


SHORT REPORT

Autism spectrum disorder during French COVID-19 lockdown: The importance of individualized support

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Abstract

Aim: This observational and repeated measures study assesses the impact of the first, most restrictive, COVID-19 lockdown in France on children with autism spectrum disorder (ASD) and their families.

Method: During the first COVID-19 lockdown, families of ASD children enrolled in the day-care centre of the child and adolescent psychiatry department of the Tours University Hospital were contacted weekly. A total of 95 parents took part in this study between the 18th of March and the 8th of May 2020. Advice and personalized support materials were provided by professionals involved in children's care. Questions regarding clinical outcomes were addressed to parents, and their assessments were reported on a 5-point Likert scale. Two time points were considered: the first 3 weeks and the three last weeks of the lockdown period.

Results: No difference was highlighted between clinical scores collected at the beginning and at the end of the lockdown. No effect of intellectual disability, accommodation type (house or apartment) or parental status was observed. The reasons for the relatively minor impact of the COVID-19 lockdown observed in this study are discussed.

Conclusions: Individualized and regular support provided by caregivers, familiar with ASD children's clinical specificities, in the context of a trusted relationship with parents may have contributed to the stability of this population. This 'tailor-made' approach should be promoted, in order to help support families of ASD children in this challenging period.

KEYWORDS

autism, caregivers' support, COVID-19, lockdown

1 | INTRODUCTION

The COVID-19 outbreak began in China at the end of 2019 and quickly spread to Europe. In France, the first lockdown of the

population began on the 17th of March 2020, and schools closed the day before. From the 2nd of April, some adaptations concerned autism spectrum disorder (ASD) children, who were allowed to go outside longer than other people (La Croix, 2020). This new situation,

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which lasted until the 11th of May, globally exposed children and parents to a full-time home life. The psychological impact of lockdown is known to be heterogeneous, including symptoms of anxiety, depression and feelings of anger and fear, which can be long-lasting (Brooks et al., 2020). The consequences of lockdown have been described in recent studies, which identified the following: anxiety and depression in children, adolescents and caregivers (Panda et al., 2020); self-reported psychological distress amongst students (Qin et al., 2021); and appetite and sleep problems in young children (Singh et al., 2020). Parents' stress also mediated lockdown's impact on children. Children of parents who reported more difficulties in dealing with this period were more likely to exhibit behavioural and emotional problems (Spinelli et al., 2020).

This full-time home life is particularly difficult for children with special educational needs and disabilities, especially for those with ASD (Asbury et al., 2020; Dhiman et al., 2020). This population requires a predictable and supportive environment, making them vulnerable due to discontinuation of care (American Psychiatric Association, 2013; Bellomo et al., 2020). Three studies, one in Portugal, another in Italy and the other in France, highlighted a negative impact of lockdown on children with ASD. The first study, involving 43 ASD children, identified increased difficulties in emotion management and more frequent and intense behaviour problems in the ASD group, compared with a neurotypical control group. Data were obtained using an anonymous questionnaire (Amorim et al., 2020). The second used an online survey to describe the impact of COVID-19 in 527 ASD children, affiliated with an Italian Autism Regional Centre. Results indicated increased difficulties in managing daily activities and more intense and more frequent behaviour problems (Colizzi et al., 2020). The third study mostly highlighted deterioration in challenging behaviours, with some worsening of sleep and stereotypical repetitive behaviours in a sample of 239 French ASD children (Berard et al., 2021). Advice on managing children with ASD, and targeted resources explaining lockdown and associated restrictions to this population, were published at the beginning of the lockdown in order to help parents at home (Brooks et al., 2020; Cluver et al., 2020). However, despite an increasingly abundant literature on support tools and transversal evaluations (Clépsy, 2022; Degli Espinosa et al., 2020; Siracusano et al., 2021; Tes Magazine, 2022), repeated measures studies are rare.

The aim of the current observational study was to describe the impact of the first, and most restrictive, French COVID-19 lockdown on children with ASD who benefit from regular rehabilitation programmes in a child and adolescent psychiatry department.

2 | METHODS

The survey concerned families of ASD children who benefited from at least one individualized rehabilitation intervention per week, in the day-care centre of the child and adolescent psychiatry department of the Tours University Hospital. ASD diagnosis was made by a child psychiatrist, according to the DSM-5 criteria, and was

complemented by an ADI-R (Lord et al., 1994) and/or ADOS-2 (Lord et al., 2012) assessment. Comorbid neurodevelopmental disorders were reported.

A phone call was arranged with families, once a week, during the 8 weeks of French lockdown. This regular contact was made by referring caregivers (nurses, special educators and psychologists) who are usually involved in the child's rehabilitation programme.

