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The COVID-19 Pandemic Impact on Households of Young Children With Special Healthcare Needs

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Abstract

Objective   This study examined how the COVID-19 pandemic differently affected households of children with versus without special healthcare needs. We compared caregivers' and children's emotional well-being (Aim 1), the utilization of preventive healthcare services for young children (Aim 2), and the promotive effects of social support on well-being outcomes (Aim 3) during the pandemic between the two groups. **Methods**   Data were drawn from an ongoing, large, longitudinal, and national survey that assessed the pandemic impact on households of young children (0–5). Analyses for Aims 1 and 2 were based on 10,572 households, among which 10.96% had children with special healthcare needs. Analyses for Aim 3 were based on a subsample of 821 families, among which 12.54% had children with special healthcare needs. **Results**   Caregivers of children with special healthcare needs exhibited more emotional distress and reported higher levels of household children's behavioral problems during the pandemic. The percentages of missed preventive healthcare visits and vaccinations were also higher in families of children with special healthcare needs due to structural barriers. Lastly, emotional social support was indirectly related to children's decreased behavioral problems through caregivers' reduced emotional distress, only among households of children without special healthcare needs. In other words, social support alone was not sufficient in promoting caregivers' and children's better well-being outcomes among households of children with special healthcare needs. **Conclusions**   The pandemic has caused extensive burdens on families of children with special healthcare needs. Actions from policymakers and early intervention service providers are urgently needed to mitigate these impacts.

Key words: anxiety; behavior problems; COVID-19; depression; healthcare services and utilization; health disparities and inequities; infancy and early childhood; parent psychosocial functioning; social support; stress.

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has had a profound impact on the well-being of families of young children in the United States and around the globe (Gassman-Pines et al., 2020; Patrick et al., 2020). Research suggests that COVID-19 has led to significantly increased levels of emotional distress and increased rates of mental health disorders among both caregivers and children (Malhi et al., 2021; Patrick et al., 2020; Power, 2020). These challenges are likely the result of increased hardships (e.g., income loss, caregiving burden, etc.), disrupted social relationships, and confinement-related stress (e.g., crowding,

disrupted daily routine; Gassman-Pines et al., 2020; Prime et al., 2020).

In parallel with increases in emotional distress, decreases have been observed in families' access to and utilization of pediatric healthcare services. In the United States, not only have there been fewer pediatric primary healthcare visits in response to health challenges such as illness and injury, but there have also been lower rates of preventive healthcare visits (i.e., well-baby/well-child checkups) and vaccines for children during the pandemic (Miller et al., 2020). Undoubtedly, these trends are the result of a combination of general public health guidance to limit social contact in order to prevent the spread of the virus, as well as a desire on the part of both parents and healthcare practitioners to limit unnecessary in-person visits to the doctor. Concerns about the safety of in-person healthcare visits have been addressed to some extent by an increase in telehealth services and drive-through clinics (Monaghesh & Hajizadeh, 2020; Wosik et al., 2020). However, these adaptations have likely only increased the inequalities in access to care experienced by households with limited access to broadband Internet and vehicular transport (e.g., low-income households, rural populations, Black and Hispanic/Latino[a] families; Camden & Silva, 2021; Campos-Castillo & Anthony, 2021; Jaffe et al., 2020). Moreover, it is unclear at present whether these adaptations in service delivery will adequately address the continuum of pediatric healthcare needs from prevention to primary care.

This paper addresses a focal topic of considerable public health importance within pediatric healthcare during the COVID-19 pandemic: emotional well-being and preventive healthcare utilization among families of young child(ren) with special healthcare needs. Special healthcare needs are defined as developmental, intellectual, physical disabilities, and chronic medical conditions (Kuo et al., 2011; McPherson et al., 1998). According to the National Survey of Children's Health (2020), approximately one in four U.S. households has one or more children with special healthcare needs. Before the pandemic, these families have experienced elevated caregiving difficulties, financial strains, and heightened vulnerability to mental health and behavioral problems (DeRigne, 2012; Foster et al., 2021). Additional resources and services are often required in order to provide adequate support for these households (Pilapil et al., 2017). During the COVID-19 pandemic, the further increased caregiving burden, elevated financial strains due to employment losses, and reduced accessibility of healthcare services due to the pandemic burden and lockdowns may put both caregivers and children in these households at even higher risk for emotional distress and mental health difficulties (McMorrow et al., 2020).

Preventive healthcare for children from birth to 18 years old is an essential service. Indeed, the regularly scheduled well-child visits recommended by the American Academy of Pediatrics (Hagan et al., 2007) provide a healthcare system contact for the great majority of families in the United States. This greatly facilitates initial screening and detection, referral for supplemental services such as special education and early intervention, and tracking of developmental progress (McPherson et al., 1998). However, there are notable gaps based on demographic characteristics in access to preventive healthcare (Hambidge et al., 2007). Families of children with special healthcare needs, in particular, often experience substantial challenges in accessing these healthcare services because of the high levels of caregiving burden and financial strain (DeRigne, 2012; Foster et al., 2021; Pilapil et al., 2017). The COVID-19 pandemic further amplifies these barriers and poses substantial challenges for children in these households to get adequate preventive healthcare services.

Prior to the pandemic, perceived social support (i.e., the perception of being cared and having a reliable social network in times of need; Friedman, 2011) was documented as a critical positive factor for households of children with special healthcare needs (Cantwell et al., 2014; Chu et al., 2010). Perceived social support can be examined with multiple components, such as the frequency of social interactions, size of social network, and the functional component (Suvak et al., 2013). We focus on the functional component of social support (i.e., the degree to which social support serves functions) that incorporates dimensions of emotional support, instrumental/tangible support, affection, and positive social interactions (Moser et al., 2012; Sherbourne & Stewart, 1991). In pre-pandemic studies, social support has been shown to attenuate caregivers' psychological stress and promote well-being outcomes among households of children with special healthcare needs (Cantwell et al., 2014), which in turn reduces young children's behavioral problems (Cantwell et al., 2014; Chu et al., 2010). However, during the pandemic, preventive measures for reducing the spread of COVID-19, such as social distancing, quarantine, and isolation, have decreased access to conventional means of social support (Saltzman et al., 2020). With the increased pandemic-induced challenges facing families of children with special healthcare needs, it remains unclear whether social support could still reduce caregivers' emotional distress and promote household children's adaptive outcomes.

