nazionale e ricontattati durante l'emergenza da SARS-CoV-2, a distanza di quasi un anno. I cambiamenti nei problemi emotivi/comportamentali dei bambini e lo stress genitoriale prima e durante la pandemia di SARS-CoV-2 sono stati valutati con i questionari Child Behavior Checklist (CBCL) e Parent Stress Index - short form (PSI). **Risultati.** L'analisi dei problemi emotivi e comportamentali dei bambini con NDD non ha mostrato differenze statisticamente significative tra il periodo precedente e quello durante la pandemia da SARS-CoV-2. Le valutazioni condotte sui genitori evidenziano un aumento dello stress genitoriale durante la pandemia. Differenze significative ($p<0,05$) sono state riscontrate in tre sottoscale: scala del disagio genitoriale (PD), scala dell'interazione disfunzionale genitore-figlio (P-CDI) e scala di risposta difensiva (DF). **Conclusioni.** Questo studio evidenzia l'aumento dello stress genitoriale e una più difficile interazione genitore-figlio nei genitori di bambini con NDD nel periodo di lockdown dovuto alla pandemia; l'individuazione di questi target di rischio può essere utile per elaborare interventi in situazioni simili. Pertanto, è necessario fornire informazioni ai caregiver per gestire e superare le sfide sperimentate durante una pandemia e fornire supporto psicologico ai caregiver di bambini con NDD.

PAROLE CHIAVE: covid-19, confinamento, isolamento sociale, neurosviluppo, benessere dei bambini, stress genitoriale, gestione dello stress, prevenzione della salute mentale.

INTRODUCTION

Starting from December 2019, after the initial outbreak in the city of Wuhan in China, a new Coronavirus called SARS-CoV-2 spread around the world until it obtained pandemic status on March 11, 2020[1]. To limit the pandemic and prevent the spread of infections, the Italian government has issued various ministerial decrees that have forced the population to implement restrictive measures and social distancing. In this emergency context, people have been subjected to various stressors deriving both from the infectious threat and from the profound changes in lifestyle habits implemented to stem the SARS-CoV-2 infection.

Day after day, the dramatic clinical reality of the devastating effects on the mental health of children and adolescents emerges as a result of the social changes that the storm from SARS-CoV-2 is bringing with it[2]. Various studies show that parents of typically developing children show an increase in stress levels mainly due to the daily management of their children engaged with DAD and the economic difficulties that the pandemic has brought in some cases[3-5].

However, the categories that are more fragile due to health problems, such as children with neurodevelopmental disorders (NDDs)[6] are of particular concern. NDDs are a group of clinical conditions that manifest in the early stages of development and are characterized by deficits in personal, social, academic, and occupational functioning. Neurodevelopmental disorders are associated with altered patterns of disorder of brain function that affects emotion, learning ability, self-control and memory which unfolds as an individual develops and grows. NDDs include Intellectual Disability (ID), Communication, speech, or language disorders, Developmental Language Disorder (DLD), Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Specific Learning Disorder (SpLD), and Motor disorders. Raising children with NDDs is particularly burdensome for parents. It was found that parents of children with NDDs show higher levels of parental stress due to the greater commitment that their child's condition imposes on them[7]. Parental stress is defined as an adverse psychological reaction due to a parent's perceived disparity between the child's demands and his or her ability to cope adequately. Numerous studies have shown that parental stress is determined by various factors, in particular intrinsic characteristics of the child and the parent and environmental factors that influence each other[8]. From here it is clear how the social distancing measures put in place to limit the infection from SARS-CoV-2 have endangered the delicate balance of children with NDDs and their families, primarily due to the impossibility of guaranteeing continuity in treatments, and then for a change in life habits and finally for the stress caused by the infectious threat[9]. It was highlighted that the sudden change in habits and lifestyle resulting from covid-19 has exacerbated their intrinsic sameness in facing the changes. This resulted in a worsening of pre-existing behavioral problems in these patients[10]. Furthermore, it was shown that the parents of NDDs children increased stress in reconciling smart working and managing daily activities such as meals, autonomy, free time, and school support[11]. However, few studies in the literature have investigate emotional-behavioral difficulties and parental stress before and during the pandemic.

Thus, we aimed to investigate parental and child adjustment in families with children with NDDs before and during lockdown. The research hypothesis of this study was that the pandemic with its restrictive and social distancing measures worsened the emotional and behavioral problems of children with NDDs and increased stress levels in the parents of these children.

