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1 **Anxiety and depression in parents of children with autism spectrum disorder during the first**
2 **COVID-19 lockdown: report from the ELENA Cohort**

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Abstract

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2 **Background:** The Covid-19 pandemic had a strong impact on mental health in the general population.
3 This study conducted during the first lockdown in France considered parents of children with Autism
4 Spectrum Disorder (ASD) prospectively followed in the ELENA Cohort. **Objectives:** We aimed to (1)
5 compare the Anxiety and Depression (AaD) levels during the lockdown between mothers and fathers,
6 (2) compare the parent's AaD between the lockdown and the last ELENA follow-up visit, and (3)
7 identify risk factors for parental AaD during lockdown among socio-demographic and children's
8 clinical characteristics. **Methods:** The Hospital Anxiety and Depression Scale (HADS) was used to
9 assess AaD in 134 parent's pairs. Parents also completed the Questionnaire about their living
10 conditions during COVID-19, their child's interventions and perceived changes about their child's
11 behaviors and sleep. Child's ASD severity, intellectual and socio-adaptive skills and parent's socio-
12 demographic characteristics were collected from ELENA follow-up. **Results:** The parents' AaD levels
13 were lower during the lockdown compared to the last ELENA visit that coincided in 96% with the
14 child's ASD diagnosis. The AaD levels were more pronounced in mothers and significantly associated
15 with the child's challenging behaviors, parents' teleworking and perceived knowledge about COVID-
16 19. The perception of an insufficient knowledge was the only risk factor for mothers' AaD.
17 **Conclusion:** Our findings highlighted the pertinence for an assessment of the mental health of main
18 caregivers of children with ASD, consideration of their gender characteristics, and the importance of
19 providing relevant information during pandemic. Future studies examining the pandemic long-term
20 effects are needed.

21 **Key words:** anxiety, depression, parents, autism spectrum disorder, COVID-19

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Introduction

The coronavirus disease 2019 (COVID-19), first detected in December 2019 in Wuhan, China, spread rapidly across the globe (Adam, 2020). By March 2020, the World Health Organization acknowledged that Europe had become the epicenter of the pandemic. Facing a surge in case numbers, the French government introduced national containment and mitigation measures mandating the closure of schools, universities and all public venues. The impact of such unprecedented restrictions to limit the spread of COVID-19 had an important psychological impact on everyday public life (Brooks et al., 2020; Dubey et al., 2020). Initial reports emphasized the psychological effects of the pandemic on frontline healthcare workers, with increasing recognition of the more extensive psychological impact of mass quarantine on other vulnerable populations. In France, anxiety symptoms were reported in 26.7% of the general population a week following the beginning of the first lockdown, twice the average rate previously observed in the general population (Chan-Chee et al., 2020).

Prior to the onset of the COVID-19 emergency, several factors were already known to be associated with the increased psychological burden of large-scale disease epidemics, notably being single, female, aged 16 to 24 years, having a low educational level, and financial hardship (Blendon et al., 2004; Brooks et al., 2020; Chan-Chee et al., 2020; Hyland et al., 2020; Liu et al., 2012; Mohammed et al., 2015). Protective factors included being male, being employed, living with a partner, having a high educational level, and favorable living conditions, e.g., larger living area and access to outdoors (Haesebaert et al., 2020; Webster et al., 2020). Although public health measures understandably focused on case fatality rates, especially among the elderly and those with pre-existing medical conditions, a handful of studies began to emphasize the substantial emotional toll of the containment measures, especially for parents living with children below 10-years during the COVID-19 lockdown (Haesebaert et al., 2020).

Past studies have consistently reported that parents of children with neurodevelopmental disorders show higher levels of distress, especially anxiety and depression (AaD) compared to controls (Barker et al., 2011; Olsson and Hwang, 2008). Based on evaluation of AaD among parents of children with autism spectrum disorder (ASD) using the standardized Hospital Anxiety and

1 Depression Scale (HADS) (Snaith, 2003), show that they are more likely to report AaD compared to
2 parents of typically developing children or children with other neurodevelopmental disorders
3 (Almansour et al., 2013; Hamlyn-Wright et al., 2007), with the period of initial diagnosis of ASD
4 being especially emotionally challenging and stressful (Lerthattasilp et al., 2015). Women regularly
5 report higher rates of AaD than men in the general population (Bekker and van Mens-Verhulst, 2007;
6 Kuehner, 2003; McLean et al., 2011; Van de Velde et al., 2010) and not surprisingly past studies have
7 also noted that mothers of children with neurodevelopmental disorders express lower levels of
8 wellbeing (Olsson and Hwang, 2008) and higher levels of depression than fathers (Singer, 2006).
9 Furthermore, mothers of children with ASD consistently report higher levels of stress and AaD than
10 the fathers (Davis and Carter, 2008; Jones et al., 2013) and a significant positive link with maternal
11 AaD was recently reported (Öz et al., 2020). Several studies have found that the severity of the
12 children's behavioral problems is related to higher levels of AaD among mothers (Barker et al., 2011;
13 Bitsika and Sharpley, 2004; Wiggins et al., 2019). Jones et al. (2013) suggested that behavioral
14 problems and adaptive deficits in children with ASD are more strongly associated with anxiety in their
15 mothers than in their fathers. The literature has also highlighted an association between the children's
16 physiological behaviors, such as sleep, and ASD behavioral severity (Türkoğlu et al., 2020) and
17 parental depressive symptoms (Meltzer, 2011).

18 In terms of the impact of the pandemic in France, a survey showed that 38% of caregivers of
19 children with ASD perceived the COVID-19 containment measures to be challenging (Centre de
20 Ressources Autisme, 2020). Researchers recently reported an increase in challenging behaviors in
21 children with ASD during the lockdown , particularly among younger children (Berard et al., 2021),
22 suggesting a negative impact of the COVID-19 pandemic on the mental health of children with ASD
23 and their parents (Guller et al., 2021).

24 The first objective of the present study was to compare the levels of AaD between mothers and
25 fathers caring for children with ASD during the first COVID-19 lockdown in France. Based on the
26 existing literature, we therefore hypothesized that the levels of AaD of the mothers would be higher. A
27 second objective was to compare the AaD levels between the lockdown and the last ELENA follow-up

1 visit. The third objective was to identify risk factors for parental AaD during the lockdown among
2 socio-demographic and clinical characteristics of children with ASD.

