

The impact of the COVID-19 pandemic on the mental health well-being among parents of children with disabilities and without disabilities

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ABSTRACT

The outbreak of COVID-19 pandemic had raised enormous threat in social, economy, health and environment globally. This study aims to identify the impact of COVID-19 pandemic on the mental health well-being among parents of children with disabilities and without disabilities. A cross-sectional study was employed, with a total of 150 parents. The tools used are Demographic Form, Depression, Anxiety and Stress Scale (DASS-21) and Perceived Stress Scale (PSS-10). Data analysis depicts that most of the parents have normal level of depression, anxiety and stress with value of 53.8%, 46.2%, 64.1% in parents of children with disabilities, and 72.2%, 58.3%, 84.7% for parents of children without disabilities. However, the parents show moderate level of perceived stress with value of 67.9% and 52.8% in parents of children with disabilities and without disabilities. The difference in mental health well-being (depression (Mean=4.92, 3.54, SD=4.10, 3.25), stress (Mean=6.63, 5.17, SD=4.09, 3.78) and perceived stress (Mean=17.40, 14.63, SD= 6.87, 5.44)) among both parents are significant ($p < 0.05$). While, the mean difference for parents of children with disability is the highest. There is significant correlation between depression with type of child's disability, between stress with gender and age, as well as between perceived stress symptoms with marital status and employment status. We can conclude that the mental health well-being of parents of children with disabilities are more affected compared to parents of children without disabilities during the COVID-19 pandemic. Furthermore, the type of child's disability (mental and physical), gender (female) employment status (working), marital status (married) and age (below 40 years old) are significant predictor to deterioration of mental health well-being among both parents. Implications offer research-based data for policymakers to create suitable and successful initiatives for parents of disabled children during COVID-19 pandemic.



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1. INTRODUCTION

In December 2019, the World Health Organization has discovered a new infectious respiratory disease in Wuhan, Hubei Province, China and named it as COVID-19 (Coronavirus Disease 2019). Investigation has discovered that SARS-CoV-2 (severe acute respiratory coronavirus syndrome 2) is a new type of coronavirus that responsible for the outbreak of this disease [9], [45], [20]. Even though COVID-19 is a relatively new coronavirus, it is suspected of causing diseases ranging from the flu virus toward more severe ailments [45]. These global outbreaks have resulted in morbidities, increasing number of deaths, and losses of billions of dollars [9]. As of today, the global COVID-19 pandemic has estimated 193,000,000 confirmed cases, as publicly announced by the governments of 195 countries around the world, with 4,140,000 deaths, which is predicted to increase as the pandemic grow. This virus is particularly infectious and can transmit through direct contact and respiratory droplets [45], [20]. With insufficient medical interventions sufficient to cure it, most countries have resorted to different types of non-pharmaceutical measures (NPIs), including lockdown [19], social distancing [23], school / university closures and non-essential businesses / workplaces, and others [19], [49]. However, these preventive initiatives have raised enormous health, environmental, economic, and social threats to the entire nation [9]. COVID-19 may have serious consequences for individual's mental health, in addition to its physical effects. A broad range of psychological effects were recorded during the Virus pandemic at the individual, societal, and worldwide levels [45]. Issues of mental wellbeing during pandemics are due to intense stress and outbreak-related anxiety, negative consequences of extended social distance, social alienation and quarantine, and loss of loved ones or caring for the ill [49], [47]. Shutdowns of school and childcare and limitations on social interactions affect young children's caregivers, which may lead to a reduction in mental health well-being in caregivers and children. They are struggling with increased demands for home education for their children while also seeking to fulfill their job requirements [11]. It gives a big impact especially for those in disadvantaged-income and congested families. Rising unemployment due to the pandemic lead to significant financial strain, debt, and job-seeking difficulties [27]. Nonetheless, when caregivers suffer psychological distress and are preoccupied with dealing to this pressure, the efficacy of their caregiving might deteriorate, particularly when a household has a disabled child [23]. Evidence has found that parents with children with disabilities face elevated parenting stress, deteriorating emotional wellness, work interruption, and decreased free time than parents with regular children [17], [18], [11].

