Intellectual and Developmental Disabilities

Race/Ethnicity Disparities in COVID-19 Worry for Caregivers of Adults with Intellectual/Developmental Disabilities

--Manuscript Draft--

Manuscript Number:	IDD-D-22-00042R2
Article Type:	Research
Keywords:	Covid-19, Caregiver Burden, Intellectual and Developmental Disability
Corresponding Author:	Ellen Fremion Baylor College of Medicine Houston, Texas UNITED STATES
First Author:	Ellen Fremion
Order of Authors:	Ellen Fremion
	Laiba Asif
	Kristen A Staggers
	K Jordan Kemere
	Ambrielle Davis
Manuscript Region of Origin:	UNITED STATES
Abstract:	TThis study investigated the race/ethnicity differences in COVID-19-related worry amongst family caregivers of adults with Intellectual and/or Developmental Disabilities (IDD) living in Texas using the COVID-Related Thoughts and Behavioral Symptoms-Adult Version (COV-TaBS-A) questionnaire. Two hundred and six caregivers completed the survey. Compared to Whites, Latino caregivers were more likely to be very concerned about having enough food and supplies (adj OR 3.41, 95% CI: 1.50, 7.74) when adjusting for being that sole caregiver and using provider services. In free text questions, caregivers described feeling overwhelmed by additional responsibilities, disruptions in home health services, and concerns about their loved ones' wellness. Study findings can be used to strategize support for caregivers of adults with IDD during pandemic/emergency situations.

August 13, 2023

Dear Editor,

Thank you for the opportunity to revise and resubmit. The reviewer's comments have been addressed as follows and revisions are highlighted in the manuscript.

Reviewer #3: Thank you for the opportunity to review your very interesting manuscript. I have several concerns regarding the methodology and approach. My main concern is that statistical analysis is not meaningful if the conceptual foundations of the study have issues.
1) Grouping Latinos and African Americans / Blacks does not allow to reveal racial / ethnic differences / disparities. These groups should only be grouped if you are analyzing White / Non-White populations' differences. Otherwise you are missing the unique experiences and challenges of each group.

Please note that results for each race/ethnicity group (African/American, Latino, White) were calculated separately (see Table 3). White race/ethnicity group was used as the reference point, but African Americans and Latino groups were compared independently to Whites.

-See results section, page 7: In Pairwise Fischer's exact tests, both African American (32.7% vs 15.8%, Holm adjusted p-value = 0.049) and Latino (44.0% vs 15.8%, Holm adjusted p-value = 0.001) caregivers were more likely to be very concerned about having enough food and supplies compared to White caregivers. Regarding the additional caregiver specific questions, both African Americans (49.1% vs 80%, Holm adjusted p-value < 0.001) and Latinos (56% vs 80%, Holm adjusted p-value = 0.007) were less likely to have increased concerns regarding their child/loved one's health compared to White caregivers.

-See results section, page 8: Compared to Whites, Latinos were more likely to be very concerned about having enough food and supplies (adj OR 3.41, 95% CI: 1.50, 7.74) when adjusting for whether they were the sole caregiver and whether they used provider services. However, after adjusting for these variables, there was no longer a significant difference between African American and White caregivers (p=0.089).

2) Analysis compounds SES and Non-White status which is not helpful in an analysis of race / ethnicity differences. Poverty is not equal to Non-White status although it is correlated.
3) The term 'worry' seems vague and different to operationalize. Suggest the term 'concerns'. I realize that 'burden' was previously used and replaced with 'worry' but it's not the same phenomenon b/c burden implies caregiver responsibilities while worry is a psychological / affective state.

For clarification, the race/ethnicity group variable was used as a separate independent variable in this study from SES variable. Please see page 4 in the methods section for definitions of our variables. This study uses insurance status as an indicator of SES based on previously published literature:
The individual with IDD's primary insurance was used as a marker of socioeconomic status as having private health insurance has previously been linked to higher household income, and Medicaid is associated with lower income status (Muntaner & Parsons, 1996; Suruda et al., 2005). For individuals with IDD affiliated with the adult clinic, private or Medicare insurance eligibility is

based on their parents' work history and benefits. Individuals with IDD in Texas are eligible for adult Medicaid based upon their individual disability determination and low-income status. Thus, individuals with Medicaid primary insurance are likely to have decreased access to economic capital."

As the aim of this study was to describe the emotional distress of caregivers and the "COV-TaBS-A includes questions to measure of COVID-related emotional distress and related behaviors of adults in the general during the COVID pandemic and is available in English and Spanish (Schneider et al., 2020)", worry (definition: to give way to anxiety or unease; allow one's mind to dwell on difficulty or troubles) may be a more specific term to describe emotional distress than concern (definition: anxiety/worry or a matter of great importance). We do appreciate the previous suggestion to change burden to worry as we are seeking to describe the emotional experience of caregivers. We hope that these explanations address the reviewer's concerns.

Minor comments:
1) In response 4) it says that Caucasian was replaced with White, yet in response 2) it is still in use : "About 20% of Caucasians reported being worried on different COV-TaBS questions". The term is also still used in Tables 1 and 4.

The term Caucasian has been removed from the manuscript and corrected in the tables.