3 **Methods**

4 *Study design*

5 The present study consisted of a cross-sectional parent survey carried out between April 27
6 and May 13, 2020, during the first COVID-19 lockdown in France (to facilitate the reading, the terms
7 “first COVID-19 lockdown” and “lockdown” are used as synonyms in this paper). The study nested
8 among families enrolled in the ELENA cohort (Baghdadli et al., 2019), a prospective multicenter
9 study including 892 children with confirmed diagnosis of ASD. The data collected cover clinical,
10 medical, social, and environmental variables collected at inclusion, and after 18, 36 and 72 months.

11 *Data collection*

12 For the present study, a letter was sent to the parents via the ELENA database electronic
13 system to invite them to participate in the online ELENA-COVID-19 study. A reminder was sent to
14 parents two weeks later by e-mail or by telephone for those who did not have access to the internet.
15 Approximately 30 questionnaires were administered by telephone by a clinical research assistant.

16 *Participants*

17 Participants were parents of children with a confirmed diagnosis of ASD followed in the
18 ELENA Cohort who both completed the HADS during the lockdown. The number of participants
19 differed for each of the three objectives of the study based on the completed questionnaires (Fig. 1).

20 For the first objective, the sample included 134 pairs of parents who completed the HADS
21 during the lockdown. For the second objective, the sample covered 94 mothers and 79 fathers who
22 completed the HADS during the lockdown and before the pandemic (data collected from the last visit
23 in the ELENA follow-up from April 2015 to March 2020). For the third objective, the sample included
24 only 94 mothers who simultaneously completed the HADS and COVID-19 Questionnaire during the
25 lockdown; the 10 fathers who completed the questionnaires were not included in this analysis.

26 ~~The ELENA cohort study was approved by the South Mediterranean Ethics Committee on the~~
27 ~~Research of Human Subjects of Marseille (ID RCB: 2014 A01423-44) and the National Commission~~

1 ~~for Computing and Liberties (CNIL number DR-2015-393)~~. The online ELENA-COVID-19 study
2 was approved by the Internal Review Board of the University Hospital of Montpellier (IRB-
3 MTP_2020_04_202000453).

4 [Insert Figure 1]

6 *Variables*

7 1. Parents' variables

8 Data collected prior the lockdown, from the last ELENA follow-up visit (Baghdadli et al., 2019),
9 were parental socio-demographic characteristics and the last HADS completed. The HADS was
10 collected for 96% of the parents at the time of the inclusion in ELENA cohort (itself determined
11 by the diagnosis of ASD to parents) and for 4% at another time but prior to epidemic. We also
12 collected data during the lockdown: the COVID-19 Questionnaire developed by the authors and
13 the HADS.

14 2. Children's variables

15 We used data collected prior the lockdown from the last ELENA follow-up visit: ADOS-2 CSS,
16 best-estimate intellectual level and VABS-II scores, and behavioral data from the COVID-19
17 Questionnaire completed by parents during the lockdown.

18 *Measures*

19 1. *COVID-19 Questionnaire*

20 Parents completed a structured online questionnaire constructed by the authors to collect data
21 during lockdown and were asked to complete only one COVID-19 Questionnaire per child. The
22 questionnaire consisted of the following four sections: (i) family environment: area of the living space
23 of the house and household composition; (ii) parental professional activity: loss or reduction of
24 employment and teleworking for the responder and his/her spouse; (iii) information on COVID-19 and
25 containment measures; and (iv) child's status: health, need for care (related or not to COVID-19), and

1 special education. Parents were also asked to rate the child’s challenging behaviors and sleep as
2 “unchanged”, “improved”, or “worsened” during the lockdown.

3 2. *The Hospital Anxiety and Depression Scale (HADS)*

4 The HADS (Zigmond and Snaith, 1983) was used to assess the AaD of the parents. This
5 reliable tool has been widely used in community and primary care practice settings, but also in studies
6 of parents of children with ASD (Almansour et al., 2013; Guller et al., 2021; Hamlyn-Wright et al.,
7 2007; Lanyi et al., 2021; Reed et al., 2016). Both mothers and fathers were invited to self- rate the 14
8 items of the French-version (Lepine et al., 1985), including seven items about depression and seven
9 about anxiety. The overall score and two sub-scores from the anxiety and depression subscales were
10 determined. The thresholds for the sub-scores were: 0 to 7, absence of anxiety or depression; 8 to 10,
11 suspected anxiety or depression; and 11 to 21, significant level of anxiety or depression. The
12 thresholds for the combined scores were: 0 to 14, no anxiety/depression, and 15 to 42, presence of a
13 significant level of combined anxiety+depression.

14 3. *Socio-demographic variables*

15 The parents’ age and education levels were extracted from the ELENA socio-demographic
16 report.

17 4. *Children’s clinical characteristics*

18 Children clinical characteristics were collected from the ELENA last follow-up visit. Symptoms
19 severity was measured using the Calibrated Severity Score (CSS) of Autism Diagnosis Observation
20 Schedule-2 (ADOS-2) (Gotham et al., 2007; Hus et al., 2014; Hus and Lord, 2014; Lord et al., 2012).
21 The intellectual level was estimated for each child using age-appropriate tests to take into account the
22 variability of skills among children by age (Howlin et al., 2014). A performance IQ was calculated if a
23 standardized test could be administered (Wechsler scales (Wechsler, 2002, 2003, 2014a, b) or K-ABC
24 II (Kaufman and Kaufman, 2013)). A developmental age was estimated from developmental scales if
25 the child could not understand the test instructions (Brunet Lézine-Revised (Brunet et al., 1997) or
26 PEP-3 (Schopler et al., 2004)) and a developmental quotient was calculated according to Stern’s
27 formula (Stern, 1912) by dividing the developmental age score by the chronological age x 100. The

1 adaptive skills were assessed with the Vineland Adaptive Behavior Scale, Second Edition (VABS-II)
2 (Sparrow, Sara S et al., 2005).

3 *Statistical analyses*

4 The outcome variable was the mothers' AaD levels during the lockdown. The following
5 potential explanatory variables from the following sources were considered for the analysis: 1) the
6 ELENA cohort: latest data collected concerning the child's CSS, VABS-II standard scores, and
7 intellectual level and 2) the ELENA-COVID-19 Questionnaire: child's age during the lockdown,
8 number of children living at home, number of outings, continuation of care during the lockdown,
9 number of rooms in the house and the number of household inhabitants, single-parent family during
10 the lockdown, parents' educational levels, parents' employment/loss of income during the lockdown,
11 teleworking, parental perceived knowledge about COVID-19, and the perception of changes in their
12 child's behaviors.

13 The mean and standard deviation (SD) are reported for continuous variables and the frequency
14 for categorical variables. Paired sample t-tests were used to compare: 1) HADS scores between the
15 mothers and fathers during the lockdown and 2) the mothers' and fathers' HADS scores between the
16 lockdown and the last ELENA follow-up visit. The association between potential explanatory factors
17 and the mothers' AaD levels observed during the lockdown was studied using Pearson chi-square or
18 Fisher exact tests for the categorical variables and Student's t-tests or Wilcoxon rank-sum tests for
19 continuous variables.

