

Study explores anxiety, concerns of families with children with neurodevelopmental conditions during COVID-19 pandemic

July 31 2023



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A study published in the *Journal of Global Health* has analyzed data from more than 6,600 families with a child with a neurodevelopmental



condition (NDC)—autism, attention-deficit/hyperactivity disorder, developmental language disorder, Down syndrome, Williams syndrome, and intellectual disability—from 70 countries, including the United States.

The study was led by Andrea Samson, associate professor of psychology at UniDistance Suisse and University of Fribourg, Switzerland, and Jo Van Herwegen, professor in developmental psychology and education at University College London's Faculty of Education and Society.

According to co-author Michael Alessandri, clinical professor of psychology and pediatrics at the University of Miami College of Arts and Sciences, the study included seven U.S. collaborators and more than 500 U.S. families.

Participating parents completed an online questionnaire about anxiety levels and concerns during the first wave of the COVID-19 pandemic. The authors were interested in how parents' and children's anxiety developed over time, and aimed to quantify to what extent families and their children with NDCs were impacted by the COVID-19 pandemic and how their anxiety levels were mitigated or aggravated by country, family, and individual child factors such as their health or other individual differences or concerns.

Because <u>anxiety levels</u> were likely affected by national demographic characteristics or <u>government policy</u>, the authors integrated data concerning how the pandemic evolved, government responses, and structural descriptors of countries from the European Centre for Disease Prevention and Control, the University of Oxford, and the CIA World Factbook.

"At the beginning of the pandemic we were worried about the many families with a child with NDC that were cut from their usual services



and institutions such as specialized schools, day care services, therapists, clinicians, or medical care," said Samson. "Since many of our research projects came to a sudden halt due to the pandemic, we dedicated our time to the creation of a survey in the first weeks of the pandemic, as well as building a network of more than 50 collaborators across the globe to help translate the questionnaire as well as to recruit families in their respective countries."

The results show that at the beginning of the pandemic, anxiety increased significantly for parents and their children with an NDC as well as their typically developing sibling (if they had any), as reported by the parents.

"While anxiety decreased again for children to almost pre-pandemic levels, this was not the case for parents, who seemed to be experiencing chronic increased stress," Samson shared.

In the final analysis, <u>parental concerns</u> related to their and their children's health, as well as their children's lack of opportunity to get physically close to others due to anti-transmission measures (e.g., social distancing), were the best predictors of parental anxiety. This means that health-related worries and concerns about limited opportunities for social interactions increased parental anxiety. The lack of social contact seems to be one of the main worries for families with a child with an NDC, likely related to concerns about their social development.

Child anxiety was best explained by the "child factors," such as their worries about COVID-19 or family conflict. The lack of routine was also identified as a significant contributor to all children's anxiety.

While parental anxiety was not impacted by the type of NDC of their child, <u>child anxiety</u> was affected by the type of NDC and NDC-specific concerns.



For example, children with Williams syndrome had the highest levels of anxiety, and the anxiety of children with autism, ADHD, and Williams syndrome was explained by concerns about the loss of routine.

"This is in line with the elevated need of children with NDCs for consistency and routine in their daily lives," said Van Herwegen. This finding indicates that the sudden changes to the daily structures of children with NDCs during the COVID-19 pandemic, due to the closure of schools and institutions, the discontinuation of mental health care services, as well as the necessary familial reorganization, greatly impacted these children and their families, independently of the country they lived in.

The researchers also noted that none of the government-level policy measures were significant factors predicting parental or child anxiety in the final models, which indicates that country-related contexts such as the public health system did not have a direct impact on anxiety.

"This finding presents a challenge in terms of understanding the implications of COVID-19, as no previous research has examined its effects on families and individuals with neurodevelopmental conditions through a global scale using cross-country models," reported lead author Vassilis Sideropoulos, a senior research technician with UCL's Faculty of Education and Society. "The absence of a clear explanation for this finding highlights the complexity of the pandemic's impact on anxiety and the need for further exploration and investigation in this field."

Van Herwegen underlines the importance of the study's findings for future policy recommendations and for developing interventions and toolkits to help parents and children cope with future crises.

More information: Vassilis Sideropoulos et al, Anxiety, concerns and COVID-19: Cross-country perspectives from families and individuals



with neurodevelopmental conditions, *Journal of Global Health* (2023). DOI: 10.7189/jogh.13.04081

Provided by University of Miami

Citation: Study explores anxiety, concerns of families with children with neurodevelopmental conditions during COVID-19 pandemic (2023, July 31) retrieved 29 April 2024 from https://medicalxpress.com/news/2023-07-explores-anxiety-families-children-neurodevelopmental.html

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