METHODS

Seventy-one children and their parents were enrolled in this study and followed up at the Child Neuropsychiatry Unit Policlinico of Bari. These subjects were subsequently assessed one year before the SARS-CoV-2 pandemic (baseline) and assessed during the lockdown period between April-July 2020. There was no signed consent acquired due to social distance measures at the hospital, however the subjects were informed about the study protocol and sleeked permission to use the acquired data for research purposes. The changes in emotional/behavioral problems of children and parenting stress before and during the SARS-CoV-2 emergency were assessed with validated questionnaires such as Child Behaviour Checklist (CBCL)[12] and Parent Stress Index in short form (PSI)[13]. During the pandemic lockdown, both measures were administered via telephone interview.

Subjects mean age was 9 years (SD=3.67), in overall enrolled subjects 14 were diagnosed with ASD, 7 AHD, 10 LD, 18 SpLD, and 22 with other neurodevelopmental conditions (e.g. intellectual disability, speech delay, expressive language disorder, fluency disorder, global developmental delay, motor developmental coordination disorder, and tic disorders). The diagnosis was based on the developmental history of the children, through direct observation, clinical interviews with parents, and administration of the standardized diagnostic tests. Exclusion criteria were based on the presence of disabling neurological diseases and psychiatric disorders in the parents.

Assessment

The assessment was carried out by administering standardized scales, the "PSI" and the "CBCL" through a telephone interview.

The PSI Short Form (PSI/SF) is a direct derivative of the Parenting Stress Index (PSI) full-length test[13]. All 36 items on the Short Form are contained on the Long Form with identical wording and are written at a 5th-grade reading level, for parents of children 12 years and younger. Each item requires the parent/caregiver to rate the degree to which she/he aggress with a statement on a five-point Likert scale (1=Strongly Agree, 2=Agree, 3=Not Sure, 4=Disagree, and 5=Strongly Disagree). This self-report uses a three factors model to measure parenting stress, to which correspond the three subscales: parenting distress (PD) scale, dysfunctional interaction parent-child (P-CDI) scale, difficult child (DC) scale. The PD scales define the level of distress that a parent perceives in his parenting role, linked to personal factors directly involved in this role. The P-CDI scale values the parenting perception of a child that doesn't respond to the family expectations and of an interaction neither reinforcing nor rewarding with the child. The DC scale values how much the parent perceives his child as easy/difficult to manage, considering some of his behavioral characteristics. The PSI-SF produces sub-

scales raw scores ranging from 12 to 60 and an overall parenting stress total score that ranges from 36 to 180; a higher score indicates a greater level of stress. A score above 85 (at the 90th percentile) indicates clinically significant parenting stress[14]. The total stress (TS) scores, obtained by the sum of the scores of the 3 subscales, can be interpreted as a stress index related to the only parenting role. The test also includes a Defensive Responding (DF) scale, useful to control the validity of the protocol, which indicates if the parent tends to give a better self-image, minimizing the problems and the perceived stress in the relationship with the child. In this study, the Cronbach's alpha reliability coefficient of this measure is 0.91 for mothers and 0.88 for fathers.

The CBCL[15] is a common tool used to assess emotional and behavioral problems in children. The first section of the scale includes 20 items related to the child's social competency, as rated by parents. These items address the child's social competency, as rated by parents. These items address the child's participation in sports, hobbies, games, activities, organizations, jobs, chores, friendships, social interactions during play, independent work, and school functioning. The second section consists of 120 items on behavior or emotional problems during the past 6 months as rated on a three-point scale. The main areas of this construct are aggression, hyperactivity, bullying, conduct problems, defiance, and violence. The following behavioral and emotional problems are also measured: aggressive behavior, anxiety/depression, attention problems, delinquent rule-breaking behavior, social problems, somatic complaints, thought problems, withdrawal, externalizing, internalizing, and total problems. Responses are recorded on a Likert scale: 0=Not true, 1=Somewhat or Sometimes true, 2=very true or often true. Lower scores indicate lower functioning on the academic performance and adaptive functioning scales. Higher scores indicate higher levels of maladaptive behavior on the syndrome, total problems, externalizing, and internalizing scales. To verify the mean differences between groups, we took into account only the common scales between CBCL/6-18 and CBCL/1 ½-5. The instrument has an internal validity of 0.90-0.91 for the scales of internalizing disorders and of 0.95-0.96 for externalizing disorders. Cronbach's coefficient alpha was 0.95 and 0.96, respectively.

Statistical analysis

All socio-demographic and clinical characteristics were entered into the statistical analysis. Quantitative variables were presented as mean ± standard deviation (SD); qualitative variables were expressed as percentages. For the analysis of the quantitative variables (CBCL and PSI scores), the Student's *t*-test for independent samples was used. The significance value was set at p less than .05. For statistical processing, we used the data processing program statistical package for social science, version 20.0 (IBM Corporation, New Orchard Road, Armonk, NY, USA).