2) Discussion section, end of first paragraph:
"The relationship between food security and health outcomes amongst caregivers of adults with IDD and race/ethnicity, is an area needing further exploration" - everyone has a race and an ethnicity. It's not a disability or medical condition to be Non-White, as one could interpret from this sentence.

Thank you, this sentence was clarified and re-worded as follows: Resource and health disparities amongst caregivers of various racial/ethnic groups as well as the relationship between food security and health outcomes amongst caregivers of adults with IDD are areas needing further study.

Race/Ethnicity Disparities in COVID-19 Worry for Caregivers of Adults with Intellectual/Developmental Disabilities

Race/Ethnicity Disparities in COVID-19 Worry for Caregivers of Adults with Intellectual/Developmental Disabilities

Abstract

This study investigated the race/ethnicity differences in COVID-19-related worry amongst family caregivers of adults with Intellectual and/or Developmental Disabilities (IDD) living in Texas using the COVID-Related Thoughts and Behavioral Symptoms-Adult Version (COV-TaBS-A) questionnaire. Two hundred and six caregivers completed the survey. Compared to Whites, Latino caregivers were more likely to be very concerned about having enough food and supplies (adj OR 3.41, 95% CI: 1.50, 7.74) when adjusting for being that sole caregiver and using provider services. In free text questions, caregivers described feeling overwhelmed by additional responsibilities, disruptions in home health services, and concerns about their loved ones' wellness. Study findings can be used to strategize support for caregivers of adults with IDD during pandemic/emergency situations.

Key Words: Covid-19, Caregiver Burden, Intellectual and Developmental Disability

Introduction

The COVID-19 pandemic affected all aspects of life for people globally. Since 2020, there have been over a million reported deaths due to COVID-19 in the United States alone (Centers for Disease Control and Prevention, 2022). The COVID-19 pandemic has disproportionately impacted African American and Latino populations as well as people with intellectual and/or developmental disabilities (IDD) regarding prevalence and mortality (Centers for Disease Control and Prevention, 2020; Courtenay & Perera, 2020; Hooper et al., 2020; Mills et al., 2020; Turk et al., 2020; Vahidy et al., 2020). The less told story is the additional worry and responsibility that family caregivers of individuals with IDD have experienced during the COVID-19 pandemic due to risk of illness and decreased community/caregiving supports and the possible race/ethnicity disparities amongst these caregivers. In addition to protecting their loved ones from COVID-19, family caregivers faced multiple challenges including implementing COVID safety guidelines with someone who may not be able/willing to comply, managing changes in care supports, and managing health exacerbations and/or behavioral changes related to altered routines (Linehan et al., 2006). However, the potential race/ethnicity-based disparities in caregiver experience and support during the pandemic are not known.

This study aimed to (1) determine if there were racial/ethnic group disparities in COVID-related worry for caregivers, and (2) describe the COVID-19 pandemic experiences of family caregivers of adults with IDD. We hypothesized that caregivers of adults with IDD from African American and Latino backgrounds living in Texas experienced disproportionate worry during the pandemic due to the disproportionate prevalence and morbidity of COVID-19 in their communities as well as their known socioeconomic differences (Turner et al., 2020).

Methods

Study design

As the concept of evaluating caregiver worry for family caregivers of adults with IDD during a pandemic is new and unexplored, concurrent nested mixed methods design to evaluate race/ethnicity differences in Covid-related worry using the adult version of the COVID-Related Thoughts and Behavioral Symptoms (COV-TaBS-A) and explore new themes regarding the caregiver experience using free text response (Creswell JW, 2003).

The adult version of the COVID-Related Thoughts and Behavioral Symptoms (COV-TaBS-A) questionnaire was used to assess caregiver-related worry due to the pandemic. The COV-TaBS-A includes questions to measure of COVID-related emotional distress and related behaviors of adults in the general during the COVID pandemic and is available in English and Spanish (Schneider et al., 2020). With the authors' permission, this measure was used in this study as there was no measure to specifically address the pandemic's impact worries and behaviors on caregivers of adults with IDD. Four additional survey questions specifically asking about increased COVID-related caregiver worry during the pandemic were also included with yes or no response and an option for free-text response: (1) Do you worry your child's healthcare needs are not being met due to COVID? (2) Do you feel overwhelmed by your caregiver responsibilities as a result of COVID? (3) Do you feel overwhelmed by other responsibilities as a result of COVID? (4) Have you been able to practice self-care during the COVID-19 pandemic? Free text responses were used for qualitative analysis to explore additional caregiver experience themes.

