BRIEF REPORT

Children's Special Health Care Needs and Caregivers' Well-Being During the COVID-19 Pandemic

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Background: **Caregivers of children with special health care needs (SHCN) report worse self-rated health when compared with caregivers of children without SHCN and have experienced significant stress during the COVID-19 pandemic. We sought to determine whether COVID-19 pandemic-era declines in well-being among caregivers of children with SHCN were steeper than among caregivers of children without SHCN.**

Methods: **We used 2020 to 2021 (pandemic-era, n = 89,560) and 2018 to 2019 (pre-pandemic, n = 57,927) data from the National Survey of Children's Health. Caregiver-reported physical and mental health outcomes were analyzed using multivariable ordinal logistic regression.**

Results: **The pandemic era was associated with 26% higher odds of reporting worse mental health among caregivers of children with SHCN (95% confidence interval [CI]: +16%, +38%), and 20% higher odds of reporting worse mental health among caregivers of children without SHCN (95% CI: +15%, +26%). The magnitudes of these changes were not significantly different from one another (*$P = .341$*).**

Conclusions: **Although caregivers of children with SHCN faced significant burdens and increased stress during the pandemic, decline in self-rated mental health among this group was similar to the trend seen among caregivers of children without SHCN. (J Am Board Fam Med 2023;00:000–000.)**

Keywords: **Caregivers, Child, Community-Based Research, COVID-19, Epidemiology, Logistic Regression, Mental Health, Pandemics, Special Health Care Needs**

Introduction

Children with special health care needs (CSHCN) are at higher risk for long-term behavioral, developmental, emotional, or physical conditions.[1] In turn, raising CSHCN can be a significant source of stress for caregivers.[2] For example, mothers of CSHCN exhibit worse mental and physical health, and higher rates of depression and anxiety than mothers of children without SHCN,[3,4] and 12% of families of CSHCN report needing mental health services for at least 1 family member.[5]

The COVID-19 pandemic exacerbated stresses associated with caring for CSHCN. For example, among caregivers of children with neurodevelopmental disorders, 43% reported a decline in mental health and 35% reported a decline in physical health[6] while caregivers of children with developmental disabilities reported elevated levels of anxiety, depression, and stress during the pandemic, compared with caregivers of children with typical development.[7–9]

Although the pandemic has created new challenges for caregivers of CSHCN, well-being and mental health have also declined among parents in general.[10–12] Therefore, it is unclear if pandemic-era deterioration in caregiver well-being was similar among all caregivers, or exacerbated among caregivers of CSHCN. In this study, we tested the hypothesis that the decline in caregiver well-being during the pandemic years was more pronounced

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among caregivers of CSHCN as compared with caregivers of children without SHCN.

Methods

We used repeated cross-sectional data from the 2018 to 2021 National Survey of Children's Health (NSCH).[13] In each sampled household, 1 caregiver completed a mail or web survey about a randomly selected child and themselves, and could provide information on a second caregiver, if applicable. In multi-child households, children age 0 to 5 years and CSHCN were oversampled. The 2020 and 2021 surveys were administered after the onset of the COVID-19 pandemic in the US, and represented the pandemic era. Cases with missing data were excluded. Institutional Review Board approval was not required as this study used deidentified public data and did not constitute human subjects research.

Our primary outcome was caregiver well-being, assessed using 2 questions. The respondent (primary caregiver) rated their own "physical health" and "mental or emotional health" on a 5-point Likert scale (1 = excellent, 2 = very good, 3 = good, 4 = fair, or 5 = poor). If another caregiver was present in the household, the respondent also rated the secondary caregiver's physical and mental health on the same scale. We analyzed caregiver physical and mental health separately, focusing on the lower value (indicating worse health) of either caregiver.

