Martínez-Castilla, P[1]

Campos, R[2]

Samson, A. C[3,4]

Van Herwegen, J[5]

Dukes, D[4,6]

Perceived Anxiety in Family Caregivers of Individuals with Autism Spectrum Disorder, Down Syndrome and Williams Syndrome during the Lockdown of the First COVID-19 Wave in Spain

1. Faculty of Psychology, Universidad Autónoma de Madrid, Madrid, Spain.
2. Faculty of Psychology, Unidistance Suisse, Brig, Switzerland.
3. Institute of Special Education, University of Fribourg, Switzerland.
4. UCL Institute of Education, United Kingdom.
5. Swiss Center for Affective Sciences, University of Geneva, Switzerland.

ABSTRACT

Background. The lockdown during the first wave of COVID-19 in Spain has been related to higher levels of anxiety in the general population. However, the emotional impact on Spanish caregivers of individuals with neurodevelopmental disorders (NDD) has not been studied so far.

Methods. An online questionnaire was distributed to Spanish organisations providing support to individuals with NDD and their families. Data from caregivers of individuals with autism spectrum disorder (ASD) (N = 17), Down syndrome (DS) (N = 25) and Williams syndrome (WS) (N = 18) were analysed.

Results. All caregivers reported concerns directly related to the pandemic and lockdown situation. Caregivers of individuals with ASD showed higher level of concern about the possibility of family conflict. All three groups reported higher levels of anxiety during the lockdown. Anxiety was predicted by previous anxiety disorder and the child's diagnosis.

Conclusions. Predictors of anxiety in caregivers of individuals with NDD differ from those previously reported in the general Spanish population. The results suggest that confinement in Spain was especially demanding for families of individuals with ASD. Public policies should consider the particular needs of people with NND and their caregivers to minimise the negative consequences of the ongoing pandemic.

Keywords. caregiver anxiety, COVID-19 in Spain, autism spectrum disorder, Down syndrome, Williams syndrome.

Actas Esp Psiquiatr 2023;51(2): 56-64 | ISSN: 1578-2735

ANSIEDAD PERCIBIDA EN FAMILIARES CUIDADORES DE PERSONAS CON TRASTORNO DEL ESPECTRO AUTISTA, SÍNDROME DE DOWN Y SÍNDROME DE WILLIAMS DURANTE EL CONFINAMIENTO DE LA PRIMERA OLA POR COVID-19 EN ESPAÑA

RESUMEN

Antecedentes. El confinamiento durante la primera oleada de COVID-19 en España se ha relacionado con niveles mayores de ansiedad en la población general. Sin embargo, no se ha estudiado el impacto emocional en los cuidadores de personas con trastornos del neurodesarrollo (TND).

Método. Se distribuyó un cuestionario a las organizaciones que prestan apoyo a las personas con TND y sus familias. Se analizaron los datos de los cuidadores de personas con trastorno del espectro autista (TEA) (N=17), síndrome de Down (N=25) y síndrome de Williams (N=18).

Resultados. Los cuidadores informaron de preocupaciones relacionadas con la situación de pandemia y confinamiento. Los cuidadores de personas con TEA mostraron mayor preocupación sobre los conflictos familiares. Los tres grupos informaron de niveles de ansiedad más altos duran-

Corresponding author:
Dr. Ruth Campos
Basic Psychology Department
Universidad Autónoma de Madrid
Campus de Cantoblanco
C/ Iván Paulov, 6 - 28049, Madrid, Spain
ruth.campos@uam.es

E-mails:
Martínez-Castilla, P.: pastora.martinez@psi.uned.es
Campos, R.: ruth.campos@uam.es
Samson, A. C.: andrea.samson@unifr.ch
Van Herwegen, J.: j.vanherwegen@ucl.ac.uk
Dukes, D.: daniel.dukes@unifr.ch

te el confinamiento. Predijeron la ansiedad el trastorno de ansiedad previo y el diagnóstico del hijo/a.

Conclusiones. Los predictores de ansiedad en los cuidadores de individuos con TND difieren de los reportados previamente en la población general española. Los resultados sugieren que el confinamiento fue especialmente duro para las familias de personas con TEA. Las políticas públicas deberían considerar las necesidades de las personas con TND y sus cuidadores para minimizar las consecuencias negativas de la pandemia.

Palabras clave. Ansiedad del cuidador; COVID-19 en España; Trastorno del Espectro Autista; síndrome de Down; síndrome de Williams.