20 Due to the sample size, AaD risk factors were explored only for mothers by multivariate
21 logistic regression. Variables with a p-value < 0.20 in univariate analysis were included in the model
22 and backward selection was used to select the model that minimized the Akaike Information Criterion
23 (AIC). The multivariate model was adjusted for the time since the diagnosis. Odds ratios (OR) with
24 95% confidence intervals are presented. The goodness-of-fit of the models was assessed using the
25 Hosmer and Lemeshow test. All statistical tests were considered significant for $p < 0.05$. Statistical
26 analyses were performed using SAS Enterprise Guide V7.13 (SAS Institute Inc., Cary, NC, USA).

27

1 **Results**

2 *Descriptive data*

3 *Parents' characteristics*

4 The mean age was 41.1 years (± 6.8) for the mothers and 44.2 years (± 7.8) for the fathers.
5 Overall, 60.2% (n = 74) of the mothers had a college/university education vs. 52.0% (n = 64) of the
6 fathers. The parents' characteristics were comparable between the samples of the ELENA-COVID-19
7 study and the ELENA cohort for age, educational level, and socio-economic status.

8 *Children's characteristics*

9 The mean age of the children was 8.6 years (± 4.0). There were 82.1% boys (n = 110).
10 Overall, 40.2% of the children (n = 51) had an IQ < 70. The mean ADOS CSS-severity score was 7.34
11 (± 1.7). The mean VABS-II scores were 70.8 (± 15.3) for communication, 71.9 (± 13.0) for daily
12 living skills, and 69.2 (± 12.9) for socialization. The children's characteristics were comparable
13 between the samples of the ELENA-COVID-19 study and the ELENA cohort.

14 *Socio-demographic characteristics during the lockdown*

15 During the COVID-19 lockdown, interventions from special education and care services were
16 maintained for 72.0% (n = 95) of the children, interrupted for 23.5% (n = 31), and 4.5% (n = 6) of the
17 children had no specialized interventions just before the lockdown. Other socio-demographic
18 characteristics during the lockdown are presented in Table 1.

19 [Insert Table 1]

20
21 *Mothers' perception of changes in their children's behavior during the lockdown*

22 In terms of their children's sleep, 60.2% of the mothers (n = 56) described it as unchanged,
23 32.3% (n = 30) as worsened, and 7.5% (n = 7) as improved. In terms of their children's challenging
24 behaviors, 32.3% of the mothers (n = 30) described them as unchanged, 50.5% (n = 47) as worsened,
25 and 17.2% (n = 16) as improved. One mother did not answer the question.

26

Comparative analysis

Objective 1: Comparison of AaD levels between mothers and fathers (n = 134 pairs) caring for children with ASD during the lockdown.

Based on paired comparisons (Figure 2), during lockdown, the HADS scores were significantly higher for the mothers than fathers for anxiety (mean difference = 2.0 (\pm 4.6), $p < 0.001$), depression (mean difference = 0.9 (\pm 4.7), $p = 0.01$), and anxiety+depression combined (mean difference = 3.0 (\pm 8.0), $p < 0.001$). The same significant differences were found during the period coinciding with the announcement of the diagnosis (data not shown).

[Insert Figure 2]

Objective 2: Comparison of parent's AaD levels (mothers, n = 94; fathers, n = 79) between the lockdown and the last ELENA follow-up visit.

Paired comparisons of the HADS scores of the mothers (Fig. 3) showed them to be lower during the lockdown than from the last ELENA follow-up visit for anxiety (mean difference = -2.5 (\pm 3.8), $p < 0.001$), depression (mean difference = -1.5 (\pm 3.9), $p < 0.001$), and anxiety+depression combined (mean difference = -4.0 (\pm 6.8), $p < 0.001$).

The fathers (Fig. 3) HADS scores were significantly lower during the lockdown than from the last ELENA follow-up visit for anxiety (mean difference = -2.3 (\pm 4.1), $p < 0.001$) and anxiety+depression combined (mean difference = -3.0 (\pm 7.8), $p = 0.001$), but were not significantly different for depression (mean difference = -0.7 (\pm 4.6), $p = 0.16$).

[Insert Figure 3]

Objective 3: Identification of the risk factors for mothers' AaD (n = 94) during the lockdown

Univariate analysis

Among the 94 mothers who simultaneously completed both the COVID-19 Questionnaire and HADS, 39.4% (n = 37) showed combined anxiety+depression. More mothers with combined

1 anxiety+depression reported worsening of their child's challenging behaviors than those without
2 (66.7% vs. 40.4%, $p = 0.02$). Telework was less common in families of mothers with combined
3 anxiety+depression than in those of mothers without (19.4% vs. 40.4%, $p = 0.04$). In addition, 41.7%
4 ($n = 15$) of mothers with combined anxiety+depression rated their perceived knowledge about
5 COVID-19 as highly insufficient or insufficient versus 14.0% ($n = 8$) of the other mothers ($p = 0.01$).

6 The child's IQ and sleep tended to be significantly associated with the mothers' combined
7 anxiety+depression ($p = 0.08$ and $p = 0.14$, respectively). Mothers with combined anxiety+depression
8 more often had children with an IQ <70 and impaired sleep than those without.

9 Other clinical characteristics of the children (age, sex, ADOS CCS-severity, and VABS-II
10 scores), their interventions, and the parents' age or education level were not significantly associated
11 with the mothers' HADS scores.

12

13 *Multivariate analysis*

14

[Insert Table 2]

15 Multivariate analysis showed that mothers who rated their perceived knowledge about
16 COVID-19 as highly insufficient or insufficient compared to those who rated it as good had a
17 significantly higher risk of having anxiety+depression combined [ORa = 4.58 (95%CI = 1.58-13.26), p
18 = 0.01] (Table 2).

Discussion

This is one of the first studies to specifically investigate AaD levels of parents of children with a confirmed ASD diagnosis during the lockdown of the COVID-19 pandemic. The AaD levels were assessed using standardized measures in a relatively large sample of parents.

In terms of the first study objective, to compare levels of AaD during the lockdown between mothers and fathers of the same child, our results showed the AaD levels to be higher for mothers than fathers, consistent with our hypothesis and results of previous research (Davis and Carter, 2008; Jones et al., 2013). Of note, women in the general population also report higher levels of AaD than men (Bekker and van Mens-Verhulst, 2007; McLean et al., 2011; Van de Velde et al., 2010). Among parents with a child with ASD, the difference between genders may also be related to differences in coping strategies (Luque Salas et al., 2017; Vernhet et al., 2019). Another interpretation is that mothers are more often the caregivers who are more highly involved in the daily care of the child, which may influence their AaD levels (McStay et al., 2014).