Studies of the well-being of households with young children during the pandemic start to emerge

(Gassman-Pines et al., 2020; Malhi et al., 2021; Patrick et al., 2020; Prime et al., 2020); however, research that focuses on families of children with special healthcare needs during this time is scarce. Focusing on individual *household/family* as an investigation unit, this study aimed to examine the pandemic impact on households of children with special healthcare needs and compare their experiences with households of children without special healthcare needs. In particular, we focused on the domains of (a) caregivers' emotional distress, (b) behavioral problems of children in these households, and (c) families' access to and utilization of healthcare services. We hypothesized that households of children with special healthcare needs would present with greater caregiver emotional distress and child(ren)'s behavioral problems (Hypothesis 1) and would experience more difficulties in accessing healthcare services (Hypothesis 2) during the pandemic, compared to families of children without special healthcare needs. The third aim of this study was to investigate whether different dimensions of social support were effective in promoting caregivers' and children's well-being outcomes among the two types of households (i.e., households of children with and without special healthcare needs). We tested mediation models in the two groups simultaneously, where social support was hypothesized to reduce children's behavioral problems through decreasing caregivers' emotional distress (Hypothesis 3).

Methods

Procedures

Data of the current study were drawn from the Rapid Assessment of Pandemic Impact on Development–Early Childhood (RAPID-EC) project. RAPID-EC is a currently ongoing national study that started from April 2020 and uses weekly/biweekly surveys to assess the impact of the pandemic on households with young children (0–5 years old). All the study procedures have been approved by the institutional review board at the University of Oregon. The RAPID-EC sampling strategy included initial recruitment (i.e., baseline) and ongoing survey assessments (i.e., follow-up surveys), which were distributed on a weekly basis at the beginning of the project (from April 6, 2020, to July 30, 2020) and then switched to an alternating biweekly basis starting from August 2020 (see Supplemental Table 1 for details). Participants were recruited through community organization email listservs, Facebook Ads, and panel services.

During each baseline assessment, primary caregivers who were interested in participation first completed an eligibility survey. To be eligible, respondents must be (a) 18 years or older, (b) the primary caregiver of a child aged 0–5 years old, (c) fluent in English and/or Spanish, and (d) living in the United States. Eligible caregivers provided online consent to recontact for follow-up assessments, completed a baseline survey, and were enrolled into a participant pool. Given the basis of convenience sampling for baseline assessments, the participant pool was not intended to be nationally representative. Then, during follow-up assessments, caregivers from the participant pool were invited by email to complete follow-up surveys. The RAPID-EC research team made extensive efforts to include more racially/ethnically diverse groups and lower-income families in the follow-up surveys. Each follow-up survey was stratified based on participants' race/ethnicity and percentage of the U.S. federal poverty level, with a goal of reaching national representativeness regarding these demographic characteristics and recruiting an equal number of participants from the four U.S. geographic regions (see Supplemental Table 2 for sampling stratification). Within each stratum, participants were randomly selected from the pool. A total of 2,000 invitation emails were sent out to selected families with the goal of obtaining a minimum of 1,000 respondents for each follow-up survey (the estimated response rate is 50%). All survey responses were manually and systematically inspected to detect and remove fraudulent responding, based on IP address, survey duration, and completely wrong responses to the attention check questions. After completing each survey, the family received $5 as an incentive. For another publication yielded from the RAPID-EC data, see Weston et al. (2021).

Participants

A total of 10,572 families who provided responses to surveys from Week 1 (April 6, 2020) to Week 55 (May 1, 2021) formed the sample to test Hypotheses 1 and 2 in this study. During this period of time, a total of 10,798 caregivers provided responses to survey questions. We reached the sample size of 10,572 by excluding 175 caregivers who did not wish to disclose their child(ren)'s disability status and an additional 51 caregivers who did not respond to the question about child(ren)'s disability status. The final sample included 10.96% ($n = 1,159$) households of child(ren) with special healthcare needs and 89.04% ($n = 9,413$) households of children without special healthcare needs. The 1,159 families of children with special healthcare needs included 4.14% ($n = 48$) reporting child(ren) with blindness or serious difficulty seeing, 8.02% ($n = 93$) with serious difficulty walking or climbing stairs, 39.43% ($n = 457$) with disabilities due to physical, mental, or emotional problems, and 70.78% ($n = 809$) with other disabilities not listed in the survey. Analyses for the third study aim were based on a subsample of 821 families who responded to the Week-15 survey (when social support was assessed as

a special topic). This subgroup included 12.54% ($n = 103$) households of children with special healthcare needs and 87.45% ($n = 718$) households of children without special healthcare needs.

The demographic characteristics of the full sample ($N = 10,572$) and the two groups (i.e., households of children with and without special healthcare needs) are presented in Table I.[1] The number of responded surveys for each family (including the baseline survey) ranged from 1 to 32 ($M = 3.47$, $SD = 3.97$). We conducted analysis of variance (ANOVA) and Tukey's post hoc tests to examine whether families' number of responses varied by race/ethnicity, pre-pandemic poverty level, children's disability status, and U.S. region. The number of responded surveys was higher among Asian caregivers, $F(6, 10543) = 12.36$, $p < .001$; caregivers who reported higher pre-pandemic income, $F(2, 9518) = 54.97$, $p < .001$; and caregivers from the Northeast region of the United States, $F(4, 10567) = 28.58$, $p < .001$. However, the number of responses did not significantly differ by status of household children's special healthcare needs, $F(1, 10570) = .26$, $p = .61$.

Measures
This section summarizes the measurement tools briefly. Survey questions mentioned in this section are listed in Supplemental Table 3. Given the RAPID-EC's nature of frequent and brief online surveys that capture numerous different domains, we used shortened or trimmed measurement tools to reduce survey length and avoid participants' fatigue. When validated measures were available for a specific domain, we selected questions from the measures that were most relevant to families' experiences during the COVID-19 pandemic. For domains with no validated measures, we developed our own survey questions.