INTRODUCTION

The COVID-19 pandemic has severely impacted everyone's lives. From the beginning of the crisis, lockdowns were imposed worldwide[1] and, consequently, a reduction in wellbeing and an increase of psychopathology and negative emotions was generally reported[2]. Among the latter, and across countries, adults' anxiety levels were described to be higher than those experienced before the crisis[2].

Although the negative emotional impact has been widespread around the world, cross-country variability has been reported in terms of the groups who were more vulnerable to the negative symptomatology related to the lockdowns. For example, while in Western countries a higher impact was reported in women than in men, in China, no significant differences were reported as a function of gender[2]. Cross-country differences have been accounted for by cultural specificities, by differences in the restrictions experienced during the lockdowns and by the numbers of infections and deaths caused by COVID-19[2-4].

Within Europe, the restrictions imposed in Spain during the first lockdown were considered among the most stringent and the number of infections and deaths was, during the same period of time, very high[1]. During the lockdown in this country, being young and being female were more likely to lead to experiencing negative emotions[3-5], as were prior psychopathology, having caring responsibilities, and having a younger child[3,5,6].

Worldwide, family caregivers of individuals with neurodevelopmental disorders (NDD) generally reported having experienced higher anxiety during the lockdowns of the first COVID-19 wave as compared to those of typically developing individuals (e.g.,[7,8]). Their higher emotional vulnerability has been related to different factors such as feelings of being overwhelmed, lack of support, and greater mental health needs[8,9]. The effects of service disruption on their children's development, the challenges imposed by being permanently at home, family finance, and becoming ill (either themselves or their children) have been reported as their main sources of concern in times of COVID-19 lockdown[10-13].

Under normal circumstances, relatives of individuals with NDD are more prone to negative emotions and mental health problems as a consequence of the greater number of challenges they face in their everyday lives[14,15]. Family caregivers of individuals with autism spectrum disorder (ASD) are particularly vulnerable to psychopathology, anxiety being a highly prevalent problem[16]. Parents of individuals with ASD experience more psychiatric difficulties than parents of individuals with other NDD, especially of those with Down syndrome (DS)[17,18]. The higher anxiety and other comparatively prevalent psychopathological conditions suffered by caregivers of individuals with ASD relates to the behavioural symptoms and challenging behaviours of their children[16]. Improvement of these symptoms and extended parenting experience accounts for the decrease of anxiety levels reported by parents of older individuals with ASD[19].

During the first COVID-19 lockdowns, there is evidence to suggest that family caregivers of individuals with ASD have experienced even higher anxiety levels than those prior to the pandemic[20]. Yet, just like in normal times, caregivers' mental health problems have also been related to their anxiety levels, a finding that has been reported in different countries such as the USA and Saudi Arabia[10,20,21]. Likewise, during the first lockdowns, female caregivers have been found to present with greater anxiety[22], although inconsistent results have been obtained in this respect[21].

Research has clearly shown that family caregivers of individuals with ASD have experienced greater anxiety than caregivers of typically developing individuals during the lockdowns (e.g., [22,23]). However, less is known about whether the anxiety levels of caregivers of individuals with ASD have also been higher than those of caregivers of individuals with other NDD. Unlike pre-pandemic times, in China and in the UK, studies have shown that the anxiety levels of family caregivers of individuals with ASD (with or without intellectual disability) were not higher than those of parents of individuals with intellectual disability (but no ASD)[8-21].

Our research aimed to further contribute to this topic by comparing anxiety levels of family caregivers of individuals with ASD and those of individuals with other NDD of known aetiology, specifically, DS and Williams syndrome

(WS) during the first COVID-19 lockdown in Spain. To our knowledge, no prior research has conducted such comparison. We also studied caregivers' main concerns during the same time. During the spring of 2020, Spain was one of the countries where the effects of COVID-19 and pandemic-related restrictions were most severe, as previously mentioned[1]. However, in this country, so far, research has focused on the negative consequences of the first COVID-19 lockdown for individuals with NDD (e.g., [24-27]) and the emotional impact on family caregivers has been less studied.