For the second study objective, to compare AaD levels reported by parents during lockdown and the last ELENA follow-up visit, we assumed that the parents' AaD levels might be higher during the lockdown than assessments prior to the COVID-19 onset, as observed in the general population (Chan-Chee et al., 2020). As parents' AaD levels were not assessed just prior to the pandemic, interpretation of its effects on their mental health must be cautious. Actually, our findings suggest, that the measures of parents' AaD levels from the last follow-up visit were higher than during the COVID-19 lockdown. One possible explanation is that completion of the HADS prior to the pandemic coincided, in 96% of cases, with the time of inception into the cohort and communication of the children's diagnosis, which is a stressful period for the parents (Lerthattasilp et al., 2015). Another possible explanation is that the parents who agreed to participate in the ELENA-COVID-19 survey were those whose emotions were better preserved. Although it may be intriguing that the prevalence of depression was lower in our sample than in the general population over the same period (approximately 10% of fathers and mothers vs 19% of the general population), another interpretation may be that the parents of children with ASD have better coping skills, acquired through their caregiver status, that they mobilized during the pandemic (Zhao and Fu, 2020). A further explanation

1 may be that the containment measures may have had a positive impact on families with ASD, who
2 were in close proximity to their children and no longer exposed to stressful situations in their daily life
3 related to recurrent transportation to children's interventions.

4 For our third objective, to identify risk factors for parental AaD during the COVID-19
5 lockdown, the limited sample size restricted us to study risk factors only among the mothers.
6 According to univariate analysis, the children's challenging behaviors, teleworking by the parents, and
7 mothers' perceived knowledge about COVID-19 were significantly associated with the mothers' AaD
8 levels. The role of the worsening of children's behaviors on the AaD of mothers, and their mental
9 health has been previously reported in the literature (Baghdadli et al., 2014; Barker et al., 2011; Jones
10 et al., 2013). We may also supposed that mothers with high levels of AaD have more difficulty in
11 coping with their children's behaviors that they may perceive as worsened. A recent study about
12 lockdown measures showed that teleworkers experienced lower well-being during lockdown than
13 workers who remained in their usual office, with this perception being stronger among women
14 (Escudero-Castillo et al., 2021). In contrast, our results suggest that parents' teleworking was
15 associated with lower AaD levels in mothers. Since teleworking was widespread in France during the
16 first lockdown, it can be assumed that mothers may perceived the benefits of the presence of their
17 partner in daily life. Lockdown measures seem to reduce the organizational constraints around
18 managing, for example, the child's accompaniments to therapies and so may have improved mother's
19 sense of wellbeing. Furthermore, we found the mothers' AaD during lockdown was not associated
20 with the child's socio-demographic or clinical characteristics, family living conditions, or continuity of
21 care. In our sample, there was a trend towards an association between the level of AaD of the mothers
22 and their child's intellectual level and sleep. This is consistent with the literature, which has shown
23 that mothers who have a child with an intellectual disability have higher levels of AaD (Sheikh et al.,
24 2018) and lower well-being (Olsson and Hwang, 2008). In addition, mothers who have reported
25 significant levels of AaD have more often had children who sleep poorly (Meltzer, 2011; Waddington
26 et al., 2020).

27 The only risk factor for AaD among mothers identified from our multivariate analyses was
28 their perceived lack of knowledge about COVID-19. This result is in accordance with those of

1 previous reports showing that adequate knowledge about the disease during pandemics is associated
2 with better adherence to containment measures and a greater sense of well-being (Webster et al.,
3 2020). In our study, good perceived knowledge about COVID-19 was not significantly linked to an
4 increased risk of AaD for mothers, in contrast to previous findings, suggesting that recurrent and
5 excessive information about a disease may have a negative impact on anxiety levels (Everts, 2013;
6 Roy et al., 2020). We suppose that parents with higher AaD levels, having stronger feeling of
7 helplessness and vulnerability, perceived that they had less knowledge than parents with lower AaD.
8 Finally, we assume that the AaD of the parents could be also related to factors that were not taken into
9 account in our study, such as parental coping strategies that need to be studied.

10 **Strengths and limitations**

11 The use of the HADS was a strength of our study in that it provided a structured, acceptable,
12 and effective dimensional assessment of AaD (Snaith, 2003), in parents having a child with ASD
13 (Almansour et al., 2013; Guller et al., 2021; Hamlyn-Wright et al., 2007; Lanyi et al., 2021; Reed et
14 al., 2016). An important strength related to the relatively large sample of children with a confirmed
15 and well-phenotyped ASD enrolled in an established cohort. In addition, this study is one of the first to
16 assess AaD in both mothers and fathers with a child with ASD during a COVID-19 pandemic
17 lockdown.

18 However, our findings must be interpreted in the context of a number of limitations. First, only
19 27% of the families enrolled in the ELENA cohort participated in the ELENA-COVID-19 study,
20 which may have introduced a response bias. We presume that the low response rate to the survey may
21 have been related to the short completion lead period (15 days) and the need to assess AaD levels in
22 real time especially in a context in which parents were less available due to school closures. One
23 possible limitation of comparing AaD levels over time is that, parents' AaD levels were not assessed
24 shortly before the pandemic, which may influence understanding of the real effects of the pandemic on
25 parents' mental health. Another limitation was that the risk factors were analyzed only for mothers
26 because of the lack of data for fathers. We did not use clinical interviews to assess parents' mental
27 health, which should be proposed in future studies and, as the clinical analysis would be finer, it may

1 probably lead to higher AaD rates. Finally, as the children's behaviors during lockdown were assessed
2 by the parental questionnaires, we assume that parents' emotional states may have influenced their
3 perception of children's behaviors.

4 **Conclusion and Implication**

5 This study suggests that AaD levels during the lockdown in France were higher in mothers
6 than in fathers of children with ASD, as found in the general population, and in previous studies in
7 parents of children with ASD. Our results also suggest that parents' AaD levels were lower during the
8 COVID-19 lockdown than before the outbreak, a time that coincides in the present study with
9 families' inclusion in the ELENA cohort and communication of the ASD diagnosis to parents. In
10 addition, positive associations were found between mothers' AaD and their perception of worsening
11 child challenging behaviors, indicating the importance to prevent behavioral difficulties through
12 parents training and supervision. The association between parental teleworking during lockdown and
13 lower AaD in mothers may be the result of sharing the daily activities with the partner. The only
14 significant risk factor for AaD found in mothers was their perceived knowledge about COVID-19,
15 which is an additional argument to facilitate for caregivers access to updated and relevant information.
16 This study leads to consider the mental health of caregivers of children with ASD (in our study,
17 mainly mothers), through information, training and long-term support. Our study conducted at the
18 beginning of the pandemic, could be extended by long-term studies of the effects of the pandemic on
19 the mental health of parents.