Special Healthcare Needs Status
Caregivers reported whether their children have different types of disabilities, including difficulty seeing, difficulty walking/climbing stairs, physical, mental, or emotional problems, and other disabilities. We further obtained information of whether each household had children with special healthcare needs based on this question.

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1 It is important to note that the race/ethnic and income distribution of the final sample was not consistent with the follow-up sampling stratification for several reasons. First, the current sample included data from both baseline and follow-up surveys; while follow-up sampling was stratified, the baseline sampling was not. Second, the aggregation of responses from multiple follow-up surveys changed the percentage of each group in the total sample because some families participated in more than one follow-up. Third, the removal of fraudulent responding also changed the percentage of each group in the final sample.

Well-Being
Caregivers' pre-pandemic emotional distress was retrospectively reported during the initial baseline survey. Caregivers also reflected their during-pandemic emotional distress during the baseline and each follow-up surveys. Emotional distress was captured by four constructs, including depressive, anxiety, stress, and loneliness symptoms. The four domains were moderately correlated with each other (r ranged from .44 to .65, $p < .001$). Scores of the four problems were transformed to a range of 0–100. Then, an average score of the four constructs was calculated to indicate caregivers' total emotional distress ($\alpha = .84$). Caregivers also reported children's internalizing (i.e., fear/anxiety) and externalizing (i.e., fussiness) problems on each of the children aged between 0 and 5 years old in the household, using two items from the Child Behavioral Checklist (Achenbach & Rescorla, 2001). When multiple children within the age range presented in the household, caregivers separately reported on each child, and the average scores across all reported children were calculated to reflect the overall children's internalizing and externalizing problems at the household level. Internalizing and externalizing symptom variables were moderately correlated ($r = .45$, $p < .001$). Further, the average score of these two symptoms in each household was calculated to indicate household children's total behavioral problems ($\alpha = .62$), and scores were transformed to a range of 0–100.

Social Support
Caregivers' perceived social support during the pandemic was assessed using the modified Medical Outcomes Study Social Support Survey (Sherbourne & Stewart, 1996), which was collected during Week 15 (July 13–16, 2020). This scale comprised four dimensions of social support: emotional/informational support (7 items; $\alpha = .95$), tangible support (4 items; $\alpha = .89$), affectionate support (3 items; $\alpha = .86$), and positive social interactions (4 items; $\alpha = .95$). The total scores of each of the four dimensions were calculated, respectively, and used in analyses.

Access and Utilization of Healthcare
Caregivers reported on a series of questions developed by the research team and indicated whether they missed preventive healthcare visits or scheduled vaccinations for children in their households, as well as the reasons for missed healthcare visits.

Data Analyses
Data analyses for Hypotheses 1 and 2 were conducted using R version 4.0.2 (R Core Team, 2020) based on the full sample of 10,572 families. Given that caregivers' emotional distress, children's behavioral

Table I. *Demographic Characteristics of the Study Sample*

Demographic characteristics		Full sample (N = 10,572)	Households of children with special health-care needs (n = 1,159)	Households of children with-out special healthcare needs (n = 9,413)
Caregivers' race	American Indian/Alaska Native	106 (1.00%)	13 (1.12%)	93 (0.99%)
	Asian	378 (3.58%)	22 (1.90%)	356 (3.78%)
	Black/African American	815 (7.73%)	92 (7.94%)	723 (7.68%)
	Native Hawaiian/Pacific Islander	13 (0.12%)	2 (0.17%)	11 (0.12%)
	White	8,011 (75.93%)	878 (75.75%)	7,133 (75.78%)
	Biracial/multiracial	663 (6.28%)	71 (6.13%)	592 (6.29%)
	Others	564 (5.35%)	76 (6.56%)	488 (5.18%)
Caregivers' ethnicity	Hispanic/Latino(a)	1,730 (16.45%)	953 (82.23%)	1,531 (16.26%)
	Non-Hispanic/Latino(a)	8,788 (83.55%)	199 (17.17%)	7,835 (83.24%)
Caregivers' gender	Male/transgender male	690 (6.53%)	80 (6.90%)	610 (6.48%)
	Female/transgender female	9,826 (92.94%)	1,067 (92.06%)	8,759 (93.05%)
	Gender variant/nonconforming	7 (0.07%)	4 (0.35%)	3 (0.03%)
	Prefer not to answer	6 (0.06%)	1 (0.09%)	5 (0.05%)
	Other	43 (0.41%)	7 (0.60%)	36 (0.38%)
Pre-pandemic poverty level	At or below 100% FPL	1,685 (17.51%)	284 (24.50%)	1,401 (14.88%)
	100% – 200% FPL	2,560 (26.61%)	335 (28.90%)	2,225 (23.64%)
	Above 200% FPL	5,376 (55.88%)	420 (36.24%)	4,956 (52.65%)
Caregivers' age group	18–24 years old	589 (5.74%)	48 (4.14%)	541 (5.75%)
	25–34 years old	6,117 (59.58%)	628 (54.18%)	5,489 (58.31%)
	35–44 years old	3,264 (31.79%)	398 (34.34%)	2,866 (30.45%)
	45–54 years old	233 (2.27%)	43 (3.71%)	190 (2.02%)
	55+ years old	64 (0.62%)	17 (1.47%)	47 (0.50%)
Children's age group	Have children below 12 months	4,527 (47.22%)	461 (39.78%)	4,066 (43.20%)
	Have children between 12 and 23 months	2,072 (21.61%)	141 (12.17%)	1,931 (20.51%)
	Have children between 24 and 35 months	1,917 (19.99%)	177 (15.27%)	1,740 (18.49%)
	Have children between 36 and 47 months	2,284 (23.82%)	255 (22.00%)	2,029 (21.56%)
	Have children between 48 and 59 months	2,400 (25.03%)	363 (31.32%)	2,037 (21.64%)
	Have children between 60 and 71 months	2,367 (24.69%)	371 (32.01%)	1,996 (21.2%)
Geographic region distribution in United States	Northeast	1,666 (15.76%)	207 (17.86%)	1,459 (15.5%)
	Midwest	2,681 (25.36%)	262 (22.61%)	2,419 (25.7%)
	South	3,596 (34.01%)	425 (36.67%)	3,171 (33.69%)
	West	2,624 (24.02%)	265 (22.86%)	2,359 (25.06%)
	Other	5 (0.05%)	0 (0%)	5 (0.05%)