In a similar vein to what has been reported in other countries for caregivers of individuals with ASD[20], we hypothesised that, in Spain, caregivers of individuals with ASD would report higher anxiety levels during the lockdown than prior to the pandemic. The same was hypothesised for caregivers of individuals with DS and those of individuals with WS. Following prior studies on anxiety predictors in the Spanish general population during the first lockdown[3,4,6], we also hypothesised that gender would predict anxiety during the lockdown, with female caregivers suffering from greater anxiety, and that both younger caregiver age and younger child age would also predict higher levels of anxiety. Based on the general literature on anxiety in caregivers of individuals with NDD [17], we hypothesised greater anxiety in caregivers of individuals with ASD as compared to caregivers of individuals with DS or WS. We also expected that prior caregiver psychopathology would predict greater anxiety, as observed in previous studies focused on caregivers of individuals with ASD both before and during the pandemic[10,16,19,20,21].

METHODS

Design and procedure

This study was part of an international study[28], approved by the Ethics Commission of UniDistance, Switzerland. Data were gathered via an online survey, through the Qualtrics platform[29].

The Spanish version of the questionnaire was distributed in Spain to different organisations providing support to individuals with NDD and their families. Data collection started on 10 April 2020, 26 days after the lockdown started in Spain, and was completed on 17th June 2020, 4 days before it finished. The full survey (in English) can be accessed through the Open Science Framework site[29].

The survey began with questions concerning socio-demographics before focusing on the experiences of individuals with NDD and their caregivers during the first lockdown of the pandemic. In this research, we focused on caregivers' anxiety levels before the pandemic and at the time of completing the survey during the lockdown. We also focused on their concerns: about illness (both in general and with respect to COVID-19 in particular, and also the possibility that either the caregiver or the child gets ill), about the child (safety with respect to COVID-19, health, having fewer occasions for social contact and interaction, not being able to approach others, ability to cope with changes in routine, becoming bored, loss of institutional support including interventions) and other personal and family issues (family conflicts -fights, aggression-, personal financial/economic situation, personal ability to keep the child entertained and motivated, work/childcare balance related to looking after the child). Caregivers rated their perceived anxiety and degree of concern about the aforementioned issues by using a five-point Likert scale.

Participants

Seventy-nine families completed the survey. Surveys for which information was not complete (N = 7) and those corresponding to families with children with other diagnoses - such as language disorder or intellectual disability of unknown aetiology- (N = 12) were excluded for this study. Data from caregivers of children and adults with ASD (N = 17), with DS (N = 25), and with WS (N = 18) were included in the analyses. All individuals with ASD, DS, or WS had intellectual disability except for six individuals with ASD. The information related to each of the groups is given in Table 1.

Table 1 Age and gender of the sample of caregivers and their children

	Caregivers of individuals with ASD	Caregivers of individuals with DS	Caregivers of individuals with WS
Caregiver's age	46.6 (32-66)	53.3 (38-65)	44.4 (26-66)
Caregiver's gender	females: 14 / males: 3	females: 19 / males: 6	females: 14 / males: 4
Caregiver's prior anxiety disorder	yes: 9 / no: 5	yes: 2 / no: 19	yes: 2 / no: 13
Child's age	13.1 (2-30)	22.5 (7-59)	13.5 (2-37)
Child's gender	females:4 / males:13	females: 14 / males: 11	females: 12 / males: 6

Actas Esp Psiquiatr 2023;51(2): 56-64 | ISSN: 1578-2735

RESULTS

Results per group for each of the concerns asked in the survey and anxiety levels reported by family caregivers are presented in Table 2. A one-way ANOVA test was conducted to study possible between-group differences in caregivers' concerns. There was only a significant effect for *family conflicts*; $F(2, 47) = 5.75$, $p = .006$, $r = .44$. Post-hoc comparisons with Bonferroni correction showed that caregivers of individuals with ASD were significantly more concerned about family conflicts than those of individuals with WS or with DS ($CI_{.95}$ = 0.10 (lower) 2.41 (upper), $p = .028$; $CI_{.95}$ = 0.32 (lower) 2.52 (upper), $p = .007$, respectively), with no significant difference between the latter two groups ($p > .05$). No other between-group significant differences were found regarding other concerns ($p > .05$).