The investigators developed a survey that included the COV-TaBS-A, the additional free response questions, demographic variables regarding the caregiver and adult with IDD, and condition variables regarding the adult with IDD. Caregiver demographic variables included gender, race/ethnicity, preferred language, relationship to the individual with IDD, marital status, being the sole caregiver, and household diagnosis of COVID-19. Demographic variables regarding the individual with IDD included gender, primary insurance (private, Medicare, or Medicaid), and having an active home and community-based state waiver. The individual with IDD's primary insurance was used as a marker of socioeconomic status as having private health insurance has previously been linked to higher household income, and Medicaid is associated with lower income status (Muntaner & Parsons, 1996; Suruda et al., 2005). For individuals with IDD affiliated with the adult clinic, private or Medicare insurance eligibility is based on their parents' work history and benefits. Individuals with IDD in Texas are eligible for adult Medicaid based upon their individual disability determination and low-income status. Thus, individuals with Medicaid primary insurance are likely to have decreased access to economic capital. Medical condition variables for the adults with IDD included primary diagnoses, technology dependence, and the home/community support services that the individuals receive. Support services for individuals with IDD offered by Texas Health and Human Services Medicaid-Waiver programs may include either nursing care, in which a licensed nurse visits the home to provide skilled services (e.g. health assessments, respiratory care, medication administration, enteral feeding, bladder catheterization, and/or wound care), or provider services, in which a non-skilled provider, who may be a family member, assists with activities of daily living (e.g. bathing, dressing, oral feeding, toileting, household chores, and supervision) (Texas Health and Human Services, 2023).

Participant Population

After obtaining approval from the Baylor College of Medicine Institutional Review Board, family caregivers were recruited via flyers, Facebook® posts, word of mouth, listservs, electronic health care record messaging, and during clinic visits from (1) Baylor Transition Medicine Clinic, a medical home for adults with IDD in Houston, Texas, (2) Texas parent-lead advocacy groups for parents of individuals with IDD including Texas Parent to Parent, Families Can, Familias Hispanicas, University of Texas Rio Grande Valley Support Group, Easter Seals, and Houston-based Down syndrome organizations, and (3) from the Texas *From Stress to Strength* network, a parent support group, from December 2020 through November 2021. Family caregivers were included if they had an adult with IDD (aged 18 or above) living in their home who required full-time supervision or assistance with activities of daily living, their preferred language was English or Spanish, and they identified as African American, Latino, or White non-Latino. Participants completed the survey in English or Spanish via the institution's RedCap® database (Harris et al., 2019). Consent was obtained via a question on the survey. If participants preferred, an interviewer met with them via video conferencing to read the survey questions verbatim and audio record the conversation. Free response questions were later transcribed verbatim into the survey form in the RedCap® database.

Data Analysis

Quantitative Data

Survey responses were summarized by means with standard deviations, medians with minimum and maximum values, or frequencies with percentages. Individual COV-TaBS-A questions were dichotomized into "sometimes or less" or "a lot or all the time" as there is not a validated scoring system for this measure. COV-TaBS-A and COVID-related caregiver worry question summary statistics were stratified by race and compared using the Fisher's exact or Chi-square test. If found to be significant, pairwise Fisher's exact tests with Holm's adjusted p-value were performed to see which race/ethnic group was different (Holm, 1979). Independent logistic regression was used to see if caregiver or patient characteristics were associated with responding 'a lot or all the time' to the questions. For logistic regression, categorical variables with low frequencies were combined for analysis. Significant factors were considered for multiple logistic regression, and factors found to be highly correlated ($r > \pm 0.5$) were not included in the same model to prevent collinearity. Backwards elimination was used to find a more parsimonious model. $P<0.05$ was considered statistically significant. Stata 16 was used for quantitative analysis.

Power Calculation

About 20% of White caregivers reported being worried on different COV-TaBS questions. Using the sample sizes we have in each group, a Chi-squared test would be able to detect an increase of 25.5%-points or more in African American or Latino participants who worried on any COV-TaBS questions with 80% power at a 1.7% significance level. A significance level of 1.7% was considered since there are 3 groups and thus 3 comparisons. This effect size is equivalent to a standard effect size (Cohen's H) of 0.55, which is considered to be a medium effect size (Cohen, 1992).

Qualitative Data

Free-text responses were iteratively reviewed by a team of at least three of the authors to develop a theme codebook using conventional content analysis. Each free-text response was reviewed by at least two authors. Coding disagreements were resolved by a third author.

Results

206 survey responses were received between December 1, 2020, and November 30, 2021 were included for analysis. Of these surveys, seven were completed by video interview, and the rest by online survey. Caregiver participant characteristics are described in Table 1, and characteristics of care recipients with IDD are described in Table 2.

Question Responses Compared Amongst Race/Ethnic Groups

COV-TaBS-A responses stratified by race are listed in Table 3. In comparing the COV-TaBS-A responses between White, African American, and Latino groups, significant differences were found regarding only Question 9: I was very concerned about having enough food and supplies ($p < 0.001$). In Pairwise Fischer’s exact tests, both African American (32.7% vs 15.8%, Holm adjusted p-value = 0.049) and Latino (44.0% vs 15.8%, Holm adjusted p-value = 0.001) caregivers were more likely to be very concerned about having enough food and supplies compared to White caregivers. Regarding the additional caregiver specific questions, both African Americans (49.1% vs 80%, Holm adjusted p-value < 0.001) and Latinos (56% vs 80%, Holm adjusted p-value = 0.007) were less likely to have increased concerns regarding their child/loved one's health compared to White caregivers.