RESULTS

The socio-demographic characteristics of the sample are summarized in Table 1. The analysis of the emotional and behavioral problems of the patients included in the study did not show significant statistical differences in the period before and during the SARS-CoV-2 pandemic in any of the variables analyzed in the CBCL questionnaire.

Table 1. Clinical and sociodemographic characteristics of patients and their parents.

Number	71
Gender	
M	52
F	19
Mean age, years (SD)	9.01±3.67
I.Q. Level child (SD)	83.31±19.43
Mother (N)	62
Age (mother) (SD)	40.37±6.36
Father (N)	56
Age (father) (SD)	43±5.76
Comorbidities	
present	59
absent	12
Diagnosis	
SpLD	18
ADHD	7
ASD	14
LD	10
Other NDDs	22

Legend: SpLD= Specific Learning Disorders; ADHD= Attention-Deficit/Hyperactivity Disorder; ASD= Autism Spectrum Disorder; LD= Language Disorders; NDDs= Neurodevelopmental Disorders.

Analysis conducted to evaluate differences in parental stress in the period before and during the SARS-CoV-2 pandemic highlights statistically significant differences in some variables of the PSI questionnaire. Significant data were found in the variable's PD (p<0.001), P-CDI (p=0.004) and DF (p=0.002), as showed in Tables 2.

No statistically significant differences were found in the other variables analyzed in the PSI questionnaire.

Table 2. Significant differences in PSI scores between group.

Group		M	S.D.	F	p-value
PD	Pre-covid-19	46,93	36,642	23.71	.001*
	During covid-19	76,29	26,809		
P-CDI	Pre-covid-19	70,94	27,58	12.04	.004*
	During covid-19	83,91	17,983		
DF	Pre-covid-19	62,94	29,482	8.99	.002*
	During covid-19	78,78	22,965		

Legend: N= Number; M= Mean; SD= Standard Deviation; SDE= Standard Deviation Error; PD= parenting distress; P-CDI= dysfunctional interaction parent-child; DC= difficult child.
*Sig <0.05

DISCUSSION

This is one of the few studies that compares behavioral and emotional problems and parenting stress before and during SARS-CoV-2 pandemic in children with NDDs and their families. The purpose of this observational study was to investigate the disease state during the SARS-CoV-2 pandemic of patients with NDDs and to evaluate the psychological effects related to social distancing measures on families.

Analyzing the scores to the CBCL questionnaire, no significant differences emerged on the emotional and behavioral problems of children with NDDs during covid-19 pandemic compared to the pre-covid period. These results reflect those of Siracusano et al.[16], who also found no significant worsening in the adaptive functioning, problematic and repetitive behaviors emerged after the compulsory home confinement in children with ASD. However, this did not appear to be true for all children with NDDs. Some studies show improvements in the behavioral aspects of children with ASD, in terms of communication, socialization, personal autonomy skills and sleep[17-19]. The containment of emergency can have a positive impact on children with ASD who are no longer exposed to stressful situations in their life. Further, a study conducted on high-functioning ASD patients (HF-ASD), no significant differences were found in the same sample of ASD patients compared to the pre-covid period. However, higher levels of anxiety, depression, and stress have been found in children with HF-ASD compared to the general population[20]. A possible explanation of these results is given by the fact that social isolation is an intrinsic characteristic of ASD patients and for this reason, the measures of social distancing have been more tolerated by these patients, thus feeling similar to others from this point of view. ASD children felt more at ease with social distancing measures because this resulted in a reduced chance of meeting people and the presence of less traffic noise. Therefore, these patients managed forced social isolation better than the general population as it is characteristic of their nature. In particular, a study showed that ASD patients with intellectual nonfunctioning and without language problems experienced greater well-being during this pandemic period than those with intellectual and language impairment[10]. Furthermore, children did not interrupt ongoing therapies thanks to the early start of telemedicine, and these children could take walks in parks to reduce the psychological distress created by forced social isolation.

On the contrary, a study found that children with NDDs reported an increase in externalizing behavior during the lockdown[21]. Child externalizing behaviors were perceived as higher by parents of children with NDD both during and before the lockdown. However, the increase in child externalizing behaviors related to the pandemic is grafted on an already high baseline in children with NDD[21]. Recent studies have looked at the emotional and behavioral aspect of ADHD children[22]. One study found that children with ADHD and with a previous low degree of severity worsened significantly in almost all dimensions examined during the lockdown. In contrast, children with moderate to severe ADHD showed significant improvement. Little fun/interest and boredom seem to be the main factors that influenced the emotional state of children during the pandemic[22]. Another study also shows that children's ADHD behaviors significantly worsened during the covid-19 outbreak in comparison to their normal state[23]. The special arrangement of school close down and staying at home might bring elevated difficulties and stress for these children[23]. Other authors instead reported improvements in restlessness and study in relation to a decrease in discomfort created by the pace imposed by school activities[24]. A study also suggests that children with NDDs had worse behavioral symptoms than pre-covid. ADHD children showed inflated conduct problems, while those with ASD exhibited decrease prosocial behaviors. Female with ASD were particularly vulnerable to increased emotional symptoms compared to males[25]. However, few authors have investigated the effects of the pandemic on other NDDs, so future studies are needed. Current studies underlines the importance of a tele-evaluation and tele-rehabilitation for a therapeutic continuity for these children[26,27]. In particular, one study demonstrates that child language samples collected via video chat are largely comparable to in-person samples in terms of key speech and language measures[28].