A 3 x 2 mixed ANOVA with group (caregivers of individuals with ASD, DS or WS) as between-subject variable, and perceived anxiety (before and during the lockdown) as repeated measure was also conducted. The two main effects were significant (group: $F(2, 47) = 7.16$, $p = .002$, $r = .48$; anxiety: $F(1, 47) = 50.18$, $p < .001$, $r = .72$) as also was the interaction between variables; $F(2, 47) = 5.94$, $p = .005$, $r = .45$. To analyse the interaction, simple effects were studied by means of Bonferroni pairwise comparisons. Perceived anxiety levels were higher during the lockdown than before for the three groups (caregivers of individuals with ASD: $CI_{.95}$ = 1.33 (lower) 2.53 (upper), $p < .001$; caregivers of individuals with DS: $CI_{.95}$ = 0.20 (lower) 1.20 (upper), $p = .007$; caregivers of individuals with WS: $CI_{.95}$ = 0.19 (lower) 1.31 (upper), $p = .01$). Before the pandemic, no between-group significant differences were found ($p > .5$). However, during the lockdown, caregivers of individuals

Table 2 Results per group for each of the concerns asked in the survey and anxiety levels reported by family caregivers

	Caregivers of i ndividuals with ASD		Caregivers of individuals with DS		Caregivers of individuals with WS	
	Mean	SD	Mean	SD	Mean	SD
Level of concern about:						
Illness in general	3.29	1.27	2.80	1.06	3.06	1.24
COVID-19	3.50	1.16	3.50	1.19	3.94	0.93
Possibility that the caregiver gets ill	3.43	1.40	3.25	1.07	4.06	0.85
Possibility that the child gets ill	3.57	1.55	4.05	1.00	4.44	0.73
Child's safety with respect to COVID-19	3.79	1.25	3.70	1.30	3.88	1.09
Child's health	3.43	1.40	3.95	1.19	4.13	1.02
Child having fewer occasions for social contact and interaction	4.07	1.44	3.32	1.42	3.69	1.40
Child not being able to approach others	3.86	1.10	3.10	1.41	3.69	1.54
Child's ability to cope with changes in routine	3.93	1.14	3.00	1.34	3.31	1.62
Child becoming bored	3.54	1.61	2.40	1.39	2.56	1.31
Loss of institutional support for child including interventions	4.14	1.10	3.25	1.48	3.63	1.02
Family conflicts (fights, aggression)	3.07 a**	1.54	1.65	1.09	1.81	1.22
Personal financial/economic situation	3.79	1.63	2.65	1.53	3.31	1.45
Personal ability to keep the child entertained and motivated	4.07	1.21	3.20	1.32	2.88	1.63
Work/childcare balance related to looking after the child	3.50	1.45	2.65	1.46	2.80	1.70
Anxiety level:						
Before the pandemic	2.29 b***	1.14	1.75 b**	1.07	1.75 b*	1.13
During the lockdown	4.21 a***	0.58	2.45	1.05	2.50	1.46

Note: [a] significant differences between caregivers of individuals with ASD and caregivers of individuals with DS or with WS. [b] significant differences before and during the lockdown. * $p = .01$, ** $p < .01$, *** $p < .001$. SD: Standard deviation.

with ASD reported higher anxiety levels than those of individuals with DS ($CI_{.95}$ = 0.81 (lower) 2.72 (upper), $p < .001$) or with WS ($CI_{.95}$ = 0.71 (lower) 2.72 (upper), $p < .001$), while no significant differences were found between the latter two groups ($p > .05$).

A multiple regression analysis was conducted to test the effect of the hypothesised predictors on anxiety levels during the lockdown. A model was built with caregiver gender, caregiver age, child age, caregiver prior anxiety disorder, and group (dummy coded) entered as predictors and perceived anxiety during lockdown as outcome. According to [30], in a regression analysis, the sample size should be higher than the number of predictors plus 50. This criterion was met (N=60, 5 predictors). Regression assumptions were also checked and met. The model was significant; $F(6, 37) = 5.70$, $p < .001$, $R^2 = .48$. The power of the test was high ($\beta = .99$), as calculated with the software developed by [31]. Yet only some of the predictors significantly contributed to explain anxiety. Presence of prior anxiety disorder significantly predicted higher anxiety levels; $t(37) = 2.38$, $p = .022$, $B = 0.10$, $SE\ B = 0.04$, $\beta = 0.34$. Group was also found to be a significant predictor so that, compared to caregivers of individuals with ASD (group reference), those of individuals with DS reported lower anxiety levels during the lockdown; $t(37) = -2.62$, $p = .013$, $B = -1.24$, $SE\ B = 0.48$, $\beta = -0.46$, as did caregivers of individuals with WS; $t(37) = -2.79$, $p = .008$, $B = -1.32$, $SE\ B = 0.47$, $\beta = -0.46$. No significant effects were found for caregiver gender, caregiver age, and child age ($p > .05$).