20

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1

References

2 Adam, D., 2020. Special report: The simulations driving the world's response to COVID-19. *Nature*
3 580(7803), 316-318.

4

5 Almansour, M.A., Alateeq, M.A., Alzahrani, M.K., Algeffari, M.A., Alhomaidan, H.T., 2013. Depression
6 and anxiety among parents and caregivers of autistic spectral disorder children. *Neurosciences*
7 (Riyadh) 18(1), 58-63.

8

9 Baghdadli, A., Miot, S., Rattaz, C., Akbaraly, T., Geoffray, M.M., Michelon, C., Loubersac, J., Traver, S.,
10 Mortamais, M., Sonié, S., Pottelette, J., Robel, L., Speranza, M., Vesperini, S., Maffre, T., Falissard, B.,
11 Picot, M.C., 2019. Investigating the natural history and prognostic factors of ASD in children: the
12 multicentric Longitudinal study of childrEN with ASD - the ELENA study protocol. *BMJ Open* 9(6),
13 e026286.

14

15 Baghdadli, A., Pry, R., Michelon, C., Rattaz, C., 2014. Impact of autism in adolescents on parental
16 quality of life. *Qual Life Res* 23(6), 1859-1868.

17

18 Barker, E.T., Hartley, S.L., Seltzer, M.M., Floyd, F.J., Greenberg, J.S., Orsmond, G.I., 2011. Trajectories
19 of emotional well-being in mothers of adolescents and adults with autism. *Dev Psychol* 47(2), 551-
20 561.

21

22 Bekker, M.H., van Mens-Verhulst, J., 2007. Anxiety disorders: sex differences in prevalence, degree,
23 and background, but gender-neutral treatment. *Gend Med* 4 Suppl B, S178-193.

24

25 Berard, M., Rattaz, C., Peries, M., Loubersac, J., Munir, K., Baghdadli, A., 2021. Impact of containment
26 and mitigation measures on children and youth with ASD during the COVID-19 pandemic: Report
27 from the ELENA cohort. *J Psychiatr Res* 137, 73-80.

28

29 Bitsika, V., Sharpley, C., 2004. Stress, anxiety and depression among parents of children with autism
30 spectrum disorder. *Australian journal of guidance and counselling* 14(2), 151-161.

31

32 Blendon, R.J., Benson, J.M., DesRoches, C.M., Raleigh, E., Taylor-Clark, K., 2004. The public's response
33 to severe acute respiratory syndrome in Toronto and the United States. *Clin Infect Dis* 38(7), 925-
34 931.

35

36 Brooks, S.K., Webster, R.K., Smith, L.E., Woodland, L., Wessely, S., Greenberg, N., Rubin, G.J., 2020.
37 The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet*
38 395(10227), 912-920.

39

40 Brunet, O., Lézine, I., Josse, D., 1997. Brunet-Lézine révisé: échelle de développement psychomoteur
41 de la première enfance: BLR. Editions et applications psychologiques.

42

43 Centre de Ressources Autisme, I.-d.-F., 2020. Synthèse de la mini-enquête lors du confinement.
44 Centre de Ressources Autisme Ile-de-France, Paris, pp. 6-p.

45

46 Chan-Chee, C., Léon, C., Lasbeur, L., Lecrique, J.-M., Raude, J., Arwidson, P., du Roscoät, E., 2020. La
47 santé mentale des Français face au Covid-19 : prévalences, évolutions et déterminants de l'anxiété au
48 cours des deux premières semaines de confinement (Enquête CoviPrev, 23-25 mars et 30 mars-1er
49 avril 2020). *Bulletin épidémiologique hebdomadaire* n°. 13, p. 260-269.

50

1 Davis, N.O., Carter, A.S., 2008. Parenting stress in mothers and fathers of toddlers with autism
2 spectrum disorders: associations with child characteristics. *J Autism Dev Disord* 38(7), 1278-1291.
3
4 Dubey, S., Biswas, P., Ghosh, R., Chatterjee, S., Dubey, M.J., Chatterjee, S., Lahiri, D., Lavie, C.J., 2020.
5 Psychosocial impact of COVID-19. *Diabetes Metab Syndr* 14(5), 779-788.
6
7 Escudero-Castillo, I., Mato-Díaz, F.J., Rodriguez-Alvarez, A., 2021. Furloughs, Teleworking and Other
8 Work Situations during the COVID-19 Lockdown: Impact on Mental Well-Being. *Int J Environ Res*
9 *Public Health* 18(6).
10
11 Everts, J., 2013. Announcing Swine Flu and the Interpretation of Pandemic Anxiety. *Antipode* 45(4),
12 809-825.
13
14 Gotham, K., Risi, S., Pickles, A., Lord, C., 2007. The Autism Diagnostic Observation Schedule: revised
15 algorithms for improved diagnostic validity. *J Autism Dev Disord* 37(4), 613-627.
16
17 Guller, B., Yaylaci, F., Eyuboglu, D., 2021. Those in the shadow of the pandemic: impacts of the
18 COVID-19 outbreak on the mental health of children with neurodevelopmental disorders and their
19 parents. *International Journal of Developmental Disabilities*, 1-13.
20
21 Haesebaert, F., Haesebaert, J., Zante, E., Franck, N., 2020. Who maintains good mental health in a
22 locked-down country? A French nationwide online survey of 11,391 participants. *Health Place* 66,
23 102440.
24
25 Hamlyn-Wright, S., Draghi-Lorenz, R., Ellis, J., 2007. Locus of control fails to mediate between stress
26 and anxiety and depression in parents of children with a developmental disorder. *Autism* 11(6), 489-
27 501.
28
29 Howlin, P., Savage, S., Moss, P., Tempier, A., Rutter, M., 2014. Cognitive and language skills in adults
30 with autism: A 40-year follow-up. *Journal of Child Psychology and Psychiatry* 55(1), 49-58.
31
32 Hus, V., Gotham, K., Lord, C., 2014. Standardizing ADOS domain scores: Separating severity of social
33 affect and restricted and repetitive behaviors. *J Autism Dev Disord* 44(10), 2400-2412.
34
35 Hus, V., Lord, C., 2014. The autism diagnostic observation schedule, module 4: revised algorithm and
36 standardized severity scores. *J Autism Dev Disord* 44(8), 1996-2012.
37
38 Hyland, P., Shevlin, M., McBride, O., Murphy, J., Karatzias, T., Bentall, R.P., Martinez, A., Vallières, F.,
39 2020. Anxiety and depression in the Republic of Ireland during the COVID-19 pandemic. *Acta*
40 *Psychiatr Scand*.
41
42 Jones, L., Totsika, V., Hastings, R.P., Petalas, M.A., 2013. Gender differences when parenting children
43 with autism spectrum disorders: a multilevel modeling approach. *J Autism Dev Disord* 43(9), 2090-
44 2098.
45
46 Kaufman, A.S., Kaufman, N.L., 2013. Kaufman assessment battery for children.
47
48 Kuehner, C., 2003. Gender differences in unipolar depression: an update of epidemiological findings
49 and possible explanations. *Acta Psychiatr Scand* 108(3), 163-174.
50

