



Factors Contributing to Psychological Ill-Effects and Resilience of Caregivers of Children with Developmental Disabilities During a Nation-wide Lockdown During the COVID-19 Pandemic

Tammy S. H. Lim^{1,2} · Mae Yue Tan^{1,2} · Ramkumar Aishworiya^{1,2} · Ying Qi Kang^{1,2} · Magdalena Yvonne Koh^{1,2} · Liang Shen³ · Shang Chee Chong^{1,2}

Accepted: 28 June 2021 / Published online: 8 July 2021

© The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature 2021

Abstract

We evaluated factors affecting psychological ill-effects and resilience of caregivers of children with developmental disabilities during the coronavirus pandemic. Depression, Anxiety, and Stress Scales (DASS-21) and Connor-Davidson Resilience Scale 25-item were administered. Logistic regression was used to identify factors associated with psychological ill-effects and resilience. DASS-21 depression, anxiety and stress scores were high; these were associated with difficulties with infection control measures, autism diagnosis, and need for early intervention services. For caregivers of children with ASD, our DASS-21 scores were significantly higher than non-pandemic scores locally and in other Asian sites. Resilience scores correlated inversely with DASS-21 scores. Targeted support to selected at-risk caregivers and improving resilience can help their coping.

Keywords COVID-19 · Caregivers · Developmental disability · Depression · Resilience · Anxiety

Introduction

The ongoing Coronavirus 2019 (COVID-19) pandemic has been unprecedented in its scale and duration of impact thus far. It has revealed gaps in societies and countries, disproportionately affecting the most vulnerable. Children and youth, and those with disabilities have been identified by the United Nations as at risk of experiencing the highest degree of socio-economic marginalization and requiring specific attention during this pandemic (Sanders, 2020). While infection and mortality rates in children are low (Idele et al., 2020), children have been affected in numerous ways, through school closures, social isolation, disrupted health delivery, negative impacts on their mental health and well-being and increased

exposure to home disputes (United Nations Educational Scientific and Cultural Organization (UNESCO) 2020).

For most children globally, the traditional school-based learning was temporarily halted when countries went into lockdown. Singapore, as well, had a period of school closure, lasting nearly 2 months during a period termed as the ‘Circuit Breaker’ (CB). This included cessation of all “non-essential services”, including suspension of therapy services and closure of early intervention centres. This was replaced by Home-based learning (HBL), which was conducted virtually with the children staying at home.

At baseline and prior to the pandemic, caregivers of children with developmental disabilities (DD) are already known to have higher levels of stress compared to typically developing (TD) children and children with chronic medical illnesses (Rivard et al., 2014). This includes higher levels of anxiety, depression and also health problems, especially among DD like autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) (Hayes & Watson, 2013). A study in Singapore by (Lai et al., 2015) reported parents of children with ASD to have more symptoms of parenting stress as well as depression compared to parents of TD children. Of note, children with conditions such as ASD and ADHD may have significant behavioral challenges and difficulties adapting to changes in daily

✉ Mae Yue Tan
mae_yue_tan@nuhs.edu.sg

¹ Child Development Unit, Khoo Teck Puat-National University Children’s Medical Institute, National University Health System, Singapore, Singapore

² Department of Paediatrics, Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore

³ Biostatistics Unit, Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore

routine during HBL. Others with learning difficulties are especially vulnerable to school closure as they lose in-class support while attempting HBL independently or with their caregiver's help.