Demographic and Clinical Variables associated with Question Responses

Independent regression analysis with the demographic variables for caregivers and the demographic and clinical variables for the individuals with IDD with the COV-TaBs-A questions revealed the following significant findings. Regarding the associations with the other demographic variables, four questions had significant findings (questions 1, 7, 8, 9). For Question 1 regarding worry, caregivers other than mothers (p=0.034), and patient gender (p=0.022) were associated with worrying a lot about COVID in independent regressions. However, these were highly correlated with each other, so a multiple regression was not created. Caregivers other than mothers were less likely to worry a lot about COVID-19 compared to mother caregivers (OR 0.38, 95% CI: 0.15, 0.93). Additionally, the odds of worrying a lot about COVID-19 were 1.96 times higher when the patient was male compared to female (95% CI: 1.10, 3.47). Those who had a change in their daily routines (OR 2.22, 95% CI: 1.01, 4.88) were more likely to be very diligent about cleaning my hands and surfaces to avoid COVID-19 (question 7) and had a higher odds of wanting to know a lot about COVID-19 (OR 3.65, 95% CI: 1.50, 8.89) (question 8).

Multiple Regression Analysis

In independent regression analysis, race/ethnicity (p=0.001), being the sole caregiver (p<0.001), and using provider services (p=0.021) were all independently associated with being very concerned about having enough food and supplies (question 9) and used for multiple regression (Table 4). Compared to Whites, Latinos were more likely to be very concerned about having enough food and supplies (adj OR 3.41, 95% CI: 1.50, 7.74) when adjusting for whether they were the sole caregiver and whether they used provider services. However, after adjusting for these variables, there was no longer a significant difference between African American and White caregivers (p=0.089). Sole caregivers had 3.32 times the odds of being very concerned about having enough food and supplies compared to those who were not sole caregivers (95% CI: 1.62, 6.79) when controlling for race and whether they used provider services. Those who used provider services were less likely to be concerned about having enough food and supplies compared to those who did not use provider services (adj OR 0.46, 95% CI: 0.23, 0.91) when adjusting for race and whether they were the sole caregiver.

Exploratory Themes from Free-Text Responses

The frequency of response themes and response examples to the free-text Covid-19 worry questions are listed in Tables 5-9. Themes regarding increased health concerns for their loved ones during the COVID-19 pandemic included: general wellness consequences, worries about contracting the virus, loss of access to care, and difficulties with mask/hygiene compliance. Many also reported increased worry due to losing nursing/provider care, difficulty accessing care, and delays in receiving medical supplies. Additionally, caregivers reported feeling more overwhelmed with increased caregiving responsibilities, isolation, and worries about contracting the virus. Many also felt more overwhelmed by other responsibilities such as COVID-19 precaution responsibilities, financial stress, and the addition of more responsibilities.

When asked about whether they could practice self-care during the COVID-19 pandemic, the majority caregivers amongst all race/ethnicity groups could practice self-care (Table 3). In free response, many cited physical activities, entertainment, working on staying healthy (such as maintaining COVID-19 hygiene precautions), maintaining other relationships, mental health/spiritual care, and maintaining a schedule with adequate rest. Among participants that answered no, the majority cited lack of time/too many responsibilities, fear of covid exposure, guilt, or fear of leaving loved one with disabilities, and lack of resources or respite care as reasons why they were not able to engage in self-care. As there were no differences in the quantitative responses to the additional caregiver-specific questions amongst race/ethnic groups and the response samples for each theme were small, further analysis to identify differences in themes amongst the groups was not pursued.

Discussion

This study sought to explore race/ethnicity differences regarding the worry of caregivers of adults with IDD living in Texas experienced during the COVID-19 pandemic. We found that Latino and African American caregivers were significantly more worried about not having sufficient food and supplies compared to Whites as hypothesized. These findings are consistent with national disparities in food insecurity amongst race/ethnic groups in the general population before the pandemic (Odoms-Young & Bruce, 2018). In 2020, the United States Department of Agriculture reported that 21.7% of African American and 17.2% of Latino households reported food insecurity compared to the national average of 10.5% (USDA Economic Research Service, 2020). As food insecurity is associated with poorer health outcomes, particularly regarding mental health concerns and cardiovascular disease risk factors (Heflin et al., 2005; Muirhead et al., 2009; Seligman et al., 2007, 2010), this finding of increased food insecurity amongst African American and Latino caregivers may suggest that these families are more at risk of adverse health outcomes. Resource and health disparities amongst caregivers of various racial/ethnic groups as well as the relationship between food security and health outcomes amongst caregivers of adults with IDD are areas needing further study.

In addition, sole caregivers had increased odds to be very concerned about having enough food and supplies compared to those who were not sole caregivers when controlling for race/ethnicity and whether they used provider services. This finding also aligns with the national data showing that households with a single woman (27.7%) or a single man (16.3%) are at higher risk for food insecurity (USDA Economic Research Service, 2020). However, when adjusting for sole caregiver status, Latinos were still more likely to be very concerned about having enough food and supplies (adj OR 3.41, 95% CI: 1.50, 7.74) compared to Whites suggesting that caregiver support may be less protective for this group in this study cohort.

Though Latino and African American caregivers were more concerned about having resources, White caregivers were significantly more likely to report increased concern about their child/loved one's health. However, the percentage of caregivers in each group reporting increased concern for their loved one's health was high overall and this finding may be associated with how this question was worded. A study regarding expression of caregiver burden for caregivers of the elderly by Calderon, et al. found that White women expressed feelings of frustration and anger regarding difficulties in caregiving whereas African Americans and Puerto Rican women used somatic symptoms to describe their struggles (Calderón & Tennstedt, 1998). Moon et al. found that the relationship between the care recipient's nationality and caregiver's race/ethnicity had complex effects on caregiver experiences and concluded that cultural backgrounds may influence both caregiver perception and expression of their experience (Moon et al., 2020). Evaluating the expression of worry and burden amongst caregivers of adults with IDD of various race/ethnicities is an area for further research.