In the NSCH, SHCN status was identified using a validated screener querying health care needs, functional limitations, and medication use.[14] Family covariates included caregivers' age, birth place, educational attainment, household income, language, and family structure. Child covariates included age, sex, race and ethnicity, and health insurance coverage. In descriptive analyses, we also examined children's health-related functional limitations and overall caregiver-rated health status (assessed on the same 5-point scale as caregiver general health).

Study variables were summarized using weighted means and proportions with 95% confidence intervals (CI) and compared by study period (pandemic vs Pre-pandemic) using Wald tests or logistic regression. Because income data were multiply imputed by NSCH staff, statistical significance of bivariate comparisons for income was determined using unadjusted logistic regression. In multivariable analysis, each caregiver well-being outcome was analyzed using ordinal logistic regression, with independent variables including study period, child SHCN status, and the interaction of period and SHCN status. All multivariable models included the covariates listed above, except for child health and functional limitation, which might have mediated the association of SHCN status with study outcomes. All analyses accounted for the survey weights, complex sampling design, and use of multiply imputed income data.[15] $P < .05$ was considered statistically significant. Stata/S.E. 16.1 (College Station, TX: StataCorp, LP) was used for all analyses.

Results

The 2018 to 2021 NSCH originally included 153,632 cases. We excluded 4312 cases due to missing data on caregiver well-being and 1833 cases due to missing data on covariates. The remaining sample included 57,927 pre-pandemic cases (2018 and 2019) and 89,560 pandemic-era cases (2020 and 2021), reflecting a planned increase in the survey sample size for the most recent 2 years. The weighted percentage of CSHCN was 19% (95% CI: 18%, 20%) pre-pandemic, and 20% (95% CI: 19%, 20%) during the pandemic.

Table 1 summarizes bivariate comparisons of study variables by pandemic versus Pre-pandemic era for families with and without CSHCN. We found a decline in mental health among caregivers of CSHCN during the pandemic, but this decline was no greater than the decline in mental health among caregivers of children without SHCN. On bivariate analysis, we found no pandemic-related trends in caregiver physical health among either caregivers of CSHCN or caregivers of children without SHCN. Notably, we found that family income trended upward among caregivers of CSHCN, but not among caregivers of children without SHCN.

Multivariable analyses are summarized in Tables 2 and 3. Among caregivers of children without CSHCN, the pandemic era was not associated with statistically significant change in the odds of reporting worse physical health (odds ratio [OR]: 1.03; 95% CI: 0.98, 1.08; $P = .323$; Table 2). The interaction term (OR: 1.07; $P = .205$) was not statistically significant, indicating that the magnitude of this trend was not meaningfully different among

Table 1. Weighted Means or Proportions with 95% Confidence Intervals of Study Variables, Stratified by Era and Child Special Health Care Needs (SHCN) Status (n = 147,487)