DISCUSSION

The social and health situation caused by the COVID-19 pandemic has been a challenge for everyone's mental health throughout the world[2], especially at first, as families and associations had to adapt to the often strict measures adopted by the different governments. In Spain, the first wave of COVID-19 involved a comparatively strict and abrupt lockdown, in which most services were suspended and all educational establishments were closed. In other countries, this situation was particularly arduous for families of individuals with NDD[7,8]. Our work collected, for the first time, the reports of Spanish family caregivers of individuals with ASD, DS or WS in relation to their concerns and anxiety level during those months.

Previous research has shown that, in the Spanish general population, anxiety during the pandemic was related to variables such as caregiver gender and age, and the age of children in their care[3-6]. Importantly, unlike what we had hypothesised, for families of individuals with NDD, these variables appear to be no longer relevant. The key factor, instead, is related to the basic fact of having a child with NDD. All three caregiver groups indicated that their anxiety levels were higher during the pandemic. Furthermore, and as we hypothesised, differences were found between the three groups, with families with a child with ASD reporting significantly higher levels of anxiety during the lockdown even though no between-group differences were found in caregivers' perceived anxiety before the pandemic. These results suggest that the first lockdown in Spain was especially demanding for families of individuals with ASD. Individuals with ASD, who tend to show particular difficulties when faced with changes in their routines and in the absence of predictability[32], perhaps unsurprisingly, may have had greater difficulty adapting to a situation as abrupt and uncertain as the beginning of the pandemic, posing a greater challenge for their families, carers and entourage. In fact, other research has reported that, during the lockdown established for the first COVID-19 wave in Spain, children and teenagers with ASD showed a higher increase in their own psychopathological symptoms as compared to peers with other NDD or psychiatric conditions[25]. As previously reported[5], and as found here, people who already endured anxiety were those who suffered most from the lockdown.

All caregivers reported concerns linked to issues directly related to the COVID-19 condition, but also to the consequences that restrictions may have for their children (e.g., *less possibilities for social interaction*, *loss of institutional support*, as well as *difficulties in keeping their child entertained*). Among the latter, the loss of institutional support has been previously noted in other countries as one the main concerns of parents with children with different NDD; in turn, the decrease in supports had an indirect negative impact on parents' mental health[33]. It should also be noted that in our study, caregivers of individuals with ASD showed a significantly higher level of concern about the possibility of *family conflicts* (i.e., fights, aggression). This concern probably stems from the higher prevalence of behavioural problems in individuals with ASD compared to other NDD[34] and the worsening of these problems arisen as a result of the lockdown[25]. The stress in families of individuals with ASD is particularly related to the behavioural problems of their children[35]. This heightened concern about family conflicts may therefore also be linked to an increased likelihood of friction among other family members. Indeed, in parents of individuals with ASD, high rates of divorce have been reported and these are related to the impact of the difficulties linked to the ASD diagnosis on the family structure[36].

This research has some limitations. First, although the whole sample size is similar to that reported in other COVID-19 related studies focused on NDD (e.g., [37]), dividing

Actas Esp Psiquiatr 2023;51(2): 56-64 | ISSN: 1578-2735

the original sample in three different diagnosis groups led to relatively small sample sizes when considering each of the groups separately. While this allowed us to tackle the main aim of the study (i.e., comparing the anxiety levels of family caregivers of individuals with ASD and those of individuals with DS and WS), the relatively small sample size of each of the three groups of the study may hinder the generalization of the results. Additionally, in this study, anxiety was not measured through a standardised scale but with a self-reported rating question. It should be here considered that results on the psychiatric difficulties of family caregivers of individuals with ASD depend on the assessment method, so that more difficulties are found when family caregivers report on their subjective experiences[18]. Despite these limitations, the study shows a relevant picture of the reality of individuals with NDD' caregivers during the first lockdown in Spain.

Individuals with NDD and their families are still to this day experiencing great difficulties due to the COVID-19 pandemic[38]. The suspension of the support system needed by these individuals (e.g., educational centres, employment centres, specific interventions, family support services...) during the first wave of COVID-19 showed how important these supports are for the quality of life and mental health of these individuals and their families[33]. As shown in our study, the challenges imposed by the lockdown established in Spain involved an increase in the anxiety levels of family caregivers of individuals with NDD, particularly of those in care for individuals with ASD. From research such as this, it is clear that it is urgent that public policies in Spain, and in other countries, place the particular needs of individuals with different NDD and their caregivers at the centre, with the aim of minimising the consequences brought about by the COVID-19 crisis.