In fact, parents' COVID-19 experiences are often linked to their child's mental impacts during confinement. As household coexistence under quarantine got more difficult, parents appeared to exhibit greater emotional difficulties in their child. Based on these finding, we may conclude that a stressful situation like confinement affects both parents and children [40]. When demand and parent stress increase and services decrease, children may also be more likely to be close to child abuse [11]. Therefore, it is necessary to recognize the influence of COVID-19 on the mental health well-being of the parent because an unprecedented event may affect both parents and children. It implies that it is extremely essential for clinicians to collaborate with caregivers to minimise distress to better improve results for families and children [23].

2. Material and Methods

This cross-sectional study involved 150 subjects. 78 were belonged to parents of children with disability who were selected from ten Community-Based Rehabilitation in Selangor and 72 were belonged to parents of children without disability who were selected among the staff in UiTM Puncak Alam, Selangor. This

study was approved by the Ethical Committee of the Faculty of Health Sciences, UiTM Puncak Alam and the Research Ethics Committee (REC) of UiTM Shah Alam (reference: 600-TNCPI (5/1/6) on 31st December 2020). The participation of the parents in this study is solely voluntary. The subjects were given the URL of the questionnaire containing the consent form, demographic form, Depression, Anxiety, and Stress Scale (DASS-21) form, and Perceived Stress Scale (PSS-10) form in English and Malay Version. Information regarding demographical backgrounds has eight variables that must be answered by the involved participants which are gender, age, marital status, educational background, employment status, household income, number of children, and the type of child disability. The DASS-21 and PSS-10 stress scales also were employed in this study to assess mental health well-being during the COVID-19 pandemic.

The DASS-21 is a self-report scale to screen for negative emotional states in three subcategories which are depression, anxiety, and stress [33]. It comprises of 7 items in each of the three DASS scales and the score is calculated using a four-point rating system. Respondents were required to rate how much of the items applied to them during the last week, scored from 0 (did not apply to me) to 3 (applied to me very much or most of the time). The final score of each domain needs to be multiplied by two. The normal depression domain scores vary from 0 to 9, whereas higher depression domain scores range from 10 to 28. The normal scores for the anxiety domain vary from 0 to 7, whereas pathological scores range from 8 to 20. The normal scores for the stress domain vary from 0 to 14, whereas the pathological values range from 15 to 34 [10]. A higher score indicates severe emotional distress. Next, the PSS-10 is an assessment that comprise of 10 items designed to evaluates the extent to which one regarded aspect of one's life as unpredictable, uncontrollable, and overloading. Participants were required to answer all questions using a 5-point rating scale varies from 0 (never) to 4 (very often), representing how often they have felt or thought about their life has been in the last month. The PSS-10 included six good items (items 1, 2, 3, 6, 9, and 10) and four negative items (items 4, 5, 7, and 8: Negative factor). The total scores varied from 0 to 40. The interpretation will be the higher the scores, the greater stress is perceived [44]. Both questionnaires have been validated and has good psychometric properties [10], [44].

2.1 Statistical analysis

The data was processed by using SPSS version 22.0 (SPSS-22) and the significance level was set at $p < 0.05$. All variables, including demographic data, DASS-21 items, and PSS-10 items, were subjected to descriptive analysis based on frequency and percent distribution. Next, the difference in mental health among parents of children with disabilities and without disabilities was analyzed by using independent t-test. Lastly, chi-square test was performed to identify the association between parents' mental health with demographic data (gender, age, marital status, educational background, employment status, household income, number of children, and the type of child disability).

3. Results

78 parents of children with disability and 72 parents of children without disability were participated in this study. Table 1 depicted the individual demographic background characteristics of the participants. Approximately 62% of the participants were female and 38% were male. Most parents ranged amongst 30 – 39 years old with value of 44 (56.4%) in the parents of children with disabilities and 30 (41.7%) in the parents of children without disabilities. Most of the parents also married with value of 141 (94%). A vast majority of the respondent were working 122 (81.3%) and 28 (18.7%) were not working. According to the responses, most of the parents achieved tertiary level of education with value of 129 (86%) and 21 (14%) achieved secondary level of education. Most family came from lower-middle monthly household income 84 (56%). Both parents of children with disabilities and without disabilities had mostly 2 children in their household with value of 31 (39.7%) and 19 (26.4%), respectively. In regard to parents of children with

disabilities, it mostly consisted of parents of children with autism spectrum disorder (ASD) with value of 46 (36.7%).