1 Lanyi, J., Mannion, A., Chen, J.L., Leader, G., 2021. Relationship between Comorbid Psychopathology
2 in Children and Adolescents with Autism Spectrum Disorder and Parental Well-being. *Developmental*
3 *Neurorehabilitation*, 1-11.
4
5 Lepine, J.P., Godchau, M., Brun, P., 1985. Anxiety and depression in inpatients. *Lancet* 2(8469-70),
6 1425-1426.
7
8 Lerthattasilp, T., Charernboon, T., Chunsuwan, I., Sirimpunkul, P., 2015. Depression and burden
9 among caregivers of children with autistic spectrum disorder. *J Med Assoc Thai* 98 Suppl 2, S45-52.
10
11 Liu, X., Kakade, M., Fuller, C.J., Fan, B., Fang, Y., Kong, J., Guan, Z., Wu, P., 2012. Depression after
12 exposure to stressful events: lessons learned from the severe acute respiratory syndrome epidemic.
13 *Compr Psychiatry* 53(1), 15-23.
14
15 Lord, C., Rutter, M., DiLavore, P., Risi, S., Gotham, K., Bishop, S., 2012. *Autism diagnostic observation*
16 *schedule—Second edition (ADOS-2)*. Los Angeles: Western Psychological Services.
17
18 Luque Salas, B., Yáñez Rodríguez, V., Tabernero Urbieto, C., Cuadrado, E., 2017. The role of coping
19 strategies and self-efficacy as predictors of life satisfaction in a sample of parents of children with
20 autism spectrum disorder. *Psicothema* 29(1), 55-60.
21
22 McLean, C.P., Asnaani, A., Litz, B.T., Hofmann, S.G., 2011. Gender differences in anxiety disorders:
23 prevalence, course of illness, comorbidity and burden of illness. *J Psychiatr Res* 45(8), 1027-1035.
24
25 McStay, R.L., Trembath, D., Dissanayake, C., 2014. Stress and family quality of life in parents of
26 children with autism spectrum disorder: parent gender and the double ABCX model. *J Autism Dev*
27 *Disord* 44(12), 3101-3118.
28
29 Meltzer, L.J., 2011. Factors associated with depressive symptoms in parents of children with autism
30 spectrum disorders. *Research in Autism Spectrum Disorders* 5(1), 361-367.
31
32 Mohammed, A., Sheikh, T.L., Gidado, S., Poggensee, G., Nguku, P., Olayinka, A., Ohuabunwo, C.,
33 Waziri, N., Shuaib, F., Adeyemi, J., Uzoma, O., Ahmed, A., Doherty, F., Nyanti, S.B., Nzuki, C.K., Nasidi,
34 A., Oyemakinde, A., Oguntimehin, O., Abdus-Salam, I.A., Obiako, R.O., 2015. An evaluation of
35 psychological distress and social support of survivors and contacts of Ebola virus disease infection
36 and their relatives in Lagos, Nigeria: a cross sectional study-2014. *BMC Public Health* 15, 824.
37
38 Olsson, M.B., Hwang, C.P., 2008. Socioeconomic and psychological variables as risk and protective
39 factors for parental well-being in families of children with intellectual disabilities. *J Intellect Disabil*
40 *Res* 52(12), 1102-1113.
41
42 Öz, B., Yüksel, T., Nasiroğlu, S., 2020. Depression-Anxiety Symptoms and Stigma Perception in
43 Mothers of Children with Autism Spectrum Disorder. *Noro Psikiyatrs Ars* 57(1), 50-55.
44
45 Reed, P., Picton, L., Grainger, N., Osborne, L.A., 2016. Impact of diagnostic practices on the self-
46 reported health of mothers of recently diagnosed children with ASD. *Int J Environ Res Public Health*
47 13(9), 888.
48
49 Roy, D., Tripathy, S., Kar, S.K., Sharma, N., Verma, S.K., Kaushal, V., 2020. Study of knowledge,
50 attitude, anxiety & perceived mental healthcare need in Indian population during COVID-19
51 pandemic. *Asian J Psychiatr* 51, 102083.
52