Note. Pre-pandemic poverty level was calculated based on 2019 annual income and household size. FPL = federal poverty level.

outcomes, and healthcare access and utilization were assessed in every baseline and follow-up survey, we selected each caregiver's most recent response for analyses to capture the latest information while also preserving strengths of the large sample size. To test Hypothesis 1, we first conducted independent-sample *t* tests to compare mean-level differences of caregivers' emotional distress and children's behavioral problems between households of children with versus without special healthcare needs. In comparisons where the equal variance assumption was violated (as suggested by significant *F* tests), the Welsh's *t* tests were conducted instead. We also used paired-sample *t* tests to examine mean-level changes of emotional well-being variables from pre- to during-pandemic. Next, in order to test the Hypothesis 2, we conducted chi-square

analysis to compare the percentages of families who missed preventive healthcare visits (for different reasons) or scheduled vaccines between households of children with versus without special healthcare needs. Notably, data of the current study spanned over a year, during which families' well-being and healthcare access might change over time. Even though assessing these trends of changes was not the main scope of this study, we provided this information as a supplemental material (see Supplemental Figure 1).

To test the third hypothesis, we used data from 821 families who responded to the Week-15 follow-up survey as well as their first and second subsequent responses after Week 15 (i.e., Follow-up 1 and Follow-up 2). We first conducted independent-sample *t* tests in R to compare dimensions of perceived social

support between households of children with and without special healthcare needs. We also conducted correlation analyses in R to examine the associations among social support, caregivers' emotional distress, and household children's behavioral problems in the two groups, respectively. Then, multigroup mediation models were constructed using path analyses with maximum likelihood estimation approach (Yuan & Bentler, 2000) in *Mplus* version 8.3 (Muthén & Muthén, 2018). In these models, we tested the mediation effects of caregivers' Follow-up 1 emotional distress on the associations between perceived social support (Week 15) and household children's Follow-up 2 behavioral problems in the two groups—families of children with and without special healthcare needs—simultaneously. The four dimensions of social support were modeled together as competing predictors. These mediation models controlled for caregivers' emotional distress at Week 15 and household children's behavioral problems in Follow-up 1 to capture short-term well-being changes. We also added pre-pandemic poverty level, minority status, employment decrease in pandemic, and caregivers' gender as covariates. When group differences presented on a specific path (i.e., when a path was significant for one group but not significant for the other group), we further conducted chi-square equivalence testing by constraining the path coefficient to be equivalent across the two groups and examining whether the chi-square model fit change (compared to the original non-constraining model) was significant.

Results

Emotional Well-Being Outcomes

The findings of emotional well-being supported Hypothesis 1 and are presented in Table II. Independent sample t tests showed that the levels of caregivers' emotional distress and household children's behavioral problems were significantly higher in families of children with special healthcare needs, compared to families of children without special healthcare needs ($p < .001$), for both pre-pandemic (retrospectively reported) and during-pandemic situations. Further, paired-sample t tests indicated that caregivers' emotional distress and household children's behavioral problems both significantly increased from pre- to during-pandemic ($p < .001$). In both groups, there were approximately 72% of caregivers indicating an increase in emotional distress symptoms of themselves, and approximately 48% reporting an increase in behavioral problems among their children since the start of the pandemic. The group differences in the rate (parent: $\chi^2(1) = .03$, $p = .86$, $\varphi = .002$; children: $\chi^2(1) = .001$, $p = .99$, $\varphi = .001$) and degree (parent: $M_{\text{difference}} = .32$, $t(5089) = .34$, $p = .73$, $d =$ .02; child: $M_{\text{difference}} = 1.63$, $t(684) = 1.34$, $p = .18$, $d = .07$) of well-being symptom increases were not statistically significant.

Access to and Utilization of Healthcare

This study found that households of children with special healthcare needs missed more preventive healthcare visits and vaccinations due to structural barriers, supporting Hypothesis 2. The results indicated that 38.21% ($n = 439$) of households of children with special healthcare needs have missed preventive healthcare visits during the COVID-19 pandemic, which was significantly higher ($\chi^2(1) = 44.98$, $p < .001$, $\varphi = .07$) than households of children without special healthcare needs (28.58%, $n = 2,672$). Among households of children with special healthcare needs, there were also 11.99% ($n = 111$) missing scheduled vaccinations for their household young children since the pandemic began, which is significantly higher ($\chi^2(1) = 13.56$, $p < .01$, $\varphi = .04$) than households of children without special healthcare needs (8.32%, $n = 662$). Table III presents the reasons for missing preventive healthcare visits. In both groups, the majority of caregivers (>70%) reported concerns over exposure to COVID-19. However, there were more caregivers of children with special healthcare needs indicating structural barriers such as inability to find childcare ($\chi^2(1) = 22.59$, $p < .001$, $\varphi = .09$), unable to get time away from work ($\chi^2(1) = 4.37$, $p < .05$, $\varphi = .04$), and caring for family members ($\chi^2(1) = 36.69$, $p < .001$, $\varphi = .11$).