Table 1. Personal socio-demographic characteristics of study sample, n=150

Socio-demographic data	Parents of children with disability (n, %)	Parents of children without disability (n, %)
Type of Parents		
<i>Father</i>	(7, 9.0)	(14, 19.4)
<i>Mother</i>	(71, 91.0)	(58, 80.6)
Age Range		
<i>Below 20 years old</i>	(1, 1.3)	(0, 0)
<i>20-29 years old</i>	(9, 11.5)	(10, 13.9)
<i>30-39 years old</i>	(44, 56.4)	(30, 41.7)
<i>40-49 years old</i>	(16, 20.5)	(19, 26.4)
<i>Above 50 years old</i>	(8, 10.3)	(13, 18.1)
Marital Status		
<i>Married</i>	(73, 93.6)	(68, 94.4)
<i>Divorced</i>	(2, 2.6)	(1, 1.4)
<i>Single parent</i>	(3, 3.8)	(3, 4.2)
Level of Education		
<i>Lower secondary</i>	(3, 3.8)	(1, 1.4)
<i>Upper secondary</i>	(7, 9.0)	(10, 13.9)
<i>Certificate/Diploma</i>	(21, 26.9)	(27, 37.5)
<i>Degree</i>	(41, 52.6)	(26, 36.1)
<i>Masters/PhD</i>	(6, 7.7)	(8, 11.1)
Employment Status		
<i>Working</i>	(50, 64.1)	(72, 100)
<i>Not working</i>	(28, 35.9)	(0, 0)
Monthly income		
<i>Below RM 2,000</i>	(14, 17.9)	(9, 12.5)
<i>RM 2,000 – RM 4,999</i>	(33, 42.3)	(28, 38.9)
<i>RM 5,000 – RM 10,000</i>	(18, 23.1)	(28, 38.9)
<i>Above RM 10,000</i>	(13, 16.7)	(7, 9.7)
Number of Children		
1	(16, 20.5)	(16, 22.2)
2	(31, 39.7)	(19, 26.4)
3	(17, 21.8)	(18, 25.0)
4	(9, 11.5)	(15, 20.8)

5	(4, 5.1)	(2, 2.8)
6	(0, 0)	(2, 2.8)
7	(1, 1.3)	(0, 0)
Type of Children's Disability		
<i>Autism Spectrum Disorder (ASD)</i>	(46, 30.7)	
<i>Down Syndrome</i>	(8, 5.3)	
<i>ADHD</i>	(4, 2.7)	
<i>Global Developmental Delay (GDD)</i>	(1, 0.7)	
<i>Cerebral Palsy</i>	(6, 4.0)	
<i>Other</i>	(13, 8.7)	

Table 2 depicted that most of the parents have normal level of depression, anxiety and stress with value of 53.8%, 46.2%, 64.1% in parents of children with disabilities, while the value for parents of children without disabilities are 72.2%, 58.3%, 84.7% respectively. However, the parents show moderate level of perceived stress with value of 67.9% and 52.8% in parents of children with disabilities and without disabilities. In contrary, the mean score highlights that depression, anxiety, stress and perceived stress are above average with value of 3.41, 3.29, 3.62 and 2.59 in parents of children with disabilities, while in parents of children without disabilities, the mean scores are 3.57, 3.29, 3.92 and 2.50.

Table 2. Frequency distribution of mental health well-being among parents of children with disabilities and without disabilities

	Parents of children with disability (n, %)	Mean (SD)	Parents of children without disability (n, %)	Mean (SD)
Depression		3.41 (0.918)		3.57 (0.836)
<i>Normal</i>	42 (53.8)		52 (72.2)	
<i>Mild</i>	8 (10.3)		9 (12.5)	
<i>Moderate</i>	21 (26.9)		8 (11.1)	
<i>Severe</i>	3 (3.8)		1 (1.4)	
<i>Extremely severe</i>	4 (5.1)		2 (2.8)	
Anxiety		3.29 (1.163)		3.29 (1.027)
<i>Normal</i>	36 (46.2)		42 (58.3)	
<i>Mild</i>	15 (19.2)		11 (15.3)	
<i>Moderate</i>	12 (15.4)		12 (16.7)	
<i>Severe</i>	8 (10.3)		1 (1.4)	
<i>Extremely severe</i>	7 (9.0)		6 (8.3)	
Stress		3.62 (0.841)		3.92 (0.622)
<i>Normal</i>	50 (64.1)		61 (84.7)	
<i>Mild</i>	10 (12.8)		3 (4.2)	