Variable	Families without CSHCN			Families with CSHCN		
	Pre-Pandemic (n = 44,345)	Pandemic Era (n = 69,160)	*P*	Pre-Pandemic (n = 13,582)	Pandemic Era (n = 20,400)	*P*
Caregiver physical health						
Excellent	0.23 (0.22, 0.23)	0.22 (0.21, 0.23)	0.506	0.13 (0.12, 0.14)	0.12 (0.11, 0.13)	0.328
Very good	0.40 (0.39, 0.41)	0.40 (0.39, 0.41)	0.678	0.34 (0.32, 0.36)	0.33 (0.32, 0.35)	0.408
Good	0.29 (0.29, 0.30)	0.30 (0.29, 0.31)	0.707	0.35 (0.34, 0.37)	0.36 (0.35, 0.37)	0.624
Fair	0.07 (0.06, 0.07)	0.07 (0.07, 0.07)	0.764	0.14 (0.12, 0.15)	0.14 (0.12, 0.16)	0.357
Poor	0.01 (0.01, 0.02)	0.01 (0.01, 0.01)	0.255	0.04 (0.03, 0.05)	0.04 (0.03, 0.05)	0.632
Caregiver mental health						
Excellent	0.34 (0.33, 0.35)	0.31 (0.30, 0.31)	<0.001	0.21 (0.20, 0.22)	0.18 (0.16, 0.19)	<0.001
Very good	0.38 (0.37, 0.39)	0.38 (0.37, 0.39)	0.884	0.35 (0.34, 0.37)	0.33 (0.32, 0.35)	0.089
Good	0.22 (0.21, 0.23)	0.24 (0.23, 0.25)	<0.001	0.31 (0.29, 0.33)	0.33 (0.32, 0.35)	0.036
Fair	0.05 (0.05, 0.06)	0.06 (0.06, 0.07)	0.001	0.11 (0.10, 0.12)	0.13 (0.12, 0.14)	0.001
Poor	0.01 (0.01, 0.01)	0.01 (0.01, 0.01)	0.046	0.02 (0.02, 0.03)	0.03 (0.02, 0.03)	0.736
Caregiver age (years)	41.1 (40.9, 41.3)	41.1 (41.0, 41.3)	0.736	43.3 (43.0, 43.6)	43.5 (43.2, 43.7)	0.369
Caregiver born outside US	0.30 (0.29, 0.31)	0.30 (0.29, 0.31)	0.467	0.18 (0.16, 0.19)	0.19 (0.18, 0.21)	0.241
Caregiver education						
High school or less	0.23 (0.22, 0.24)	0.24 (0.23, 0.24)	0.578	0.21 (0.20, 0.23)	0.20 (0.19, 0.22)	0.404
Some college	0.26 (0.25, 0.27)	0.24 (0.23, 0.25)	0.001	0.30 (0.29, 0.32)	0.29 (0.28, 0.31)	0.513
Four-year college degree	0.51 (0.50, 0.52)	0.52 (0.52, 0.53)	0.031	0.49 (0.47, 0.50)	0.50 (0.49, 0.52)	0.155
Household language						
English	0.84 (0.83, 0.85)	0.84 (0.83, 0.84)	0.217	0.93 (0.92, 0.94)	0.91 (0.90, 0.92)	0.031
Any other language	0.16 (0.15, 0.17)	0.16 (0.16, 0.17)	0.217	0.07 (0.06, 0.08)	0.09 (0.08, 0.10)	0.031
Household structure						
Two parents	0.75 (0.74, 0.76)	0.74 (0.73, 0.74)	0.026	0.64 (0.62, 0.66)	0.66 (0.64, 0.67)	0.250
Single mother	0.16 (0.15, 0.17)	0.17 (0.16, 0.18)	0.021	0.24 (0.22, 0.26)	0.23 (0.21, 0.24)	0.216
Any other	0.09 (0.09, 0.10)	0.09 (0.09, 0.10)	0.701	0.12 (0.11, 0.13)	0.12 (0.11, 0.13)	0.984
Child age (years)	8.3 (8.2, 8.4)	8.2 (8.2, 8.3)	0.790	10.3 (10.2, 10.5)	10.4 (10.3, 10.6)	0.508
Child sex						
Female	0.51 (0.50, 0.52)	0.50 (0.50, 0.51)	0.955	0.43 (0.41, 0.44)	0.43 (0.41, 0.44)	0.924
Male	0.49 (0.48, 0.50)	0.50 (0.49, 0.50)	0.955	0.57 (0.56, 0.59)	0.57 (0.56, 0.59)	0.924
Child race and ethnicity						
Non-Hispanic White	0.51 (0.50, 0.52)	0.51 (0.50, 0.51)	0.869	0.54 (0.52, 0.56)	0.52 (0.51, 0.54)	0.117
Non-Hispanic Black	0.12 (0.12, 0.13)	0.12 (0.12, 0.13)	0.975	0.16 (0.15, 0.17)	0.15 (0.14, 0.17)	0.518
Hispanic or Latino	0.26 (0.25, 0.27)	0.26 (0.25, 0.27)	0.870	0.20 (0.18, 0.22)	0.23 (0.21, 0.25)	0.014
None of the above	0.11 (0.11, 0.12)	0.11 (0.11, 0.12)	0.544	0.10 (0.09, 0.11)	0.09 (0.08, 0.10)	0.335
Child health insurance						
Private	0.62 (0.61, 0.63)	0.62 (0.61, 0.63)	0.887	0.56 (0.54, 0.57)	0.56 (0.54, 0.57)	0.886
Public	0.27 (0.26, 0.28)	0.27 (0.26, 0.28)	0.682	0.37 (0.36, 0.39)	0.37 (0.35, 0.38)	0.646
Other	0.04 (0.03, 0.04)	0.04 (0.03, 0.04)	0.502	0.03 (0.03, 0.04)	0.03 (0.03, 0.04)	0.851
None	0.07 (0.07, 0.08)	0.07 (0.07, 0.08)	0.377	0.04 (0.03, 0.05)	0,04 (0,03, 0.05)	0.567
Child health condition limits age-typical activities						
Never[a]	0.95 (0.95, 0.96)	0.97 (0.96, 0.97)	<0.001	0.48 (0.47, 0.50)	0.51 (0.50, 0.53)	0.024
Sometimes	0.04 (0.04, 0.05)	0.03 (0.03, 0.04)	<0.001	0.38 (0.36, 0.39)	0.37 (0.36, 0.39)	0.621
Often	0.00 (0.00, 0.00)	0.00 (0.00, 0.00)	0.193	0.08 (0.07, 0.10)	0.07 (0.06, 0.07)	0.007
Always	0.00 (0.00, 0.00)	0.00 (0.00, 0.00)	0.793	0.05 (0.05, 0.06)	0.05 (0.04, 0.06)	0.644