Advice and supporting materials were provided, by professionals, to address specific difficulties encountered by families during this period. Several ways of supporting parents and children were proposed (Centre de Ressources Autisme Centre-Val de Loire—C.R.A., Centre-Val de Loire, 2021; DICOM_Marie.M, 2021; SantéBD, 2021): simplified information about the COVID pandemic, adapted activities/games, sensorimotor activities, visual schedules/pictograms, psychological support, specialized teaching advice, special outings, addition/modification of drug treatment and daily hospitalization (in exceptional cases).

Various clinical outcomes were explored by asking parents to define the difference between the current level of each behaviour and its basal state: child anxiety, family anxiety, behaviour problems, negative impact on sleep, negative impact on appetite, negative impact on school work, family tension, lockdown intolerance, difficulties in following a schedule and isolation behaviour. Parents' assessments of child behaviour changes were rated, by professionals, on a 5-point Likert scale: (1) *not at all*, (2) *a little*, (3) *moderately*, (4) *a lot* or (5) *enormously*. Two time points were considered for each child: the first 3 weeks (T1) and the three last weeks (T2) of the lockdown period. The type of accommodation (apartment or house) and parental status were also recorded.

SphinxOnline v 4.16 was used for data collection. Student's *t* tests and linear mixed-effect models with repeated measures (patient as random effect; time and intellectual disability (ID), accommodation type and parental status as fixed effects) were carried out to study the effect of the lockdown on clinical variables between T1 and T2 time points.

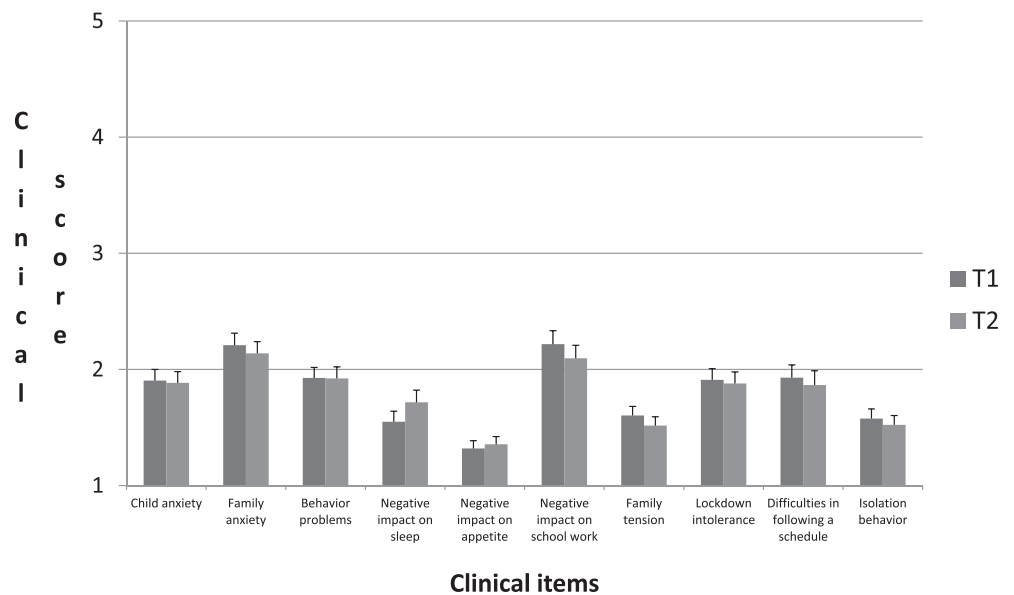
3 | RESULTS

A total of 95 parents took part in this study between the 18th of March and the 8th of May 2020. The sample of ASD children was composed of 78 boys (82.1%) and 17 girls (17.9%), between 2 and 16 years of age (mean: 7.1 years; SD: 3.3 years).

Thirty-two children (33.7%) presented with an ID associated with ASD, 12 had language disorders (12.6%) and 7 had motor disorders (7.4%); 58 families (61%) were living in an apartment, and the majority of parents were in a relationship (66.3%), 19 of them were separated (20.0%) and 13 isolated (13.7%).

No statistical difference was observed between parents' assessments at T1 (mean: 1.82; SD: 0.59) and T2 (mean: 1.78; SD: 0.59), $t(188) = 0.44$, $p = 0.66$. This result was independent of child ID (ID effect: $p = 0.54$; interaction ID \times Time: $p = 0.83$), accommodation type (accommodation type effect: $p = 0.12$; interaction

FIGURE 1 Clinical items (mean \pm SEM) at T1 and T2 time points ($N = 95$)



Accommodation Type \times Time: $p = 0.61$) and parental status (parental status effect: $p = 0.88$; interaction Parental Status \times Time: $p = 0.93$).