Social Support and Emotional Well-Being

Analyses on social support and well-being indicated that caregivers of children with special healthcare needs perceived less social support, and the promotive effect of social support on reducing caregivers' emotional distress and children's behavioral problems was diminished among households of children with special healthcare needs. These analyses were based on a subsample of 821 families, with 12.54% ($n = 103$) having at least one child with special healthcare needs. During the pandemic, caregivers of children with special healthcare needs perceived significantly lower levels of emotional/informational support ($M_{\text{difference}} = -.38$, $t(819) = -3.47$, $p < .001$, $d = .37$), tangible/instrumental support ($M_{\text{difference}} = -.51$, $t(819) = -4.57$, $p < .001$, $d = .79$), affectionate support ($M_{\text{difference}} = -.45$, $t(819) = -3.67$, $p < .001$, $d = .43$), and positive social interactions ($M_{\text{difference}} = -.38$, $t(819) = -3.26$, $p < .01$, $d = .34$), compared to caregivers of children without special healthcare needs. For both groups, all dimensions of social support were significantly correlated with lower levels of caregivers' emotional distress and household

Table II. *Caregivers' and Children's Well-being Results (N = 10,572)*

Mean levels of well-being	Family of children with special healthcare needs (n = 1,159)			Family of children without special healthcare needs (n = 9,413)			Independent sample t test results
	Mean	SD	95% CI of mean	Mean	SD	95% CI of mean	
Caregivers' Emotional Distress							
Total problems							
Pre-COVID-19	35.60	21.29	[34.38, 36.83]	26.42	18.85	[26.03, 26.80]	$t(1389.6) = 14.03, p < .001, d = .48$
During COVID-19	51.40	24.87	[49.97, 52.83]	41.49	24.20	[41.01, 41.98]	$t(10,500) = 13.06, p < .001, d = .41$
Paired-sample t tests	$t(1148) = 22.82, p < .001, d = .67$			$t(9344) = 69.03, p < .001, d = .71$			
Depressive symptoms							
Pre-COVID-19	26.31	26.81	[24.77, 27.85]	16.12	22.05	[15.68, 16.57]	$t(1356.6) = 12.42, p < .001, d = .45$
During COVID-19	38.36	31.52	[36.55, 40.18]	27.62	28.14	[27.05, 28.19]	$t(1383.7) = 11.03, p < .001, d = .38$
Paired-sample t tests	$t(1148) = 13.92, p < .001, d = .41$			$t(9339) = 44.06, p < .001, d = .45$			
Anxiety symptoms							
Pre-COVID-19	34.38	29.12	[32.71, 36.06]	24.64	25.95	[24.12, 25.16]	$t(1392.6) = 10.87, p < .001, d = .37$
During COVID-19	47.93	32.11	[46.08, 49.78]	37.64	30.82	[37.01, 38.26]	$t(10,500) = 10.64, p < .001, d = .33$
Paired-sample t tests	$t(1148) = 14.38, p < .001, d = .42$			$t(9343) = 43.15, p < .001, d = .45$			
Stress							
Pre-COVID-19	43.27	29.02	[41.60, 44.94]	32.78	25.90	[32.25, 33.30]	$t(1389.3) = 11.73, p < .001, d = .40$
During COVID-19	64.64	30.89	[62.86, 66.42]	52.60	32.06	[51.95, 53.24]	$t(10,327) = 11.98, p < .001, d = .38$
Paired-sample t tests	$t(1129) = 20.85, p < .001, d = .62$			$t(9183) = 58.12, p < .001, d = .61$			
Loneliness							
Pre-COVID-19	38.49	24.48	[37.08, 39.90]	32.13	22.67	[31.67, 32.58]	$t(1412.1) = 8.42, p < .001, d = .28$
During COVID-19	55.20	27.33	[53.63, 56.78]	48.69	27.00	[48.14, 49.23]	$t(10,494) = 7.71, p < .001, d = .24$
Paired-sample t tests	$t(1146) = 20.01, p < .001, d = .59$			$t(9340) = 63.58, p < .001, d = .66$			
Children Behavioral Problems							
Total problems							
Pre-COVID-19	34.44	25.81	[32.95, 35.93]	21.30	20.81	[20.88, 21.72]	$t(1435.2) = 16.80, p < .001, d = .60$
During COVID-19	48.56	28.21	[46.94, 50.19]	35.07	26.09	[34.54, 35.6]	$t(1397.7) = 15.41, p < .001, d = .48$
Paired-sample t tests	$t(577) = 13.13, p < .001, d = .45$			$t(4503) = 39.27, p < .001, d = .58$			
Externalizing symptoms							
Pre-COVID-19	43.24	30.35	[41.49, 44.99]	30.62	28.04	[30.05, 31.19]	$t(1498.4) = 13.69, p < .001, d = .44$
During COVID-19	59.65	31.92	[57.82, 61.49]	47.74	31.91	[47.09, 48.38]	$t(10,474) = 11.93, p < .001, d = .37$
Paired-sample t tests	$t(575) = 12.66, p < .001, d = .48$			$t(4499) = 36.76, p < .001, d = .58$			
Internalizing symptoms							
Pre-COVID-19	25.7	30.78	[23.93, 27.48]	11.95	22.48	[11.5, 12.41]	$t(1392.1) = 14.68, p < .001, d = .57$
During COVID-19	37.34	34.33	[35.36, 39.32]	22.39	29.56	[21.79, 22.99]	$t(1356.5) = 14.09, p < .001, d = .45$
Paired-sample t tests	$t(573) = 9.73, p < .001, d = .29$			$t(4477) = 28.49, p < .001, d = .39$			

Note. Pre-COVID indicates caregivers' retrospective report on their emotional distress and their children's behavioral problems. *SD* = standard deviation; CI = confidence interval; *d* = Cohen's *d* (effect size for *t* tests).

Table III. *Conditions and Reasons for Missed Preventive Healthcare Visits (N = 10,572)*

Conditions	Family of children with special healthcare needs (n = 1,159)			Family of children without special healthcare needs (n = 9,413)			Statistical test results
	Count	Pct	95% CI of Pct	Count	Pct	95% CI of Pct	
Did not miss preventive healthcare visits	720	61.79%	[58.98%, 64.60%]	6,676	71.42%	[70.50%, 72.33%]	$\chi^2(1) = 44.98, p < .001, \varphi = .07$
Missed preventive healthcare visits	439	38.21%	[35.40%, 41.02%]	2,672	28.58%	[27.67%, 29.50%]	
– Reasons:							
Cost	32	7.29%	[4.86%, 9.72%]	173	6.47%	[5.54%, 7.41%]	$\chi^2(1) = .29, p = .59, \varphi = .01$
Unable to get time away from work	46	10.48%	[7.61%, 13.34%]	199	7.45%	[6.45%, 8.44%]	$\chi^2(1) = 4.37 \ p < .05, \varphi = .04$
Inability to find childcare	81	18.45%	[14.82%, 22.08%]	280	10.48%	[9.32%, 11.64%]	$\chi^2(1) = 22.59, p < .001, \varphi = .09$
Concern over exposure to COVID-19	311	70.84%	[66.59%, 75.09%]	1,963	73.47%	[71.79%, 75.14%]	$\chi^2(1) = 1.19, p = .28, \varphi = .02$
Caring for family members	54	12.30%	[9.23%, 15.37%]	129	4.83%	[4.02%, 5.64%]	$\chi^2(1) = 36.69, p < .001, \varphi = .11$
Vaccine hesitation	27	6.15%	[3.9%, 8.4%]	185	6.92%	[5.96%, 7.89%]	$\chi^2(1) = .24, p = .62, \varphi = .01$
Other reasons	51	11.62%	[8.62%, 14.61%]	356	13.32%	[12.03%, 14.61%]	$\chi^2(1) = .82, p = .36, \varphi = .02$