A recent systemic review and meta-analysis (Salari et al., 2020) showed that the psychological health in the general population across the world has been affected negatively during the COVID-19 pandemic, with increased prevalence of depression, anxiety and stress. The analysis included studies with various validated tools; the Depression, Anxiety, and Stress Scales (DASS-21) in at least five studies in this review allowed comprehensive evaluation of the three areas of stress, anxiety and depression through a random effects model, deriving a prevalence of 29.6%, 31.9% and 33.7% for stress, anxiety and depression, respectively. While there has been some literature about the mental and emotional health of parents in general (Russell et al., 2020), there has been limited information specific to caregivers of children with DD. This group of caregivers are at heightened susceptibility to psychological ill-effects due to reasons stated above. Preliminary data from Italy during the COVID-19 pandemic suggests that parents of children with mental or physical illness are more likely to feel more burnout, and also tend to feel less supported, than parents of well children (Fontanesi et al., 2020). Unchecked emotional health issues of caregivers can compromise their abilities to give care and form nurturing relationships with their children. Caregiver depression is associated with worse socioemotional and learning outcomes in children (Barrero-Castillero et al., 2019). In addition, children with DD are particularly vulnerable to abuse and neglect when adults are not able to cope well emotionally (Griffith, 2020). When the protective factor of a responsive caregiver-child relationship is diminished, children (especially those with DD) become even more vulnerable to the trauma of this pandemic (Yoshikawa et al., 2020). The pandemic hence has potential to amplify adverse childhood events and compound intra-familial adversity if the mental health and well-being of caregivers are neglected (Bryant et al., 2020).

This study aims to examine the psychological impact in caregivers of children with DD during this pandemic, particularly the rates of depression, stress and anxiety symptoms. In line with this, we wanted to explore if there were particular demographic factors, child factors (e.g. diagnosis, requiring therapy, amount of HBL received, compliance with infection control measures, etc.), and caregiver factors (e.g. concerns, perceptions and protective factors such as resilience), which may be associated with psychological ill-effects in caregivers. Our secondary aim was to evaluate if any of these factors may also contribute to resilience. This would facilitate identification of specific strategies to

provide guidance for policies and supports for families with DD.

Methods

Study Design and Sample

This was a cross-sectional anonymous questionnaire-based study, administered via a secure online platform over 6 weeks, from mid-May 2020 to the end of June 2020. This period was during and just after the CB in Singapore, which occurred from April to June 2020.

Study inclusion criteria were participants who were the main caregivers of a child between the ages of 0 and 18 years, with 1 or more of the following conditions: ASD, global developmental delay (GDD), intellectual disability (ID), language delay, cerebral palsy, visual or hearing impairment, ADHD, learning disability (e.g. dyslexia) and, could comprehend and respond to questions in the English language.

Potential participants were recruited through the Child Development Unit at the National University Hospital Singapore (one of the two nationally designated tertiary providers of Developmental and Behavioral Pediatrics services in the country), through community early intervention centres and special education (SPED) schools across Singapore. A snowball sampling method was adopted where electronic digital mailers containing information about the study were sent to eligible caregivers through relevant organizations. Study information was also available on the hospital's social media platforms, such as Facebook and Instagram. Participants were allowed to share the study link with other caregivers.

Study Measures

The study questionnaire included questions on caregiver and child demographics, family socioeconomic status (SES), caregiver's perceptions of experiences and concerns during the pandemic, and on the support systems they had. For each concern, caregivers were also asked to rate the severity of their concerns on a Likert scale of 1 to 5.

In addition, respondents completed the Depression, Anxiety, and Stress Scales (DASS-21) (Lovibond & Lovibond, 1995) and Connor-Davidson Resilience Scale 25-item (CD-RISC 25) (Connor & Davidson, 2003).

The DASS-21 is a well-established instrument that has been validated to measure symptoms in the subscales of depression (DASS-D), anxiety (DASS-A) and stress (DASS-S) in adults, providing independent measures as well as recommended severity thresholds (Antony et al., 1998). Cut-off scores above 9, 7 and 14, respectively, indicate a positive screen for

depression, anxiety and stress. Levels of each are further classified into mild, moderate, severe and extremely severe. The DASS-21 has demonstrated sound psychometric properties in clinical research and has been validated for use in Asia (Oei et al., 2013). It has been used locally in previous studies to look at psychological well-being of caregivers of children with autism, and was found to have good internal consistency and cultural adaptability (Lai et al., 2015). This provided us with a baseline for comparison of scores to pre-pandemic times. The scale has also been used to look at the mental health status of the general population during the COVID-19 pandemic in Asia (Wang et al., 2020), and similarly would provide a reference for us when comparing prevalence of stress, anxiety and depression across other Asian studies (Salari et al., 2020). In this study, good internal reliability on all 3 subscales of the DASS-21 was obtained: Cronbach's alpha was 0.92, 0.81 and 0.89 for DASS-D, DASS-A, and DASS-S, respectively.