CONCLUSIONS

The first wave of COVID-19 had large negative effects across the world. Within Europe, Spain was one the countries where the impact was more severe[39]. Prior research has shown how typically developing adults and children suffered as a consequence of the first lockdown taken place in this country (e.g., [3-5, 40]). Other studies have rather focused on the emotional impact of the lockdown in children and adults with NDD[24-27]. However, less was known about this impact in their caregivers. Our study aimed to fill this gap by considering whether differences would arise as a function of child diagnosis. Thus, this research is the first to show how the specific diagnosis of the child made a significant contribution to the anxiety levels of family caregivers. The anxiety levels of caregivers of individuals with ASD were higher than those of caregivers of individuals with DS or WS, and their concerns about possible family conflicts were also higher. Therefore, caregivers of individuals with ASD were particularly vulnerable to the negative emotional effects of the first COVID-19 lockdown in Spain. We have also shown that, during that time, in the families with individuals with the NDD here studied, predictors of anxiety differed from those reported for the general population[3-6]. The results of the study lead us to conclude that the different needs of these caregivers and their children should be taken into account when designing future policies for mental health care.

Conflict of interest statement

The authors declare no conflicts of interest

Source of funding

Swiss National Science Foundation (PP00P1_176722 for Andrea Samson), Research Funds of the Unidistance Suisse and the European Federation Williams Foundation. Spanish Ministry of Science and Innovation (PID2020-117087GB-I00).

Ethics approval

This research was approved by the Ethics Commission of UniDistance, Switzerland

Acknowledgements

We are truly grateful to all the families who participated in this study.

REFERENCES

1. Thomas H, Angrist N, Cameron-Blake E, Hallas L, Kira B, Majumdar S, et al. *Oxford COVID-19 Government Response Tracker*. Oxford: Blavatnik School of Government; 2020.

2. Cénat JM, Dalexis RD, Guerrier M, Noorishad PG, Derivois D, Bukaka J, ... Rousseau C. Frequency and correlates of anxiety symptoms during the COVID-19 pandemic in low-and middle-income countries: a multinational study. *J. Psychiatr. Res.* 2021; 132: 13-17. https://doi.org/10.1016/j.jpsychires.2020.09.031

3. González-Sanguino C, Ausín B, Castellanos MÁ, Saiz J, López-Gómez A, Ugidos C, Muñoz M. Mental health consequences during the initial stage of the 2020 Coronavirus pandemic (COVID-19) in Spain.

Brain Behav. Immun. 2020; 87: 172-176. https://doi.org/10.1016/j.bbi.2020.05.040

4. Justo-Alonso A, García Dantas A, González Vázquez AI, Sánchez Martín M, Río Casanova LD. How did different generations cope with the COVID-19 pandemic?: early stages of the pandemic in Spain. *Psicothema* 2020; 32: 490-500. https://doi.org/10.7334/psicothema2020.168

5. Sandín B, Valiente RM, García-Escalera J, Chorot P. Impacto psicológico de la pandemia de COVID-19: Efectos negativos y positivos en población española asociados al periodo de confinamiento nacional. *Rev. Psicopatol. Psicol. Clín.* 2020; 25. https://doi.org/10.5944/rppc.27569

6. Romero E, López-Romero L, Domínguez-Álvarez B, Villar P, & Gómez-Fraguela JA. Testing the effects of COVID-19 confinement in Spanish children: The role of parents' distress, emotional problems and specific parenting. *Int. J. Environ. Res. Public Health* 2020; 17: 6975. https://doi.org/10.3390/ijerph17196975

7. Tsibidak, A. Anxiety, meaning in life, self-efficacy and resilience in families with one or more members with special educational needs and disability during COVID-19 pandemic in Greece. *Res. Dev. Disabil.* 2021; 109: 103830. https://doi.org/10.1016/j.ridd.2020.103830

8. Willner P, Rose J, Stenfert Kroese B, Murphy GH, Langdon PE, Clifford C, ... Cooper V. Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities. *J. Appl. Res. Intellect. Disabil.* 2020; 33: 1523-1533. https://doi.org/10.1080/20473869.2020.1764257

9. Asbury K, Fox L, Deniz E, Code A, Toseeb U. How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? *J. Autism Dev. Disord.* 2021; 51: 1772-1780. https://doi.org/10.1007/s10803-020-04577-2