Note. CI = confidence interval; Pct = percentage.

children's behavioral problems ($p < .05$; see Supplemental Table 4).

Results of the multigroup analyses are presented in Table IV and Figure 1. Among families of children without special healthcare needs, higher levels of emotional social support were associated with significant decreases in caregivers' emotional distress during Follow-up 1 ($\beta = -.08$, $p < .05$), which was further linked to household children's reduced behavioral problems during Follow-up 2 ($\beta = .15$, $p < .001$). Other dimensions of social support and covariates (i.e., pre-pandemic poverty level, minority status, employment decrease, and caregivers' gender) were not significantly linked to well-being outcomes. The indirect effect of emotional social support on household children's behavioral problems via changes in caregivers' emotional stress among families of children without special healthcare needs was significant ($\beta = -.01$, $p < .05$). In contrast, among families of children with special healthcare needs, the associations between all dimensions of social support and follow-up caregivers' emotional distress, and between caregiver's emotional distress and follow-up household children's behavioral problems ($\beta = .17$, $p = .64$) were not significant. Instead, pre-pandemic poverty level ($\beta = -.24$, $p < .01$) was significantly related to caregivers' elevated emotional distress, and employment decrease was significantly linked to household children's elevated behavioral problems ($\beta = .31$, $p < .05$). Additionally, female caregivers experienced more emotional distress compared to male caregivers ($\beta = .17$, $p < .01$).

Chi-square equivalence testing further showed that the group differences in the path linking emotional social support and caregivers' emotional distress ($\Delta\chi^2(1) = 5.13$, $p < .05$), as well as in the path associating caregivers' emotional distress and children's behavioral problems ($\Delta\chi^2(1) = 4.49$, $p < .05$) were both significant. These findings partially supported the third hypothesis and suggested that emotional social support could significantly promote caregivers' better emotional well-being and further enhance children's optimal behavioral outcomes among households of children without special healthcare needs. However, among families of children with special healthcare needs, dimensions of social support were not sufficient in promoting children's better behavioral outcomes through reducing caregivers' emotional distress.

Discussion

Households of children with special healthcare needs have been substantially impacted by the COVID-19 pandemic. Comparisons between pre- and during-pandemic situations showed that caregivers in both groups experienced more emotional distress of

Table IV. *Multigroup Mediation Model on the Associations Among Social Support, Caregivers' Emotional Distress, and Children's Behavioral Problems (n = 821)*

Paths	Family of children with special healthcare needs (n = 103)			Family of children without special healthcare needs (n = 718)			Chi-square tests for group differences
	B (SE)	β	95% CI	B (SE)	β	95% CI	
Path a:							
SS—Emotional/Informational (W15) → Caregivers' Emotional Distress (FL1)	−.19 (.25)	−.09	[−.68, .30]	−.22 (.10)	−.08	[−.42, −.03]*	$\Delta\chi^2(1)$ = 5.13*
SS—Tangible (W15) → Caregivers' Emotional Distress (FL1)	.08 (.28)	.04	[−.47, .63]	.06 (.11)	.02	[−.17, .28]	—
SS—Affectionate (W15) → Caregivers' Emotional Distress (FL1)	.34 (.35)	.17	[−.36, 1.03]	−.11 (.13)	−.04	[−.36, .15]	—
SS—Positive Social Interaction (W15) → Caregivers' Emotional Distress (FL1)	−.40 (.30)	−.20	[−1.00, .19]	.01 (.11)	.00	[−.21, .22]	—
Path b:							
Caregivers' Emotional Distress (FL1) → Children's Total Problems (FL2)	.24 (.15)	.17	[−.05, .53]	.23 (.06)	.15	[.12, .36]***	$\Delta\chi^2(1)$ = 4.49*
Path c':							
SS—Emotional/Informational (W15) → Children's Total Problems (FL2)	−.41 (.44)	−.13	[−1.27, .45]	.04 (.21)	.01	[−.37, .44]	—
SS—Tangible (W15) → Children's Total Problems (FL2)	−.83 (.52)	−.26	[−1.85, .19]	−.14 (.24)	−.03	[−.61, .33]	—
SS—Affectionate (W15) → Children's Total Problems (FL2)	.72 (.64)	.24	[−.53, 1.97]	−.03 (.28)	−.01	[−.58, .52]	—
SS—Positive Social Interaction (W15) → Children's Total Problems (FL2)	.07 (.55)	.02	[−1.02, 1.15]	.03 (.23)	.01	[−.43, .49]	—
Indirect Effects:							
Path a × Path b (Emotional/Informational SS)	−.05 (.08)	−.02	[−.23, .08]	−.05 (.03)	−.01	[−.11, −.01]*	—
Path a × Path b (Tangible SS)	.02 (.08)	.01	[−.14, .20]	.01 (.03)	.00	[−.04, .07]	—
Path a × Path b (Affectionate SS)	.08 (.11)	.03	[−.10, .35]	−.03 (.03)	−.01	[−.09, .03]	—
Path a × Path b (Positive Social Interaction SS)	−.10 (.10)	−.03	[−.35, .06]	.00 (.03)	.00	[−.05, .06]	—
Control							
Caregivers' Emotional Distress (W15) → Caregivers' Emotional Distress (FL1)	.68 (.07)	.78	[.54, .82]***	.76 (.03)	.75	[.71, .82]***	—
Pre-Pandemic Poverty Level → Caregivers' Emotional Distress (FL1)	−.13 (.05)	−.24	[−.21, −.04]**	.00 (.02)	.00	[−.03, .04]	$\Delta\chi^2(1)$ = .18
Minority Status → Caregivers' Emotional Distress (FL1)	−.01 (.19)	−.01	[−.38, .36]	.09 (.06)	.04	[−.02, .20]	—
Employment Decrease in Pandemic → Caregivers' Emotional Distress (FL1)	−.57 (.30)	−.20	[−1.16, .02]	.02 (.16)	.01	[−.30, .34]	—
Caregiver Gender → Caregivers' Emotional Distress (FL1)	.85 (.31)	.17	[.24, 1.45]**	.14 (.12)	.03	[−.10, .37]	$\Delta\chi^2(1)$ = .37*
Children's Total Problems (FL1) → Children's Total Problems (FL2)	.02 (.00)	.44	[.01, .03]***	.03 (.00)	.50	[.02, .03]***	—
Pre-Pandemic Poverty Level → Children's Total Problems (FL2)	.06 (.55)	.08	[−.09, .21]	.01 (.04)	.01	[−.06, .09]	—
Minority Status → Children's Total Problems (FL2)	.12 (.37)	.04	[−.61, .85]	.00 (.12)	.00	[−.23, .24]	—
Employment Decrease in Pandemic → Children's Total Problems (FL2)	1.26 (.57)	.31	[.15, 2.38]*	.16 (.36)	.03	[−.55, .88]	$\Delta\chi^2(1)$ = 4.56*
Caregiver Gender → Children's Total Problems (FL2)	−.02 (.54)	.00	[−1.07, 1.04]	.30 (.24)	.04	[−.17, .78]	—

