Family Wellbeing and Mental Health Status in Caregivers of Children with Neurodevelopmental Disabilities during the COVID-19 Pandemic

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INTRODUCTION

- Individuals with neurodevelopmental disabilities including attention-deficit/hyperactivity disorder (ADHD), Fragile X Syndrome (FXS), Down Syndrome (DS), and Autism Spectrum Disorder (ASD) demonstrate a variety of developmental delays with expressive language and behavioral challenges as well as social and academic impairments.
- Caregivers of these youth may experience higher rates of mental health symptoms (e.g. anxiety and depression) and more strained family dynamics compared to the general population.
- Caregiver mental health status and family well-being could be further impacted as a result of the COVID-19 pandemic.

OBJECTIVE

1) Examine symptoms of caregiver mental health and family well-being since the onset of the COVID-19 pandemic.
2) Identify which individual and household characteristics might contribute to parent mental health status and family well-being.
3) Assess the type and frequency at which caregivers report accessing mental health services for themselves.

METHODS

Participants
- 94 caregivers participated in a survey-based study examining the impacts of COVID-19 on youth with neurodevelopmental disabilities and their parent mental health and family well-being.
- 87% of the respondents were the biological mother, 11% were the biological father, and the remaining 2% were the adoptive mother.
- The ethnic/racial distributions from our sample were 66% White, non-Hispanic/Latino; 24% Black, Indigenous, and/or Hispanic/Latino; 7% Asian; and 3% reported unknown.
- In accordance with the Pew guidelines for household income, 37% were considered low-middle income, 35% were considered middle income, 8% were considered low-middle income, 35% were considered middle income, 8% were considered middle-upper income, and 10% were considered upper income.

Measures
- Symptom Checklist-90-Revised (SCL-90-R) measured caregiver mental health status by the Anxiety and Depression subscales.
- Family Environment Scale (FES) measured family well-being across Cohesion, Expressiveness, Conflict subdomains.
- General population mental health status was measured using both normed sample references as well as data from the CDC Household Pulse Survey collected in response to COVID-19.

RESULTS

Caregiver Self-Reported Symptoms of Mental Health Status and Family Well-Being

Figure 1.1 One Sample t-Tests highlight several significant differences between the sampled caregivers’ t-scores on the SCL-90-R and FES when compared to the normed sample mean of 50.

Figure 1.2 The prevalence of adults endorsing symptoms of anxiety or depression within a clinical range from October 2020 to June 2021 were significantly higher for our sample of participants, with both our sample and the general population being significantly higher than pre-pandemic prevalence rates.

Clinical Service Utilization amongst Caregiver Respondents

Figure 3. Frequencies were calculated to determine caregiver access to mental health services. Most participants reported to receive therapies, including psychiatric medication management or counseling as well as support groups. Over a third of respondents do not receive clinical services.

DISCUSSION/CONCLUSION

- Caregiver self-reports of depression, anxiety, and family conflict were statistically significantly elevated compared to national averages.
- Clinically-relevant symptoms for anxiety and depression were increased from national levels both before and since the onset of COVID-19.
- Household income was determined as a significant predictor for caregiver anxiety and depression. With other individual and child characteristics also predicting mental health and family well-being.
- The majority of caregivers reported to receive mental health services while a substantial percentage have not accessed services.
- Our findings indicate caregivers of children with neurodevelopmental conditions as a particularly impacted population by the COVID-19 pandemic.

ACKNOWLEDGEMENTS

I would like to express my gratitude to Professor Leonard Abbeduto and Professor Angela John Thurman for welcoming me into their laboratory with guidance and mentorship. Special thank you to Dr. Lauren Bullard for her assistance, teaching, and direction throughout this project. Thank you to the Kennedy Krieger Institute’s Center for Diversity in Public Health Leadership Training for the opportunity to conduct this research.
• Individuals with neurodevelopmental disabilities such as attention-deficit/hyperactivity disorder (ADHD), fragile X syndrome (FXS), Down syndrome (DS), and/or autism spectrum disorder (ASD) demonstrate a variety of developmental delays

• Parents of these youth may experience higher rates of mental health symptoms and more strained family dynamics

• Parent mental health and family well-being could be further impacted as a result of the COVID-19 pandemic
OBJECTIVES

1) Examine symptoms of parent mental health and family well-being since the onset of the COVID-19 pandemic.

1) Identify which individual and household characteristics might contribute to parent mental health status and family well-being.

1) Assess the type and frequency at which caregivers report accessing mental health services for themselves.
METHODS

Participants
• 94 parents participated in a survey based study examining the impacts of COVID-19 on youth with NDD, parent mental health, and family well-being.

<table>
<thead>
<tr>
<th>Relationship to Youth</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Biological Mother</td>
<td>87%</td>
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<tr>
<td>Biological Father</td>
<td>11%</td>
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<td>Adoptive Mother</td>
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<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Percent</th>
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<tbody>
<tr>
<td>White, non-Hispanic/Latinx</td>
<td>66%</td>
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<tr>
<td>Black, Indigenous, Hispanic/Latinx</td>
<td>24%</td>
</tr>
<tr>
<td>Asian</td>
<td>7%</td>
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<td>3%</td>
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<table>
<thead>
<tr>
<th>Pew Household Income Tier</th>
<th>Percent</th>
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<tbody>
<tr>
<td>Low Income</td>
<td>37%</td>
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<tr>
<td>Low-Middle Income</td>
<td>6%</td>
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<td>Middle Income</td>
<td>35%</td>
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<tr>
<td>Middle-Upper Income</td>
<td>8%</td>
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<tr>
<td>Upper Income</td>
<td>10%</td>
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</tbody>
</table>

Measures
• Symptom Checklist-90-Revised (SCL-90-R) □ Anxiety and Depression
• Family Environment Scale (FES) □ Cohesion, Expressiveness, and Conflict
• CDC Household Pulse Survey collected in response to COVID-19
RESULTS

Figure 1.1 One sample t-tests highlight several significant differences between the sampled parents’ t-scores on the SCL-90-R and FES when compared to the normed sample mean of 50.

Figure 1.2 The prevalence of adults endorsing symptoms of anxiety or depression within a clinical range from October 2020 to June 2021 were significantly higher for our sample of participants.
Figure 2. A series of multiple linear regressions show that both household income tier and caregiver race and ethnicity were significant predictors of anxiety and depression, while household income tier and child disability diagnostic category were significant predictors of family cohesion.
Figure 3. Frequencies were calculated to determine caregiver access to mental health services. Most participants reported to receive therapies, including psychiatric medication management or counseling as well as support groups. Over a third of respondents do not receive clinical services.
DISCUSSION

• Our findings indicate caregivers of children with neurodevelopmental conditions as a particularly vulnerable population by the COVID-19 pandemic.

• Caregiver self reports of depression, anxiety, and family conflict were statistically significantly elevated compared to national averages.

• Clinically-relevant symptoms for anxiety and depression were increased from national levels since the onset of COVID-19.

• Household income was determined as a significant predictor for caregiver anxiety and depression. With other individual and child characteristics also predicting mental health and family well-being.

• The majority of caregivers reported to receive mental health services while a substantial percentage have not accessed services.