Qualitative analysis to identify free-text response themes revealed that many caregivers were concerned about wellness (physical activity, mental health, etc.), difficulties with mask/hygiene compliance, loss of access to healthcare, delays in medical supply delivery, and loss of nursing/provider care for their loved-one with IDD during the pandemic. In turn, many caregivers reported increased caregiver responsibilities and feelings of isolation. Several studies have cited loss of access to healthcare during the pandemic. In a study conducted by Drum et al., 56% of adults with IDD lost access to regular healthcare during the pandemic. Moreover, 38% of respondents reported new challenges to obtaining healthcare treatment, healthcare access, and/or prescriptions during the COVID-19 outbreak (Drum et al., 2020). A similar study by Jeste et al. found that approximately half of the children and adults with IDD surveyed were unable to see a healthcare provider when needed and 30% of the participants lost access to all therapies required prior to the COVID-19 pandemic (Jeste et al., 2020). Thus, further evaluation of barriers accessing timely care and strategic planning to increase access to care (e.g., telehealth supports) are needed to optimize access to care and care supports for those with IDD in preparation for potential future emergency situations (Pellegrino & DiGennaro Reed, 2020).

When asked about whether they could practice self-care during the COVID-19 pandemic, most caregivers could practice self-care. Many cited physical activities, entertainment, working on staying healthy (such as maintaining COVID-19 hygiene precautions), maintaining other relationship, mental health/spiritual care, and maintaining a schedule with adequate rest as self-care strategies. While several studies have examined the role of mindfulness-based interventions and informal supports in reducing caregiver stress in non-pandemic times in the general population, the efficacy of leisure activities in building caregiver resiliency has not been extensively examined and remains an area for future research (Ó Donnchadha, 2018; Weiss et al., 2018). Additionally, several caregiver support groups have developed materials to promote caregiver well-being, further examination of the impact of such groups on the well-being of caregivers of adults with IDD is needed (Autism Speaks, 2021).

Limitations

This survey study was sent to caregivers affiliated with a clinic for IDD or affiliated with Texas-based advocacy organizations. Thus, there may be a selection bias in representing caregivers who are already linked to at least some community resources. In addition, home and community-based services vary from state to state so this study may not be representative of caregivers' experiences of receiving necessary support in other locations. We recognize that the questions used for this study have not been validated but were used because they specifically assessed caregiver worry during COVID-19 and were relevant to the experience of caregivers of adults with IDD. Further validation studies are needed for the COV-TaBs-P and should include caregivers of adults with IDD. Additionally, further study is needed to evaluate the differences between various caregiver characteristics and the qualitative themes identified in this study.

Conclusions

This survey study identified race/ethnicity and sole caregiver status as factors associated with increased worry of caregiving for adults with IDD during the COVID-19 pandemic regarding sufficiency of food and supplies. However, caregivers who had provider support were less likely to be very concerned about food and supplies. Caregiver social determinant of health screenings, particularly asking about food and supplies as well as provider supports, administered by clinics caring for adults with IDD or managed care insurance plans may help to identify vulnerable caregivers of adults with IDD who need extra support during emergency situations.

References

Autism Speaks. (2021). *COVID-19 information and resources for families*.

Calderón, V., & Tennstedt, S. L. (1998). Ethnic Differences in the Expression of Caregiver Burden. *Journal of Gerontological Social Work*, *30*, 159–178.

Centers for Disease Control and Prevention. (2020). *Race , Ethnicity , and Age Trends in Persons Who Died from COVID-19 May-August 2020*. *69*.

Centers for Disease Control and Prevention. (2022, April 4). *COVID Data Tracker*. US Department of Health and Human Services, CDC.

Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*, 155–159. https://doi.org/10.1037/0033-2909.112.1.155

Courtenay, K., & Perera, B. (2020). *COVID-19 and people with intellectual disability : impacts of a pandemic*. *2012*. https://doi.org/10.1017/ipm.2020.45

Creswell JW, P. C. V. G. M. H. W. (2003). Advanced mixed methods research designs. In A. Tashakkori & C. Teddlie (Eds.), *In: Handbook of Mixed Methods in Social and Behavioral Research* (pp. 209–240). Sage.