1 Schopler, E., Lansing, M., Reichler, R., Marcus, L., 2004. Psychoeducational Profile Third Edition (PEP-
2 3). Pro-Ed ed. USA.
3
4 Sheikh, M.H., Ashraf, S., Imran, N., Hussain, S., Azeem, M.W., 2018. Psychiatric Morbidity, Perceived
5 Stress and Ways of Coping Among Parents of Children With Intellectual Disability in Lahore, Pakistan.
6 *Cureus* 10(2), e2200.
7
8 Singer, G.H., 2006. Meta-analysis of comparative studies of depression in mothers of children with
9 and without developmental disabilities. *Am J Ment Retard* 111(3), 155-169.
10
11 Snaith, R.P., 2003. The Hospital Anxiety And Depression Scale. *Health Qual Life Outcomes* 1, 29.
12
13 Sparrow, S.S., Balla, D.A., Cicchetti, D.V., 2005. Vineland-II: Survey Forms Manual; Vineland Adaptive
14 Behavior Scales; Survey Interview Form and Parent/caregiver Rating Form; a Revision of the Vineland
15 Social Maturity Scale by Edgar A. Doll. Pearson Assessments.
16
17 Stern, W., 1912. The psychological methods of intelligence testing.
18
19 Türkoğlu, S., Uçar, H.N., Çetin, F.H., Güler, H.A., Tezcan, M.E., 2020. The relationship between
20 chronotype, sleep, and autism symptom severity in children with ASD in COVID-19 home
21 confinement period. *Chronobiol Int* 37(8), 1207-1213.
22
23 Van de Velde, S., Bracke, P., Levecque, K., 2010. Gender differences in depression in 23 European
24 countries. Cross-national variation in the gender gap in depression. *Soc Sci Med* 71(2), 305-313.
25
26 Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., Baghdadli, A., 2019.
27 Coping strategies of parents of children with autism spectrum disorder: a systematic review. *Eur*
28 *Child Adolesc Psychiatry* 28(6), 747-758.
29
30 Waddington, H., McLay, L., Woods, L., Whitehouse, A.J.O., 2020. Child and Family Characteristics
31 Associated with Sleep Disturbance in Children with Autism Spectrum Disorder. *J Autism Dev Disord*
32 50(11), 4121-4132.
33
34 Webster, R.K., Brooks, S.K., Smith, L.E., Woodland, L., Wessely, S., Rubin, G.J., 2020. How to improve
35 adherence with quarantine: rapid review of the evidence. *Public Health* 182, 163-169.
36
37 Wechsler, D., 2002. Wechsler primary and preschool scale of intelligence.
38
39 Wechsler, D., 2003. Wechsler intelligence scale for children—Fourth Edition (WISC-IV).
40
41 Wechsler, D., 2014a. WISC-V: Administration and scoring manual. NCS Pearson, Incorporated.
42
43 Wechsler, D., 2014b. WPPSI-IV, échelle d'intelligence de Wechsler pour enfants. ECPA.
44
45 Wiggins, L.D., Rubenstein, E., Daniels, J., DiGuiseppi, C., Yeargin-Allsopp, M., Schieve, L.A., Tian, L.H.,
46 Sabourin, K., Moody, E., Pinto-Martin, J., Reyes, N., Levy, S.E., 2019. A Phenotype of Childhood
47 Autism Is Associated with Preexisting Maternal Anxiety and Depression. *J Abnorm Child Psychol*
48 47(4), 731-740.
49
50 Zhao, M., Fu, W., 2020. The resilience of parents who have children with autism spectrum disorder in
51 China: a social culture perspective. *Int J Dev Disabil*, 1-12.
52

1 Zigmond, A.S., Snaith, R.P., 1983. The hospital anxiety and depression scale. Acta Psychiatr Scand
2 67(6), 361-370.

3

4

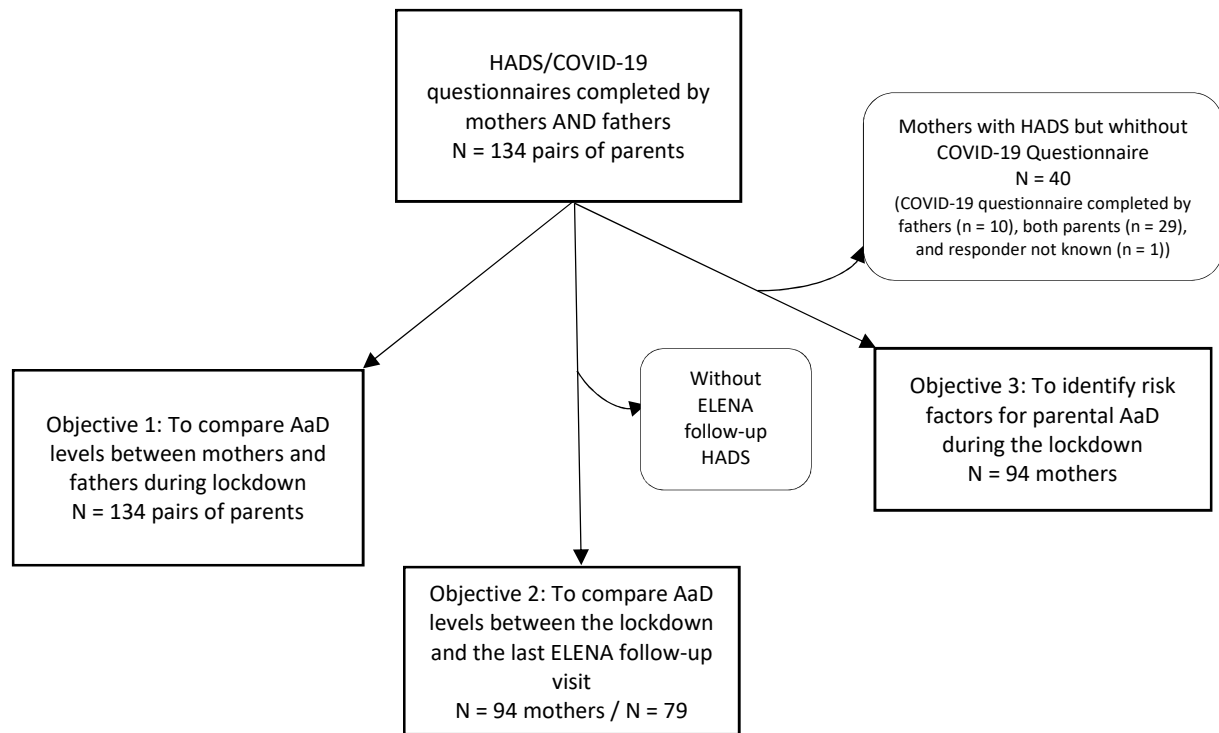
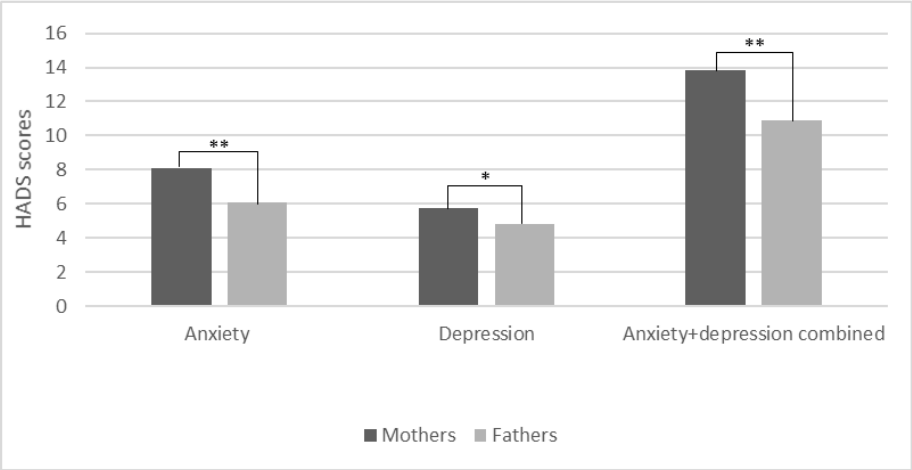


Figure 1. Flow chart of participants



**p < 0.001, *p = 0.01

Figure 2. Paired comparison of AaD levels between mothers and fathers (n = 134 pairs) caring for children with ASD during the lockdown.