<i>Moderate</i>	12 (15.4)		2 (2.8)	
<i>Severe</i>	5 (6.4)		5 (6.9)	
<i>Extremely severe</i>	1 (1.3)		1 (1.4)	
PSS		2.59 (0.653)		2.50 (0.557)
<i>Low</i>	18 (23.1)		32 (44.4)	
<i>Moderate</i>	53 (67.9)		38 (52.8)	
<i>High</i>	7 (9.0)		2 (2.8)	

Based on Table 3, it showed that the P-value more than 0.05 for anxiety. Thus, the mean difference in mental health well-being (anxiety) among parents of children with disabilities and without disabilities are not statistically significant with value of (p=0.202, 95% CI -0.41, 1.92). Nevertheless, the mean difference in mental health well-being (depression, stress and perceived stress) among both parents are statistically significant with value of (p=0.023, 95% CI 0.19, 2.57) for depression, (p=0.025, 95% CI 0.19, 2.74) for stress, and (p=0.007, 95% CI 0.76, 4.78) for perceived stress.

Table 3. Mean difference in mental health well-being (depression) among parents of children with disabilities and without disabilities

	Parents of Children with Disability	Parents of Children without Disability
Depression		
Mean (SD)	4.92 (4.10)	3.54 (3.25)
P-value	0.023	
Anxiety		
Mean (SD)	4.53 (3.68)	3.94 (3.28)
P-value	0.202	
Stress		
Mean (SD)	6.63 (4.09)	5.17 (3.78)
P-value	0.025	
Perceived Stress		
Mean (SD)	17.40 (6.87)	14.63 (5.44)
P-value	0.007	

*P<0.05 indicates a statistically significant difference among the groups

Table 4 – Table 7 showed that there is a significant association between depression with type of child’s disability (X² (5.571, p=0.018), association between stress with gender (X² (5.725, p=0.017) and age (X² (4.578, p=0.032), as well as association between perceived stress with marital status (X² (4.467, p=0.035) and employment status (X² (4.191, p=0.041). In contrary, there is no significant association between anxiety with parent’s demographic data (p>0.05).

Table 4. Association between Depression with Parent’s Demographic Data

	Depression n (%)	Normal n (%)	X² statistic	P-value
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Gender				
Male	5 (23.8)	16 (76.2)	1.909	0.167
Female	51 (39.5)	78 (60.5)		
Age				
Below 40 y/o	40 (42.6)	54 (57.4)	2.932	0.087
Above 40 y/o	16 (28.6)	40 (71.4)		
Marital status				
Married	50 (35.5)	91 (64.5)	3.521	0.061
Other	6 (66.7)	3 (33.3)		
Level of Education				
Lower level	7 (33.3)	14 (66.7)	0.167	0.683
Upper level	49 (38.0)	80 (62.0)		
Employment status				
Working	42 (34.4)	80 (65.6)	2.361	0.124
Not working	14 (50.0)	14 (50.0)		
Monthly salary				
Lower middle	35 (41.7)	49 (58.3)	1.532	0.216
Upper middle	21 (31.8)	45 (68.2)		
Number of children				
Below 5	52 (36.9)	89 (63.1)	0.207	0.649
Above 5	4 (44.4)	5 (55.6)		
Type of children's disability				
Mental and Physical Disability	36 (50.0)	36 (50.0)	5.571	0.018
Others	0 (0.0)	6 (100.0)		

Table 5. Association between Anxiety with Parent's Demographic Data

	Anxiety n (%)	Normal n (%)	X² statistic	P-value
Gender				
Male	8 (38.1)	13 (61.9)	0.96 0	0.327
Female	64 (49.6)	65 (50.4)		
Age				
Below 40 y/o	48 (51.1)	46 (48.9)	0.94 7	0.331
Above 40 y/o	24 (42.9)	32 (57.1)		
Marital status				
Married	65 (46.1)	76 (53.9)	3.40 1	0.065
Other	7 (77.8)	2 (22.2)		