Drum, C. E., Oberg, A., Ditsch, J., Cooper, K., & Carlin, R. (2020). *COVID-19 & ADULTS WITH Serious Difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury*. www.aahd.us

Harris, P. A., Taylor, R., Minor, B. L., Elliott, V., Fernandez, M., O'Neal, L., McLeod, L., Delacqua, G., Delacqua, F., Kirby, J., & Duda, S. N. (2019). The REDCap consortium: Building an international community of software platform partners. *Journal of Biomedical Informatics*, *95*(May), 103208. https://doi.org/10.1016/j.jbi.2019.103208

Heflin, C. M., Siefert, K., & Williams, D. R. (2005). Food insufficiency and women's mental health: Findings from a 3-year panel of welfare recipients. *Social Science and Medicine*, *61*(9), 1971–1982. https://doi.org/10.1016/j.socscimed.2005.04.014

Hooper, M. W., Napoles, A. M., & Perez-STable, E. J. (2020). COVID-19 and Racial/Ethnic Disparities. *JAMA*, *323*(24), 2466–2467. https://doi.org/10.1002/jclp.20757

Jeste, S., Hyde, C., Distefano, C., Halladay, A., Ray, S., Porath, M., Wilson, R. B., & Thurm, A. (2020). Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. *Journal of Intellectual Disability Research*, *64*(11), 825–833. https://doi.org/10.1111/jir.12776

Linehan, M. M., Comtois, K. A., Murray, A. M., Brown, M. Z., Gallop, R. J., Heard, H. L., Korslund, K. E., Tutek, D. A., Reynolds, S. K., & Lindenboim, N. (2006). Two-year randomized controlled trial and follow-up of dialectical behavior therapy vs therapy by experts for suicidal behaviors and borderline personality disorder. *Archives of General Psychiatry*, *63*(7), 757- 766. https://doi.org/10.1001/archpsyc.63.7.757

Mills, W. R., Sender, S., Lichtefeld, J., Romano, N., Reynolds, K., Price, M., & Phipps, J. (2020). *Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA. d*, 489–496. https://doi.org/10.1111/jir.12740

Moon, H. E., Haley, W. E., Rote, S. M., & Sears, J. S. (2020). Caregiver Well-being and burden: Variations by Race/Ethnicity and care recipient nativity status. *Innovation in Aging*, *4*(6), 1–13. https://doi.org/10.1093/geroni/igaa045

Muirhead, V., Quiñonez, C., Figueiredo, R., & Locker, D. (2009). Oral health disparities and food insecurity in working poor Canadians. *Community Dentistry and Oral Epidemiology*, *37*(4), 294–304. https://doi.org/10.1111/j.1600-0528.2009.00479.x

Muntaner, C., & Parsons, P. E. (1996). Income, social stratification, class, and private health insurance: A study of the baltimore metropolitan area. *International Journal of Health Services*, *26*(4), 655–671. https://doi.org/10.2190/1Y3T-HPQ6-ADBH-55WC

Ó Donnchadha, S. (2018). Stress in caregivers of individuals with intellectual or developmental disabilities: A systematic review of mindfulness-based interventions. In *Journal of Applied Research in Intellectual Disabilities* (Vol. 31, Issue 2, pp. 181–192). Blackwell Publishing Ltd. https://doi.org/10.1111/jar.12398

Odoms-Young, A., & Bruce, M. A. (2018). Examining the Impact of Structural Racism on Food Insecurity Implications for Addressing Racial/Ethnic Disparities. *Family and Community Health*, *41*, S3–S6. https://doi.org/10.1097/FCH.0000000000000183

Pellegrino, A. J., & DiGennaro Reed, F. D. (2020). Using telehealth to teach valued skills to adults with intellectual and developmental disabilities. *Journal of Applied Behavior Analysis*, *53*(3), 1276–1289. https://doi.org/10.1002/jaba.734

Schneider, S. C., Weinzimmer, S. A., Amos Nwankwo, G. N., Cepeda, S. L., & Storch, E. A. (2020). *COVID-Related Thoughts and Behavioral Symptoms, Parent Proxy Version (COV-TaBS-P).* Research Gate. doi: 10.13140/RG.2.2.36152.08966

Seligman, H. K., Bindman, A. B., Vittinghoff, E., Kanaya, A. M., & Kushel, M. B. (2007). Food insecurity is associated with diabetes mellitus: Results from the National Health Examination and Nutrition Examination Survey (NHANES) 1999-2002. *Journal of General Internal Medicine*, *22*(7), 1018–1023. https://doi.org/10.1007/s11606-007-0192-6

Seligman, H. K., Laraia, B. A., & Kushel, M. B. (2010). Food insecurity is associated with chronic disease among low-income nhanes participants. *Journal of Nutrition*, *140*(2), 304–310. https://doi.org/10.3945/jn.109.112573

Suruda, A., Burns, T. J., Knight, S., & Dean, J. M. (2005). Health insurance, neighborhood income, and emergency department usage by Utah children 1996-1998. *BMC Health Services Research*, *5*. https://doi.org/10.1186/1472-6963-5-29

Texas Health and Human Services. (2023). *Intellectual or Developmental Disabilities (IDD) - Long-term Care*. Texas Health & Human Services Commission. https://www.hhs.texas.gov/services/disability/intellectual-or-developmental-disabilities-idd-long-term-care

Turk, M. A., Landes, S. D., Formica, M. K., & Goss, K. D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends : TriNetX analysis. *Disability and Health Journal*, *xxxx*, 100942. https://doi.org/10.1016/j.dhjo.2020.100942

Turner, A., LaVeist, T., Richard, P., & Gaskin, D. (2020). *ECONOMIC IMPACTS OF HEALTH DISPARITIES IN TEXAS 2020*.