Note. SS = social support. W15 = Week 15. FL1 = Follow-up 1, assessed during each family's first response subsequent to Week 15. FL2 = Follow-up 2, assessed during each family's second response subsequent to Week 15. Pre-pandemic poverty level was obtained based on 2019 household income and size and coded as 1 = at or below 100% FPL, 2 = 100% − 200% FPL, and 3 = above 200% FPL. Minority status and Employment decrease in pandemic were both coded as 0/1 binary variables. Caregiver gender was coded as 1 = female and 0 = male. Model fit indices for the non-constrained multigroup model: $\chi^2(20)$ = 31.05, p = .05, CFI = .99, SRMR = .03. Indirect effects were tested using the RMediation package.
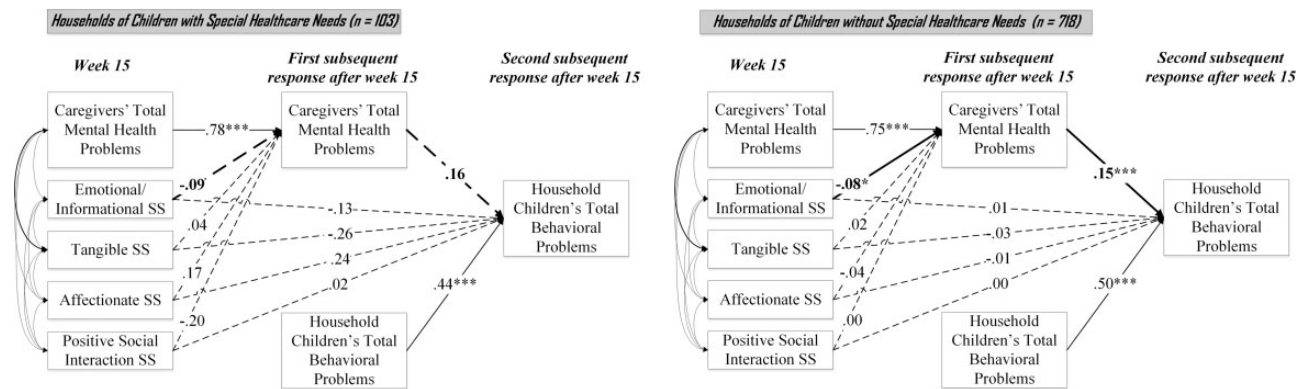
*p < .05, **p < .01, ***p < .001.

Figure 1. Multigroup mediation model on the associations among social support, caregivers' emotional distress, and household children's behavioral problems.

Note. SS = Social support. Both models controlled for families' pre-pandemic poverty level, caregivers' employment decrease, caregivers' gender, and minority status. Covariates are not included in the figure for clarify. Solid lines indicate significant associations; dashed lines indicate nonsignificant associations. Bolded thicker lines indicate paths where significant group differences were found. *$p < .05$, **$p < .01$, ***$p < .001$.

themselves and behavioral problems of their children during the pandemic. Group comparison indicated that in households of children with special healthcare needs, caregivers experienced more emotional distress, and children exhibited more behavioral problems, compared to families of children without special healthcare needs. Moreover, caregivers of children with special healthcare needs reported that children in their households missed more preventive healthcare visits and vaccinations due to structural barriers, despite their higher needs for additional healthcare services. Social support was traditionally viewed as a positive factor that promotes caregivers' and children's well-being outcomes (Cantwell et al., 2014; Chu et al., 2010). However, our mediation analyses found that only the emotional dimension of social support was related to children's decreased behavioral problems via caregivers' reduced emotional distress, and this indirect effect was only significant among households of children without special healthcare needs.

The COVID-19 pandemic exacerbated the severe emotional distress among caregivers of children with special healthcare needs. Many factors may contribute to the pandemic-related deleterious emotional distress among these caregivers. Before COVID-19, families of children with special healthcare needs have already been struggling with unemployment, financial strains, social isolation, and high levels of caregiving burden for caring for children with disabilities (DeRigne, 2012). The pandemic led to elevated unemployment rates, income loss, and declining economics, which further exacerbated these families' financial difficulties (Power, 2020; Prime et al., 2020). In addition, many in-home and community-based services for children with special healthcare needs were discontinued or shifted to remote delivery during the pandemic (Boyle et al., 2020; Navas et al., 2021). This led to considerably more daily stress and caregiving burden

because caregivers had to provide more care for children with special healthcare needs, including assisting with mobility, feeding, and other basic life skills (Provenzi et al., 2020). Efforts to control the spread of COVID-19, such as social distancing, quarantine, and isolation, also prevented caregivers from getting support from social networks that understood their complex and difficult situations. Overall, elevated economic difficulties, caregiving burden, and social isolation might all contribute to the increased emotional distress since the pandemic among caregivers of children with special healthcare needs.