Level of Education				
Lower level	7 (33.3)	14 (66.7)	2.10 4	0.147
Upper level	65 (50.4)	64 (49.6)		
Employment status				
Working	58 (47.5)	64 (52.5)	0.05 5	0.814
Not working	14 (50.0)	14 (50.0)		
Monthly salary				
Lower middle	40 (47.6)	44 (52.4)	0.01 1	0.916
Upper middle	32 (48.5)	34 (51.5)		
Number of children				
Below 5	67 (47.5)	74 (52.5)	0.21 9	0.640
Above 5	5 (55.6)	4 (44.4)		
Type of children's disability				
Mental and Physical Disability	41 (56.9)	31 (43.1)	3.615	0.057
Others	1 (16.7)	5 (83.3)		

Table 6. Association between Stress with Parent's Demographic Data

	Stress n (%)	Normal n (%)	X² statistic	P-value
Gender				
Male	1 (4.8)	20 (95.2)	5.725	0.017
Female	38 (29.5)	91 (70.5)		
Age				
Below 40 y/o	30 (31.9)	64 (68.1)	4.578	0.032
Above 40 y/o	9 (16.1)	47 (83.9)		
Marital status				
Married	35 (24.8)	106 (75.2)	1.693	0.193
Other	4 (44.4)	5 (55.6)		
Level of Education				
Lower level	3 (14.3)	18 (85.7)	1.742	0.187
Upper level	36 (27.9)	93 (72.1)		
Employment status				
Working	28 (23.0)	94 (77.0)	3.158	0.076
Not working	11 (39.3)	17 (60.7)		

Monthly salary				
Lower middle	23 (27.4)	61 (72.6)	0.189	0.664
Upper middle	16 (24.2)	50 (75.8)		
Number of children				
Below 5	36 (25.5)	105 (74.5)	0.268	0.605
Above 5	3 (33.3)	6 (66.7)		
Type of children's disability				
Mental and Physical Disability	28 (38.9)	44 (61.1)	3.640	0.056
Others	0 (0.0)	6 (100.0)		

Table 7. Association between Perceived Stress with Parent's Demographic Data

	High perceived stress n (%)	Low perceived stress n (%)	X² statistic	P-value
Gender				
Male	1 (4.8)	20 (95.2)	0.066	0.797
Female	8 (6.2)	121 (93.8)		
Age				
Below 40 y/o	8 (8.5)	86 (91.5)	2.814	0.093
Above 40 y/o	1 (1.8)	55 (98.2)		
Marital status				
Married	7 (5.0)	134 (95.0)	4.467	0.035
Other	2 (22.2)	7 (77.8)		
Level of Education				
Lower level	1 (4.8)	20 (95.2)	0.066	0.797
Upper level	8 (6.2)	121 (93.8)		
Employment status				
Working	5 (4.1)	117 (95.9)	4.191	0.041
Not working	4 (14.3)	24 (85.7)		
Monthly salary				
Lower middle	4 (4.8)	80 (95.2)	0.519	0.471
Upper middle	5 (7.6)	61 (92.4)		
Number of children				

Below 5	9 (6.4)	132 (93.6)	0.611	0.434
Above 5	0 (0.0)	9 (100.0)		
Type of children's disability				
Mental and Physical Disability	7 (9.7)	65 (90.3)	0.641	0.423
Others	0 (0.0)	6 (100.0)		

4. Discussion

This cross-sectional study found that parents of children with disabilities and without disabilities had normal level of depression, anxiety and stress which are similar to the findings by [29], [30] stating that parents of children with ASD has better mental health outcomes as they adopted adaptive coping techniques when confronted with caregiving burden. It reported that parents of ASD children effectively utilized adaptive and maladaptive coping mechanisms, with an inclination for adaptive coping mechanisms. It was also assumed that both parents had a normal level of mental health well-being because majority of them came from middle- income families. Several studies have found that families in low-income households had worse caregiver mental health than families in middle-income homes, possibly because to the more severe effects of limited financial resources in low-income families [43], [52], [34]. Another finding shows that the mean score of the level of depression and stress among parents of normal children is higher than parents of disabled children as most of them must work from home. Juggling continued employment duties with extra family obligations and homeschooled has created substantial difficulties for parents who were eligible to work (i.e. essential employees) and parents who work from home. Meanwhile, parents who have lost their employment must handle childcare and homeschooling responsibilities while addressing additional financial issues and economic pressures connected to their incapacity to work and/or job loss. All these problems have alleviated psychological distress of the parents [15], [3].