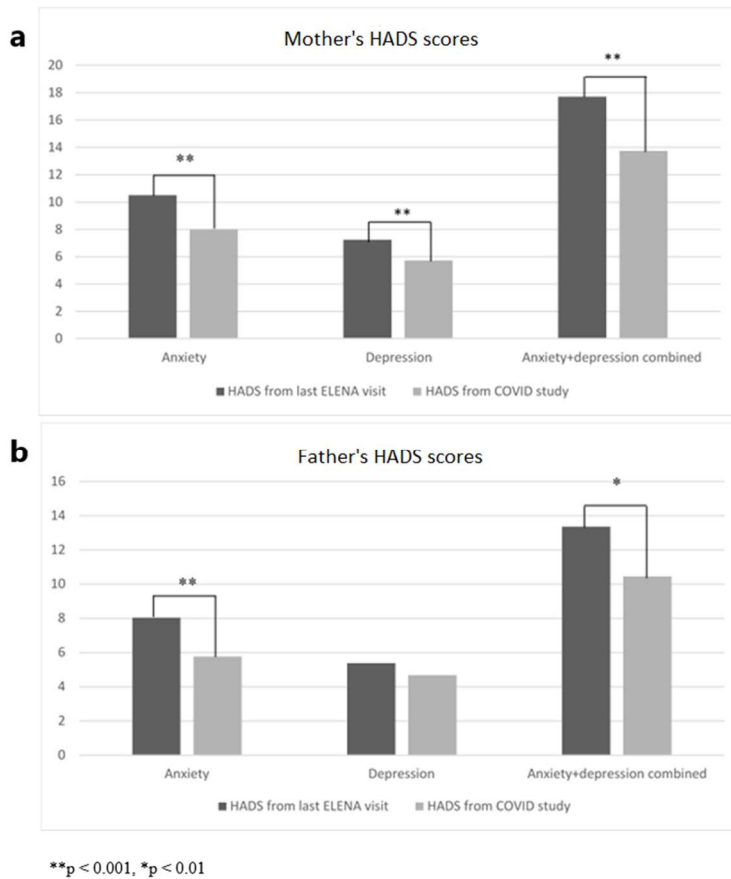


Figure 3. Paired comparison of parents' AaD levels between lockdown and the last ELENA follow-up visit. (a) Mother's HADS scores (n = 94). (b) Father's HADS scores (n = 79).

Table 1. Socio-demographic characteristics during the lockdown.

	Mothers	Fathers
Parental characteristics		
Age (years)	N = 134 41.10 (\pm 6.76)	N = 134 44.22 (\pm 7.84)
Educational level	N = 123	N = 123
Elementary	.	3 (2.44%)
High school	49 (39.84%)	56 (45.53%)
College/ University	74 (60.16%)	64 (52.03%)
Environmental characteristics		
Parent living alone during containment	N = 129	N = 96
No	114 (88.37%)	91 (97.79%)
Yes	15 (11.63%)	5 (5.21%)
Number of children	N = 129 2.01 (\pm 0.92)	N = 129 2.03 (\pm 0.91)
Adequacy between room number and inhabitants:	N = 129	N = 96
Room number < inhabitants	23 (17.83%)	20 (20.83%)
Rooms number \geq inhabitants	106 (82.17%)	76 (79.17%)
Access to outdoors	N = 129	N = 96
No	8 (6.20%)	7 (7.29%)
Yes	121 (93.80%)	89 (92.71%)
Going out during the lockdown with the child	N = 128	N = 96
No	34 (26.56%)	27 (28.13%)
Yes	94 (73.44%)	69 (71.88%)
Perceived knowledge about COVID-19	N = 128	N = 96
Highly insufficient or insufficient	32 (25.00%)	27 (28.13%)
Good	66 (51.56%)	44 (45.83%)
Very good	30 (23.44%)	25 (26.04%)
Professional situation		
Professional situation	N = 115	N = 80
Working	73 (63.48%)	73 (91.25%)
Continuity of activities	19 (31.15%)	26 (42.62%)
Complete shutdown of activity	11 (18.03%)	10 (16.39%)
Partial technical unemployment	5 (8.20%)	6 (9.84%)
Full technical unemployment	3 (4.92%)	3 (4.92%)
Telework	23 (37.70%)	16 (26.23%)
Retired	.	2 (2.50%)
Job search	5 (4.35%)	3 (3.75%)
At home	37 (32.17%)	2 (2.50%)
Spouse's professional situation	N = 115	N = 83
Working	93 (80.87%)	56 (67.47%)
Continuation of activities	33 (42.31%)	12 (27.27%)
Complete shutdown of activity	12 (15.38%)	10 (22.73%)
Partial technical unemployment	8 (10.26%)	6 (13.64%)
Full technical unemployment	5 (6.41%)	3 (6.82%)
Telework	20 (25.64%)	13 (29.54%)
Retired	2 (1.74%)	.
In search of employment	6 (5.22%)	3 (3.61%)
At home	2 (1.74%)	23 (27.71%)
Not concerned	12 (10.43%)	1 (1.20%)
At least one adult at home working	N = 128	N = 96
No	11 (8.59%)	6 (6.25%)
Yes	117 (91.41%)	90 (93.75%)
At least one adult at home teleworking	N = 128	N = 96
No	87 (67.97%)	66 (68.75%)
Yes	41 (32.03%)	30 (31.25%)
Loss of income during containment	N = 128	N = 96

No	78 (60.94%)	52 (54.17%)
Yes	50 (39.06%)	44 (45.83%)

Data are presented as the mean (SD) or N (%).

Table 2. Risk factors for mothers' AaD (n = 94)

	N	Crude OR			Adjusted OR*		
		OR	95% CI	Pvalue	OR	95% CI	P value
VABS-II Communication score (units = 10)	92	0.79	[0.61-1.04]	0.09			
Challenging behaviors							
Improved vs unchanged	93	1.49	[0.39-5.78]	0.56			
Worsened vs unchanged		3.43	[1.24-9.52]	0.02			
Sleep	93						
Improved vs unchanged		0.85	[0.15-4.78]	0.85			
Worsened vs unchanged		2.41	[0.97-6.00]	0.06			
Perceived knowledge about COVID-19							
Very good vs good	93	1.13	[0.38-3.38]	0.23	1.12	[0.38-3.36]	0.23
Insufficient or highly insufficient vs good		4.55	[1.58-13.14]	0.01	4.58	[1.58-13.26]	0.01
At least one adult teleworking							
Yes vs no	93	0.36	[0.13-0.95]	0.04			
Best-estimate IQ							
< 70 vs ≥ 70	90	2.18	[0.91-5.19]	0.08			

*Adjusted for the time since diagnosis