USDA Economic Research Service. (2020). *Food Security in the U.S.*

Vahidy, F. S., Nicolas, J. C., Meeks, J. R., Khan, O., Pan, A., Jones, S. L., Masud, F., Sostman, H. D., Phillips, R., Andrieni, J. D., Kash, B. A., & Nasir, K. (2020). Racial and ethnic disparities in SARS-CoV-2 pandemic: Analysis of a COVID-19 observational registry for a diverse US metropolitan population. *BMJ Open*, *10*(8). https://doi.org/10.1136/bmjopen-2020-039849

Weiss, J. A., Tajik-Parvinchi, D., Maughan, A. L., & Lake, J. (2018). Family Wellness in Intellectual and Developmental Disabilities: a Balanced Approach. *Curr Dev Disord* , *5*, 157–164.

Table 1

Caregiver Participant Characteristics (Total N=206)

Age	Median 56 years [20-80]
	N (%)
Sex	
Female	191 (92.7)
Male	15 (7.3)
Race/Ethnicity	
White, non-Latino	101 (49)
African American	55 (26.7)
Latino	50 (24.3)
English as the preferred language	
	192 (93.2)
Relationship to individual with IDD	
Mother	175 (85)
Father	7 (3.4)
Grandparent	13 (6.4)
Sibling	3 (1.5)
Other	8 (3.9)
Marital Status	
Married	133 (64.6)
Separated/Divorced	39 (18.9)
Single	34 (16.5)
Sole Caregiver for the Individual with IDD?	
	100 (48.5)
Positive COVID-19 in the household?	
	24 (11.7)

Table 2

Characteristics of the Care Recipients with IDD (N =206)

Age	Median age 26 years [18=72]
Gender	**N (%)**
Female	92 (44.7)
Male	114 (55.3)
Primary Insurance	
Private	67 (32.5)
Medicare	48 (23.3)
Medicaid	91 (44.2)
Home and Community Based Waiver Recipient?	
	131 (63.6)
Primary Diagnosis	
Autism Spectrum Disorder	51 (24.8)
Cerebral Palsy	38 (18.4)
Down Syndrome	41 (19.9)
Other IDD Diagnosis /Dual diagnosis	76 (36.9)
Technology dependence	
Number of individuals with at least one technology	67 (32.5)
Number/percent per each technology	
Feeding tube	26 (12.6)
Tracheostomy tube	4 (1.9)
Ventilator dependent	4 (1.9)
Baclofen pump	3 (1.5)
Wheelchair	56 (23.7)
Typical activity during the day before COVID	
Home with family	89 (43.2)
Home with provider/nurse	11 (5.3)
Day program	61 (29.6)
Other	45 (21.8)
Was there a change in activities due to COVID?	174 (84.5)
Nursing and provider services received?	
Nursing	20 (9.7)
Provider	101 (49)
Both	18 (8.7)
Has the individual been diagnosed with COVID?	
	17 (8.3)

Table 3

Question Response Comparisons Amongst Race/Ethnic Groups

	White, Non-Latino (N=110)		African American, Non-Latino (N=55)		Latino (N=50)		P-value
	N	(%)	N	(%)	N	(%)	
COV-TaBS-A Questions							
Question 1: I worried a lot about COVID-19							0.248
Sometimes or less	62	(61.4)	36	(65.5)	25	(50.0)	
A lot or all the time	39	(38.6)	19	(34.5)	25	(50.0)	
Question 2: It was hard to sleep because of COVID-19							0.093
Sometimes or less	92	(91.1)	51	(92.7)	40	(80.0)	
A lot or all the time	9	(8.9)	4	(7.3)	10	(20.0)	
Question 3: I could not stop thinking about terrible things that might happen because of COVID-19							0.076
Sometimes or less	85	(84.2)	42	(76.4)	34	(68.0)	
A lot or all the time	16	(15.8)	13	(23.6)	16	(32.0)	
Question 4: I felt irritable or angry because of COVID-19							0.461
Sometimes or less	87	(86.1)	46	(83.6)	39	(78.0)	
A lot or all the time	14	(13.9)	9	(16.4)	11	(22.0)	
Question 5: I felt isolated or lonely because of COVID-19							0.545
Sometimes or less	75	(74.3)	45	(81.8)	39	(78.0)	
A lot or all the time	26	(25.7)	10	(18.2)	11	(22.0)	
Question 6: I was more distressed about COVID-19 than other people							0.499
Sometimes or less	80	(79.2)	48	(87.3)	41	(82.0)	
A lot or all the time	21	(20.8)	7	(12.7)	9	(18.0)	
Question 7: I was very diligent about cleaning my hands and surfaces to avoid COVID-19							0.421
Sometimes or less	30	(29.7)	11	(20.0)	13	(26.0)	
A lot or all the time	71	(70.3)	44	(80.0)	37	(74.0)	