In households of children with special healthcare needs, young children also exhibited more internalizing and externalizing symptoms during the pandemic. This finding was not surprising given that financial difficulties and caregiving stress, two strong predictors of children's well-being, were significantly amplified by the pandemic (Arakelyan et al., 2019). For children with special healthcare needs in these households, many of them lost support from early intervention services during the pandemic. Even with services shifted to remote delivery, some children's abilities to interact with service providers virtually were highly limited by their disability conditions and technology requirements (e.g., access to the Internet, computers, and smartphones; Boyle et al., 2020; Navas et al., 2021), so the quality of services that children received might be reduced. In these households, siblings of children with special healthcare needs also exhibited increased behavioral problems during the pandemic, which was consistent with previous literature and likely due to the elevated financial difficulties, caregivers' stress, and siblings' worsened well-being (Giallo et al., 2014).

In this study, we also found that only the emotional dimension of social support significantly reduced children's behavioral problems through attenuating

caregivers' emotional distress, and this effect only presented among households of children without special healthcare needs. Other dimensions of social support, such as instrumental support, affection, and positive social interactions, did not predict improvement in caregivers' emotional well-being. In contrast, among households of children with special healthcare needs, all dimensions of social support were not sufficient in promoting caregivers' and children's well-being outcomes. Instead, among these families, pre-pandemic poverty was significantly and positively linked to caregivers' emotional distress, and employment decrease was significantly and positively related to household children's behavioral problems. These findings suggested that financial difficulties among these households were particularly detrimental for the well-being outcomes of both caregivers and young children, and the negative consequences of financial difficulties could not be fully counter-balanced by the positive effects of social support. Other barriers such as the difficulty in accessing healthcare and intervention services and high caregiving burden might have more substantial and direct impacts on caregivers' and children's well-being in households of children with special healthcare needs during the COVID-19 pandemic.

Lastly, our finding indicated that, in households of children with special healthcare needs, young children (including the child[ren] with special healthcare needs and their siblings) had missed more preventive healthcare visits and scheduled vaccinations. Except for the concern over exposure to COVID-19, more structural barriers existed in households of children with special healthcare needs and kept children from attending these healthcare visits. These barriers included caregivers' lack of childcare, inability to get time away from work, and the need to take care of other family members. Without regular preventive healthcare visits and vaccinations, children with special healthcare needs, in particular, might miss critical early developmental screenings and experience an increased risk for contracting severe illnesses that they are particularly vulnerable to. Missing preventive healthcare visits also means less access to resources, such as therapies and intervention programs, which are designed to promote these children's optimal developmental outcomes. Moreover, when young children miss preventive healthcare visits, they might also miss diagnostic opportunities to be identified as having developmental difficulties. The lack of or late diagnosis of developmental difficulties or special healthcare needs will delay these children's access to appropriate early intervention services, leading them to miss critical windows for intervention. Overall, reduced access to healthcare services in households of young children with special healthcare needs may lead to severe and negative developmental outcomes, such as delays in achieving key childhood milestones.

Limitations

This study has several limitations. First, all the data used in analyses were based on caregivers' reports, which might cause reporting biases. Many survey questions were items selected from validated measurements or developed by the research team to reflect the special situations of the COVID-19 pandemic. Thus, the validity and reliability of these measurements have not been established. In addition, pre-pandemic variables (including caregivers' emotional distress, household children's behavioral problems, and social support) were obtained through caregivers' retrospective report at the same time when they reported during-pandemic situations. This could cause biases as caregivers might purposefully compare pre- and during-pandemic situations while answering related survey questions. Second, even though the research team made extensive efforts to recruit families from minority race/ethnic groups and low-income settings, the convenience sample limited the generalizability of study findings. Third, perceived social support and caregivers' emotional distress might vary by the type of caregiver and family structure, but this study did not have the capacity to examine these differences. Fourth, despite the longitudinal sampling design, the effect of social support on caregivers' and children's well-being was short-term and transient. More studies that examine the long-term effect of the COVID-19 pandemic on households of young children with special healthcare needs are still needed. Lastly, with the *households/families* of children with special healthcare needs as investigation units, we could not single out the experiences of children with special healthcare needs from other children (i.e., their siblings) in the same households. Thus, we could not conclude that children with special healthcare needs, in particular, exhibited more behavioral problems and missed more preventive healthcare visits during the pandemic. Despite these limitations, RAPID-EC is a rare dataset that included large, longitudinal, and national samples of households with young children. This study answered important questions about the experiences of families of children with special healthcare needs during the COVID-19 pandemic and has significant implications for policymakers and early intervention service providers.

Implications

The COVID-19 pandemic has caused extensive burdens on families of children with special healthcare needs that appear to be causing severe well-being issues and limiting their access to essential healthcare

services. Additional funding should to be provided to directly support the health, material, and emotional needs of these households. Increased resources can be used to provide more financial, socio-emotional, and mental health support to caregivers of children with special healthcare needs. This should include expanded home visits, special childcare support, mental health consultations, and prioritizing access to preschool and other early childhood intervention services when re-opening schools. Additionally, innovative strategies are needed to resolve technology barriers and increase families' access to early intervention and healthcare services. Lastly, the pediatric health system can play a role in addressing these issues by adopting flexible strategies for access that goes beyond conventional telehealth that has been employed, asking families' concerns and fostering trust, and offering additional services (e.g., on-site childcare) to help families overcome the structural barriers.

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Supplementary Data

Supplementary data can be found at: https://academic.oup.com/jpepsy.

Conflicts of Interest

The funders/sponsors had delegates who were members of the National Advisory Team for the research projects. No other conflicts of interest are declared.

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