Taken together, these studies suggest that internalizing and externalizing problems during the lockdown may vary according to the neurodevelopmental conditions. This would also explain why no differences emerged in the current study among internalizing and externalizing problems between before and during the lockdown, based on the comparison of CBCL mean score.

With respect to parental stress, we found problematic scores emerged in the following areas: PD, P-CDI, and DF. PD is defined as an adverse psychological reaction due to a parent's perceived disparity between the child's demands and his or her ability to cope adequately. P-CDI describes a parent who perceives their child as not meeting parental expectations or even as a negative element of their life. Such relationships can be subjected to severe stress with the risk of developing dysfunctional parental behaviors and/or behavioral and emotional problems on the part of the children. DF represents the adoption of a defense mechanism by the parent in the face of difficult relationships and problem behaviors of the children. Our data agree with previous studies that showed an increase in the level of parenting stress in caregivers of children with NDDs[11,21]. These findings suggest that during the covid-19 pandemic, parents of children with NDDS seem to experience increased challenges and/or an additional burden in trying to meet the demands inherent to their parental role. On the other hand, as previously mentioned, has shown that even in the parents of children with typical development there was an increase in PD[3-5]. Parents found themselves having to reconcile personal life, work, and the education and management of their children. Parents found themselves working from home, with related logistical problems and at the same time managing their children in the context of personal autonomy, management of meals, school activities, and free time. The main causes of PD seem to depend on the difficult home management of children with NDDs: difficulties relating to DAD and task management, the absence of the support teacher, the suspension in some cases of the enabling therapy with subsequent behavioral deterioration. In addition, a study conducted in Japan states has highlighted that limited work flexibility of mothers and the absence of help from grandparents worsened the quality of life of parents and contributed to the increase of parental stress[29,30].

It seems possible that parental stress during the lockdown is perceived as anguish by the parent which compromises the

ability to be a support for the children, sometimes causing the onset or worsening of pre-existing behavioral problems and the alteration of the child's emotional well-being. All this leads to the establishment of a dysfunctional parent-child relationship, due to the parent's difficulty in getting in tune with the child's requests. According to some studies, this kind of dysfunctional relationship can represent a risk factor for the onset and worsening of childhood psychopathologies and possible maltreatment[3,31]. Some authors identify as risk factors for the increase in PD: pre-existing pathologies, disabilities, being a single parent or, on the contrary, a large family, temporary loss of work, and consequent economic difficulties. Furthermore, the mothers seem to have suffered more from the stress of this condition since in Italian culture the mother is the child's main caregiver. In addition to this, the stress was increased directly by relatives/friends affected by covid-19[32,33]. In the literature, it emerged that despite the psychological distress experienced by parents during the pandemic, some of them appreciated the opportunity to spend more time with their own children and strengthen the parent-child relationship[21].

Therefore, according to these data, we can infer that NDDs families need more psychological support, especially to help parents to manage the challenges of their children during the covid-19 pandemic. This is an important aspect that should be considered in planning support interventions, as it can reduce parental stress and, in turn, improve the family's wellbeing.

The limitations of our study are the limited number of the sample, that of having interviewed with a single parent, mainly mothers with a low number of fathers recruited, and the fact that the telephone interview has reduced the empathy that can instead establish from a clinical interview in the presence.

CONCLUSIONS

In conclusion, this study demonstrates how the SARS-CoV-2 pandemic has impacted the lives of parents and children with NDDs. Changes in family routines have led to increased parental stress and a problematic relationship between parents and children. This suggests that it's important to identify children and families at risk, who need more than others support and targeted interventions. Further, this study suggests the need for specific telerehabilitation interventions for these families, that can provide continuity of care during the pandemic time. It is necessary to provide caregivers information to manage and overcome challenges experienced during a pandemic and providing psychological support for parents. However, future studies are needed to understand how caregivers have to manage the changes and navigating new challenges derived from covid-19 restrictions, so as to tailor interventions and supports.

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