Question 8: I wanted to know a lot about COVID-19, such as frequently checking the news, social media							0.386
Sometimes or less	53	(52.5)	27	(49.1)	31	(62.0)	
A lot or all the time	48	(47.5)	28	(50.9)	19	(38.0)	
Question 9: I was very concerned about having enough food and supplies							**0.001**
Sometimes or less	85	(84.2)	37	(67.3)	28	(56.0)	
A lot or all the time	16	(15.8)	18	(32.7)	22	(44.0)	
Additional Caregiving-Specific Questions							
Do you have any increased concerns regarding your child’s/loved one’s health during the COVID							**<0.001**
No	20	(20.0)	28	(50.9)	22	(44.0)	
Yes	80	(80.0)	27	(49.1)	28	(56.0)	
Do you worry your child's healthcare needs are not being met due to COVID?							0.300
No	76	(76.0)	46	(83.6)	43	(86.0)	
Yes	24	(24.0)	9	(16.4)	7	(14.0)	
Do you feel overwhelmed by your caregiver responsibilities as a result of COVID-19							0.866
No	59	(59.0)	35	(63.6)	31	(62.0)	
Yes	41	(41.0)	20	(36.4)	19	(38.0)	
Do you feel overwhelmed by other responsibilities as a result of COVID-19?							0.695
No	61	(61.0)	32	(58.2)	33	(66.0)	
Yes	39	(39.0)	23	(41.8)	17	(34.0)	
Have you been able to practice self-care during the COVID-19 pandemic?							0.135
No	31	(31.0)	19	(34.5)	9	(18.0)	
Yes	69	(69.0)	36	(65.5)	41	(82.0)	

Table 4

Multiple logistic regression for being very concerned about having enough food and supplies

	Adj. Odds ratio	**95% Confidence Interval**		**p-value**
Race-ethnicity				**0.013**
White	Reference	.	.	.
African American	2.09	0.90	4.86	0.089
Latino	3.41	1.50	7.74	**0.003**
Sole caregiver	3.32	1.62	6.79	**0.001**
Uses provider services	0.46	0.23	0.91	**0.026**

Table 5

Do you have any increased concerns regarding your child's health during the COVID-19 pandemic?

Themes	Wellness Consequences	Worry about contracting the virus	Loss of access to care	Difficulty with mask/hygiene compliance	Other
Response Frequency	26	109	20	11	4
Example responses	“I am very concerned about his mental health. He refuses to leave our home now, just to go for a ride. He endured agoraphobia as a small child for several years and I am fearful he may return to that state. I am also concerned about his social and emotional health.”	“If my child were to get COVID-19, by being nonverbal, how could they explain to me how they are feeling? If they had to be hospitalized, I couldn't be with them.”	“During the shutdown over a year ago, therapy and mental health services went online and [my son] requires in person treatment for trauma.”	“My son, though an adult, doesn't truly understand social distancing or personal space. My concern was that because of this inability to stay safely distanced “	“How I'm going to take care of my son it’s just me and him.”

Table 6

Do you worry that you child's healthcare needs (i.e. medical, nursing, DME, medications, etc.) are not being met as a result of COVID-19?

Themes	Nursing/Provider Care	Difficulty with Accessing Care	Supply delays
Response Frequency	5	48	6
Example responses	"Our child received nursing care at school and at night. He has lost access to both of those during the pandemic."	"My husband lost his job for a year, and we didn't have insurance." "I have been incredibly sick since having Covid that I'm behind with doctor appointments."	"Delivery of some of his medical supplies were delayed."

Table 7

Do you feel overwhelmed by your caregiver responsibilities as a result of COVID-19?

Themes	Increased caregiving responsibilities	Isolation	Worry about contracting the virus	Other
Frequency of response	57	14	22	7
Example responses	"I am a caregiver for both my son, as well as my mother with Alzheimer's and numerous other serious health issues. Trying to provide care for them both and challenge them mentally, physically, and emotionally is overwhelming."	"I'm managing his depression and loneliness." "With limited social activities it is harder to keep him off the iPad and more active…"	"[I have] increased stress trying to keep loved one safe/healthy for fear of hospitalization and not being able to be with him."	"I have been diagnosed with Post Covid migraines and Fatigue which makes caregiving more difficult."

Table 8

Do you feel overwhelmed by other responsibilities as a result of COVID-19?

Themes	COVID Precaution Responsibilities	Financial stress	Additional responsibilities	Other
Response Frequency	24	12	49	8
Example responses	"I'm sanitizing everything, making sure other family members in house do the same. I'm taking all necessary precautions with those she comes in contact with; limiting contact with unknowns."	"We're struggling to keep the lights on and buy enough food- the pandemic has severely limited resources as family members who used to help are now unemployed and unable to contribute."	Covid has added more work to my busy schedule and a lot less help from others who were willing in the past. No one can enter our home nor can I leave other than curbside grocery and pharmacy pick up."	"I'm worried about my other adult children as I have seen them become a bit depressed by COVID."

Table 9

Have you been able to practice self-care during the COVID-19 pandemic? If yes, what do you do?

Themes	Physical Activity	Entertainment	Work on staying healthy	Maintain other relationships	Mental health/ spiritual care	Adequate rest and maintain a schedule
Response Frequency	55	24	61	16	22	32
Example responses	"I'm riding my stationary bike daily and doing exercises from my room."	"I read, watch movies, bake, try new recipes."	"I'm trying to protect myself more from not getting sick, avoid going out if not necessary."	"I attend webinars, visit friends and family on a regular basis through Zoom and/or Facetime."	"Bible study, counseling." "Listen to music for meditation or meditation coaching apps."	"Good sleep, good meals, and reading" "Maintain a regular daily schedule."