Next, findings demonstrates that parents of disabled children show high level of depression, stress and perceived stress compared to parents of normal children which corresponding to the studies by [21], [41], [5] who reporting that parents of disabled children face more stress and a greater variety of parenting challenges, such as more health problems, emotions of constraint, and higher levels of parental depression than parents of non - disabled children They also have more caregiving responsibilities compared to parents of normal children which increase psychological disorder, raising concerns about the effects of work–family conflict on caregiver well-being [36], [37]. The progressive devoting of so much time to parenting and caring has driven parents to the edge of breakdowns [50]. Moreover, this study found that the level of anxiety does not depicts any significant difference among both parents. According to [1], there is no strong relationship between the child's type of impairment and their parents' state anxiety or trait anxiety. Even though, the parents of disabled children showed greater levels of trait anxiety, but they utilised the problem-solving technique to deal with it [30]. The findings also show the association between depression with type of child disability (mental and physical disabilities). This result is corroborated by [12], who observed that parents of children with developmental delay, autism [2], [42], and intellectual disability [46] not only suffer greater levels of stress than families with typical development, but their mental health in general may be affected as well. Previous research indicates that the risk of depression is increased if the child has co-morbid impairments that show as a combination of physical and cognitive deficits [46]. Meeting the high care needs of afflicted children takes a lot of time, commitment, and tolerance. Their limited opportunities to rest, having entertainment, or take a bit of time alone themselves result in exhaustion, burnout, and

unhappiness [42], [12]. In terms of gender, gender (female) is significantly associated with stress. According to [13], [6], women are progressing worse than males in the pandemic. Mothers who regularly assume the position of primary caregiver may sacrifice their own well-being to satisfy the needs of their children [26]. Due to school closures, learning materials have been supplied remotely, and it is anticipated that moms have taken on the responsibility of ensuring teaching takes place at home [4] as cited in [48]. High levels of caregiver load and emotional distress may make it difficult to balance multiple care obligations.

Furthermore, this study also depicts the association between stress with parents' age (below 40 years old). It might be anticipated that the transition to parenting is challenging, especially for working parents who must manage their children's demanding requirements with job obligations, all while coping with normal variations in psychological adjustment [24]. As the parenting role takes precedence, parents frequently disregard their own demands on behalf of the children, that can have negative consequences for the partners' well-being [32]. In addition, current finding also shows that married couple perceived stress during this pandemic. Although studies by [28], [31], [39] found that married people are happier and have less stressful situations as they have someone around to help provide a means of socializing, another study by [27] proved the other way by saying that being in a romantic relationship involves a variety of disadvantages, including the spread of negative emotions. When couples face challenges, such as financial issues or a lack of support from their spouse, they may suffer a significant drop in marital satisfaction, which can contribute to an increase in stress levels.

Even though numerous studies have indicated that parents who have a disabled child are more stressed and anxious than parents who do not have any disabled children, the current study found the opposite [7], [16], [14], [35]. This is consistent with earlier study, which found that parents manage their anxiety by utilising problem solving as a coping mechanism [30], [1]. Furthermore, a significant association was discovered in the study between community acceptance of the disabled child and parents' state-trait anxiety levels. Parents whose disabled child had been embraced by the community reported less anxiety [1]. It was anticipated that majority of the children with disabilities who participated in the current study attend community-based rehabilitation (CBR), thus their acceptance by the community reduced parents' anxiety. The limitation of this study is the sample size in this study are small. As a result, there was a greater likelihood of accepting a misleading premise as genuine, which hampered appropriate support claims of having reached legitimate conclusions.

5. Conclusion

Overall, this study found that parents of children with disability has higher level of depression, stress and perceived stress due to Covid-19 Pandemic. There were several factors influencing mental health well-being including type of child disability, gender, age, marital status, and employment status. Thus, the study concluded that the mental health well-being among parents of children with disabilities were significantly affected compared to parents of children without disabilities during the Covid-19 pandemic.

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