10. Manning J, Billian J, Matson J, Allen C & Soares N. Perceptions of families of individuals with Autism Spectrum Disorder during the COVID-19 crisis. *J. Autism Dev. Disord.* 2020; *1-9*. https://doi.org/10.1007/s10803-020-04760-5

11. Neece C, McIntyre LL, Fenning R. Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *J. Intellect. Disabil. Res. 2*020; 64: 739-749. https://doi.org/10.1111/jir.12435

12. Sideropoulos V, Dukes D, Hanley M, Palikara O, Rhodes S, Riby DM., Samson AC, Herwegen J. The impact of COVID-19 on anxiety and worries for families of individuals with special education needs and disabilities in the UK. *J. Autism Dev. Disord. 2*021. https://doi.org/10.1007/s10803-021-05168-5

13. Tokatly LI, Leitner Y, Karnieli-Miller O. Core experiences of parents of children with autism during the COVID-19 pandemic lockdown. *Autism* 2021; 25: 1047-1059. https://doi.org/10.1177/1362361320984317

14. Ashworth M, Palikara O, Van Herwegen J. Comparing parental stress of children with neurodevelopmental disorders: The case of Williams syndrome, Down syndrome and autism spectrum disorders. *J. Appl. Res. Intellect. Disabil.* 2019; 32: 1047-1057. https://doi.org/10.1111/jar.12594

15. McConnell D, Savage A. Stress and resilience among families caring for children with intellectual disability: Expanding the research agenda. *Curr. Dev. Disord. Rep.* 2015; 2: 100-109. https://doi.org/10.1007/s40474-015-0040-z

16. Schnabel A, Youssef GJ, Hallford DJ, Hartley EJ, McGillivray JA, Stewart M, ... Austin DW. Psychopathology in parents of children with autism spectrum disorder: A systematic review and meta-analysis of prevalence. *Autism* 2020; 24: 26-40. https://doi.org/10.1177/1362361319844636

17. Hayes SA, Watson SL. The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *J. Autism Dev. Disord.* 2013; 43: 629-642. https://doi.org/10.1007/s10803-012-1604-y

18. Yirmiya N, Shaked M. Psychiatric disorders in parents of children with autism: a meta-analysis. *J. Child Psychol. Psychiatry* 2005; 46: 69-83. https://doi.org/10.1111/j.1469-7610.2004.00334.x

19. Pozo P, Sarriá E. Still stressed but feeling better: Well-being in autism spectrum disorder families as children become adults. *Autism* 2015; 19: 805-813. https://doi.org/10.1177/1362361315583191

20. Althiabi Y. Attitude, anxiety and perceived mental health care needs among parents of children with Autism Spectrum Disorder (ASD) in Saudi Arabia during COVID-19 pandemic. *Res. Dev. Disabil.*

Actas Esp Psiquiatr 2023;51(2): 56-64 | ISSN: 1578-2735

2021; 111: 103873. https://doi.org/10.1016/j.ridd.2021.103873

21. Ren J, Li X, Chen S, Chen S, Nie Y.. The influence of factors such as parenting stress and social support on the state anxiety in parents of special needs children during the COVID-19 epidemic. *Front. Psychol.* 2020; 11. https://doi.org/10.3389/fpsyg.2020.565393

22. Wang L, Li D, Pan S, Zhai J, Xia W, Sun C, Zou M. The relationship between 2019-nCoV and psychological distress among parents of children with autism spectrum disorder. *Glob. Health* 2021; 17: *1-14.* https://doi.org/10.1186/s12992-021-00674-8

23. Corbett BA, Muscatello RA, Klemencic ME, Schwartzman JM. The impact of COVID-19 on stress, anxiety, and coping in youth with and without autism and their parents. *Autism Res.* 2021. https://doi.org/10.1002/aur.2521

24. Amor AM, Navas P, Verdugo MÁ, Crespo M. Perceptions of people with intellectual and developmental disabilities about COVID-19 in Spain: a cross-sectional study. *J. Intellect. Disabil. Res.* 2021; 65: 381-396. https://doi.org/10.1111/jir.12821