Continued

Table 1. Continued

Variable	Families without CSHCN			Families with CSHCN		
	Pre-Pandemic (n = 44,345)	Pandemic Era (n = 69,160)	*P*	Pre-Pandemic (n = 13,582)	Pandemic Era (n = 20,400)	*P*
Child overall health						
Excellent	0.73 (0.72, 0.74)	0.74 (0.73, 0.74)	0.783	0.36 (0.35, 0.38)	0.37 (0.35, 0.38)	0.914
Very good	0.21 (0.20, 0.22)	0.21 (0.20, 0.22)	0.628	0.36 (0.35, 0.38)	0.36 (0.35, 0.38)	0.993
Good	0.05 (0.04, 0.05)	0.05 (0.04, 0.05)	0.983	0.21 (0.20, 0.23)	0.21 (0.20, 0.22)	0.759
Fair	0.00 (0.00, 0.01)	0.00 (0.00, 0.01)	0.660	0.05 (0.04, 0.06)	0.06 (0.05, 0.07)	0.511
Poor	0.00 (0.00, 0.00)	0.00 (0.00, 0.00)	0.143	0.01 (0.01, 0.01)	0.01 (0.00, 0.01)	0.278
Family income (% FPL)						
<100	0.18 (0.17, 0.19)	0.18 (0.17, 0.18)	0.675	0.22 (0.20, 0.24)	0.19 (0.17, 0.21)	0.040
100 to 199	0.22 (0.20, 0.23)	0.20 (0.20, 0.21)	0.138	0.22 (0.21, 0.24)	0.22 (0.21, 0.24)	0.885
200 to 399	0.29 (0.28, 0.30)	0.29 (0.29, 0.30)	0.260	0.26 (0.24, 0.27)	0.29 (0.27, 0.30)	0.007
400 or greater	0.32 (0.31, 0.33)	0.33 (0.32, 0.33)	0.292	0.30 (0.28, 0.31)	0.30 (0.28, 0.31)	0.704

[a] Includes children with no health conditions.
Abbreviations: CSHCN, children with special health care needs; FPL, Federal poverty level; US, United States.

caregivers of CSHCN (OR for pandemic vs Pre-pandemic era among caregivers of CSHCN = 1.03 × 1.07 = 1.10; 95% CI: 1.002, 1.20; *P* = *.046*).