On a 5-point Likert scale, eight clinical items (child anxiety, behaviour problems, impact on sleep, impact on appetite, family tension, lockdown intolerance, difficulties in following a schedule and isolation behaviour) had an average score of less than 2 at both T1 and T2 time points; only two items (family anxiety and impact on school work) were rated between 2 and 3 at both time points (Figure 1).

4 | DISCUSSION

Our study was a parent survey describing the impact of the most restrictive French COVID-19 lockdown in ASD children. Children were followed by referring caregivers, who regularly contacted families and offered adapted and personalized support tools during this period. Contrary to concerns about worsening of clinical condition during lockdown, no difference was highlighted between parents' assessments collected at the beginning and at the end of this period, in our sample.

Our results conflict with those of other studies, which highlighted more frequent and intense behaviour problems (Berard et al., 2021; Colizzi et al., 2020), increased anxiety and a negative impact on emotional management in children with ASD during lockdown (Amorim et al., 2020). To address these behavioural challenges, several supports were proposed by our caregivers. The suggested home interventions aimed to reduce boredom, to provide adapted activities and maintain a structured and predictable environment (Bellomo et al., 2020; Children with autism and COVID-19, 2021). Simplified information resources were provided to share news of the pandemic and to manage children's anxiety (Lim et al., 2020). Specialized and personalized tools were provided to maintain pedagogical and sensorimotor activities at home (Singh et al., 2020), alternating with longer outings made possible after the 2nd of April (La Croix, 2020).

Furthermore, regular contact with professionals involved in the regular rehabilitation programme of the child contributed to parents' perception of social support, which is known to reduce parenting stress (Ren et al., 2020), and children's psychological problems (Spinelli et al., 2020). In line with Berard et al. (2021), continuity in service delivery would have a behavioural impact on ASD children (Berard et al., 2021).

Despite no reported clinical change in ASD children, our study highlighted minor changes in family anxiety and negative impact upon school work. These results support an impact of COVID-19 lockdown in parents, as recently documented in the literature. Indeed, parents recruited from child- and family-serving agencies and educational settings in the Western United States reported changes in their mood and stress levels during the COVID-19 pandemic (Brown et al., 2020), and additionally, physical and emotional neglect of themselves and verbal aggression towards children were highlighted in a national survey (Lee, Ward, Lee, et al., 2021). Lei et al. (2020) described an increased prevalence of anxiety and depression in neurotypical adults during lockdown, which may have been a factor in our parents' distress. Furthermore, many parents had to support their children's schooling in addition to their own work during lockdown. This is difficult to achieve, as the education of children with ASD presents several particularities and requires specific materials (Marsh et al., 2017). In support of this, a negative association between parenting stress and parents' perceived preparation to educate at home has been shown (Lee, Ward, Chang, et al., 2021).

Otherwise, our outcomes may be linked to autism's sameness dimension (Szatmari et al., 2006), associated with the tendency to seek immutability and to be afraid of changes (American Psychiatric Association, 2013). The decrease in social interactions and exterior sensory inputs during lockdown could have helped to maintain environmental stability. Indeed, the slower pace of life and increased family time were identified, by parents, as positive features (Pavlopoulou et al., 2020). Positive coping strategies were also

reported during the pandemic, such as establishing routines at home, using behavioural strategies to support children's development or engaging in exercise, meditation or social support (Neece et al., 2020). Moreover, the independence of accommodation type and parental status on our sample evolution may highlight the significance of routine and environmental stability. In line with Berard et al. (2021), living conditions seemed to have no effect on ASD children behaviours (Berard et al., 2021).

Our investigation has some limitations, mainly due to the short time available for setting up the study and the extreme reactivity needed to collect data during the French lockdown. First, this is an observational study, and therefore, no causative link can be identified between experimental outcomes and caregivers' support. Second, clinical points were evaluated by parents and rated by professionals who know the children: This method does not ensure uniformity of measurements. Furthermore, we did not use validated scales that would enable a more precise assessment. Third, our study was based on children recruited from a single centre, with specific procedures, which limits generalization to other situations.

5 | CONCLUSION

The results of this parent survey describe the impact of the first and most restrictive French COVID-19 lockdown in ASD children. No significant changes in emotional experience and behaviour of ASD children were identified during this period. ASD particularities and parents' adjustments to the situation could have contributed to this clinical stability. Moreover, these results are likely to be linked to regular support, offered by referring caregivers, with established relationships with children and families. Caregivers were familiar with children's clinical specificities and proposed personalized tools, suggesting that this 'tailor-made' approach should be promoted, in order to help families of ASD children to cope during this challenging period.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to report and did not receive funding for this project. They have full access to data and have the right to publish them. All authors participated in a meaningful way in the preparation of the manuscript.

ETHICS STATEMENT

Approval of the Tours University Hospital Ethics Committee in Human Research was granted for this project (No. 2020 079).

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