25. López-Serrano J, Díaz-Bóveda R, González-Vallespí L, Santamarina-Pérez P, Bretones-Rodríguez A, Calvo R, Lera-Miguel S. Psychological impact during COVID-19 lockdown in children and adolescents with previous mental health disorders. *Rev. Psiquiatr. Salud Ment.* 2021; Apr 24:S1888-9891(21)00035-5. https://doi.org/10.1016/j.rpsm.2021.04.002. Lugo-Marín J, Gisbert-Gustemps L, Setien-Ramos I, Español-Martín G, Ibañez-Jimenez P, Forner-Puntonet M, ... Ramos-Quiroga JA. COVID-19 pandemic effects in people with Autism Spectrum Disorder and their caregivers: Evaluation of social distancing and lockdown impact on mental health and general status. *Res. Autism Spectr. Disord.* 2021; 83: 101757. https://doi.org/10.1007/s10803-020-04760-5

26. Navas P, Amor AM, Crespo M, Wolowiec Z, Verdugo MÁ. Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective. *Res. Dev. Disabil.* 2021; 108: 103813. https://doi.org/10.1016/j.ridd.2020.103813

27. Dukes D, Van Herwegen J, Alessandi M, Alnemary F, Amani Rad J, Banta Lavenex P, Bolshakov N, Bölte S., Ying Ca, R, Campos R, Chirita-Emandi AP Costa A, Costanzo F, di Poi G, Des Portes V, Faivre L, Famelart N, Fisher M, Gamaiunova L, ... Samson AC. Introducing the COVID-19 crisis special education needs coping survey. *PsyArXiv.* Preprint; 2021, February 15. https://doi.org/10.31234/osf.io/rtswa

28. Van Herwegen J, Dukes D, Samson A. COVID19 Crisis Response Survey for families of Individuals with Special Needs 2020; https://doi.org/10.17605/OSF.IO/5NKQ9

29. American Psychiatry Association. *Diagnostic and statistical manual of mental disorders*, 5th ed. APA, Washington, DC; 2013.

30. Harris RJ. *A Primer of Multivariate Statistics* (2nd ed). New York: Academic Press; 1985.

31. Soper DS. *Post-hoc Statistical Power Calculator for Multiple Regression* [Software]. Available from https://www.danielsoper.com/statcalc.

32. Bentenuto A, Mazzoni N, Giannotti M, Venuti P, de Falco S. Psychological impact of Covid-19 pandemic in Italian families of children with neurodevelopmental disorders. *Res. Dev. Disabil.* 2021; 109: 103840. https://doi.org/10.1016/j.ridd.2020.103840

33. Eisenhower AS, Baker BL, Blacher J. Preschool children with intellectual disability: syndrome specificity, behaviour problems, and maternal well-being. *J. Intellect. Disabil. Res.* 2005; 49: 657-671. https://doi.org/10.1111/j.1365-2788.2005.00699.x

34. Nieto C, López B, Gandía H. Relationships between atypical sensory processing patterns, maladaptive behaviour and maternal stress in Spanish children with autism spectrum disorder. *J. Intellect. Disabil. Res.* 2017; 61: 1140-1150. https://doi.org/10.1111/jir.12435

35. Hartley SL, Barker ET, Seltzer MM, Floyd F, Greenberg J, Orsmond G, Bolt D. The relative risk and timing of divorce in families of children with an autism spectrum disorder. *J. Fam. Psychol.* 2010; 24: 449-457. https://doi.org/10.1037/a0019847

36. Mumbardó-Adam C, Barnet-López S, Balboni G. How have youth with Autism Spectrum Disorder managed quarantine derived from COVID-19 pandemic? An approach to families perspectives. *Res. Dev. Disabil.* 2021; 110. https://doi.org/10.1016/j.ridd.2021.103860

37. Iovino EA, Caemmerer J, Chafouleas SM. Psychological distress and burden among family caregivers of children with and without developmental disabilities six months into the COVID-19 pandemic. *Res. Dev. Disabil.* 2021; 114: 103983. https://doi.org/10.1016/j.ridd.2021.103983

38. Ayuso-Mateos JL, Mediavilla R, Rodriguez KR, Bravo MF. Informing the response to COVID-19 in Spain: priorities for mental health research. *Rev Psiquiatr Salud Ment.* 2021; 14:79-82. https://doi.org/10.1016/j.rpsm.2021.04.001

39. Giménez-Dasí M, Quintanilla L, Lucas-Molina B, Sarmento-Henrique R. Six weeks of confinement: psychological effects on a sample of children in early childhood and primary education. *Front. Psychol.* 2020; 11: 590463. doi: 10.3389/fpsyg.2020.590463