Considering mental health, we found that during the pandemic, caregivers of children without SHCN had 20% higher odds of reporting worse mental health as compared with the pre-pandemic era (OR: 1.20; 95% CI: 1.15, 1.26; *P* < *.001*; Table 3). This was statistically indistinguishable from the association between era and mental health among caregivers of CSHCN (OR: 1.20 × 1.05 = 1.26; 95% CI: 1.16, 1.38; *P* < *.001*), as the interaction between era and SHCN status did not reach statistical significance (OR: 1.05; *P* = *.341*).

Discussion

The onset of the COVID-19 pandemic was associated with a profound increase in stress and mental health issues.[16] Caregivers of CSHCN encounter unique stressors associated with their children's health conditions,[17] and a growing literature has documented how these caregivers' mental health has been undermined by the pandemic.[18,19] However, using repeated cross-sectional data from a nationally representative survey, we found that caregivers of CSHCN and caregivers of children without SHCN experienced similar declines in mental health during the pandemic. This finding calls attention to possible sources of support and resilience among caregivers of CSHCN during the pandemic. It also underscores the importance of population-level approaches to protect mental health and well-being during a time of pervasive stress and social isolation.

Caregivers of CSHCN were known to experience a greater burden of psychological and emotional issues as compared with caregivers of children without SHCN.[4,5,20] At the pandemic's outset, declines in well-being among caregivers of CSHCN were widely anticipated,[21,22] and in early studies, caregivers of CSHCN reported increased anxiety, stress, and depression due to taking care of CSHCN without adequate support.[6,23] However, while accumulating evidence supports a decline in mental health among parents of CSHCN during the pandemic,[6,23,24] other studies identified similar declines in mental health among all parents.[25] Our data indicate that trends in mental health among caregivers of CSHCN were statistically indistinguishable from a broader decline in mental health among children's caregivers; and, indeed, from a general population-level decline in mental health.[16]

These findings may be related to experiences of resilience and sources of support among caregivers of CSHCN during the COVID-19 pandemic. Caregivers of CSHCN faced significant burden and stress related to navigating a changing health care system and the shifting risks of a novel pathogen. However, spending more time with family may have counteracted anxiety during the pandemic,[26] and a further source of support might have come from health care providers, as families with CSHCN

Table 2. Multivariable Ordinal Logistic Regression Model of Caregiver Physical Health, with Higher Values Indicating Worse Health (n = 147,487)

Variable	OR	95% CI	*P*
Child special health care needs			
Family without CSHCN	Ref.		
Family with CSHCN	1.69	1.57, 1.83	<0.001
Era			
Pre-pandemic	Ref.		
Pandemic	1.03	0.98, 1.08	0.323
CSHCN x pandemic era interaction	1.07	0.96, 1.19	0.205
Caregiver age (years)	1.03	1.02, 1.03	<0.001
Caregiver born outside US	0.71	0.66, 0.76	<0.001
Caregiver education			
High school or less	Ref.		
Some college	0.99	0.91, 1.07	0.746
Four-year college degree	0.63	0.58, 0.68	<0.001
Household language			
English	Ref.		
Any other language	0.77	0.70, 0.86	<0.001
Household structure			
Two parents	Ref.		
Single mother	0.92	0.85, 0.98	0.017
Any other	0.75	0.68, 0.82	<0.001
Child age (years)	1.01	1.002, 1.01	<0.001
Child sex			
Female	Ref.		
Male	0.97	0.93, 1.02	0.197
Child race and ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	1.04	0.96, 1.12	0.298
Hispanic or Latino	1.26	1.16, 1.36	<0.001
None of the above	1.25	1.17, 1.33	<0.001
Child health insurance			
Private	Ref.		
Public	1.38	1.28, 1.48	<0.001
Other	0.98	0.86, 1.12	0.755
None	0.92	0.82, 1.04	0.171
Family income (% FPL)			
<100	Ref.		
100 to 199	0.85	0.77, 0.93	0.001
200 to 399	0.79	0.72, 0.86	<0.001
400 or greater	0.55	0.50, 0.67	<0.001

Abbreviations: CI, confidence interval; CSHCN, children with special health care needs; FPL, Federal poverty level; OR, odds ratio; Ref, reference; US, United States.

might have had more continuous interactions with health systems than other families in the first years of the pandemic. Meanwhile, financial stressors associated with caring for CSHCN might have been alleviated by pandemic-era policies.[27–29] Consistent with this hypothesis, our descriptive analysis found that the poverty rate decreased only among caregivers of CSHCN during the pandemic, but not among caregivers of children without SHCN.

Our conclusions are subject to some limitations, including assessment of SHCN status for only 1 child per household, underestimating caregiving burden in families where the sample child did not

Table 3. Multivariable Ordinal Logistic Regression Model of Caregiver Mental Health, with Higher Values Indicating Worse Health (n = 147,487)

Variable	OR	95% CI	*P*
Child special health care needs			
Family without CSHCN	Ref.		
Family with CSHCN	1.88	1.74, 2.03	<0.001
Era			
Pre-pandemic	Ref.		
Pandemic	1.20	1.15, 1.26	<0.001
CSHCN x pandemic era interaction	1.05	0.95, 1.16	0.341
Caregiver age (years)	1.00	1.00, 1.00	0.735
Caregiver born outside US	0.69	0.65, 0.75	<0.001
Caregiver education			
High school or less	Ref.		
Some college	1.09	1.00, 1.18	0.042
Four-year college degree	0.92	0.85, 0.99	0.048
Household language			
English	Ref.		
Any other language	0.67	0.60, 0.75	<0.001
Household structure			
Two parents	Ref.		
Single mother	1.06	0.99, 1.14	0.101
Any other	0.71	0.65, 0.78	<0.001
Child age (years)	1.00	1.00, 1.01	0.216
Child sex			
Female	Ref.		
Male	0.95	0.91, 0.99	0.012
Child race and ethnicity			
Non-Hispanic White	Ref.		
Non-Hispanic Black	0.75	0.69, 0.81	<0.001
Hispanic or Latino	1.03	0.96, 1.11	0.418
None of the above	1.19	1.11, 1.27	<0.001
Child health insurance			
Private	Ref.		
Public	1.22	1.14, 1.31	<0.001
Other	0.96	0.84, 1.09	0.534
None	0.96	0.85, 1.07	0.459
Family income (% FPL)			
<100	Ref.		
100 to 199	0.91	0.83, 1.01	0.068
200 to 399	0.90	0.82, 0.98	0.018
400 or greater	0.69	0.62, 0.75	<0.001

Abbreviations: CI, confidence interval; CSHCN, children with special health care needs; FPL, Federal poverty level; OR, odds ratio; Ref, reference; US, United States.

have SHCN. This bias, however, might have been mitigated by oversampling of CSHCN. Another limitation arises from survey completion by 1 caregiver, resulting in proxy report of the second caregiver's well-being.

Despite these limitations, our study reveals that the pandemic-era trend of declining mental health was similar between caregivers of CSHCN and caregivers of children without SHCN. Leveraging caregivers' contact with their children's health care providers may assist in supporting caregivers' mental health, but strategies to improve caregiver mental health should also include broad population-based approaches that match the global scope of the

pandemic's effects. Future studies are needed to determine whether pandemic-era trends represent transient or enduring shocks to caregiver mental health, and how worsening caregiver mental health might affect later-life well-being among caregivers and their children.

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