The CD-RISC 25-item scale (English version) is a validated scale widely used to measure resilience in various populations. It gives a score ranging from 0 to 100, with higher scores reflecting greater resilience (Connor & Davidson, 2003). It has been used widely in looking at psychological resilience in various populations during COVID-19 pandemic (Killgore et al., 2020), and previous studies in Singapore had adopted it to measure resilience in caregivers of the elderly with good internal reliability (Ong et al., 2018).

Ethics approval was obtained from the National Healthcare Group Domain Specific Review Board, Singapore prior to the commencement of this study. This was an anonymised survey and explanation of the study aims was provided, with implied consent for all who returned the survey results.

Analysis

Data was analyzed using the IBM Statistical Package for the Social Sciences software version 26. Descriptive analysis was performed. To determine the factors associated with caregiver's depression, anxiety and stress incidence on the DASS, all potential risk factors were screened by univariate analysis. Chi-square test was used for categorical factors, while two sample *T* test or Mann–Whitney *U* test, whichever was more appropriate, was used for numerical factors. Variables with *p* value less than 0.1 were selected. Logistic regression with backward model selection was used to determine the final risk factors associated with depression, anxiety and stress incidence of caregivers. Generalized linear model with backwards model selection was used to determine factors associated with caregiver's resilience.

Results

Demographics of Caregivers and Children

A total of 120 caregivers completed the survey, of which the data from 107 caregivers was complete and included for analysis. Thirteen caregivers were excluded from analysis as the diagnosis or age of their children did not meet the inclusion criteria.

Table 1 shows the demographic characteristics of caregivers. The majority (80.4%) of respondents were female, with a mean age of 40.5 years (SD 6.0). Approximately half (52.3%), had a tertiary education (degree and above). Most (96.3%) lived in government-subsidized apartments (also known as Housing and Development Board, HDB, flats). This is representative of the average individual in the country where 80.0% of residents live in subsidized housing (Department of Statistics Singapore, 2019). Most (91.6%) were married and more than half were employed (57.9%). Sixty-nine percent did not have other caregivers at home to help with the care of their children. The mean number of people in the household was 4.7 (SD 1.4). Some households had more than one child with DD; the mean was 1.2 (SD 0.5).

The mean age of the children with disability in this cohort was 7.6 years (SD 4.1). Just over half (57.0%) had a diagnosis of ASD. About two-thirds (67.3%) were receiving regular therapy. About 28.0% of these children were in special education (SPED) schools, which are designed exclusively for children with moderate to severe DD in Singapore. SPED schools adopt a curriculum with emphasis on basic literacy, vocational and daily living skills. Majority (86.0%) had HBL during the CB, with a mean of 4.3 (SD 1.5) days per week of HBL; about a third (31.5%) had 3 or more hours a day of HBL.

Major Concerns of Caregivers

About 79.4% of caregivers were concerned that their child would regress or stagnate developmentally with a mean severity score of 4.0 out of 5 (SD 0.9) (Table 2). Two-thirds, 61.7% were concerned that their child could not cope with the HBL with a mean severity rating score of 4.2 (SD 0.8).

When asked to rate on a 5-point scale, caregivers felt that guidance received from teachers and therapists during HBL was average in effectiveness, with a mean Likert score of 3.4 (SD 1.0). Sixty-five percent of the parents in this study did not receive any additional support (including financial or emotional) during school closure, and 71.0% reported that no healthcare professional (e.g. from

Table 1 Demographics of caregivers and their child/children with developmental disability (DD)

Characteristic	n	%
Caregivers (n = 107)		
Female	86	80.4
Male	21	19.6
Highest education qualification		
Primary	1	0.9
Secondary	13	12.1
Polytechnic/Institute of technical education	33	30.8
Junior college	1	0.9
Diploma	3	2.8
Degree/Post graduate and above	56	52.3
Housing		
HDB 1- or 2- room	0	0
HDB 3-room	2	1.9
HDB 4-room	103	96.3
HDB 5-room/executive	0	0
Condominium/other apartments	2	1.9
Landed property	0	0
Monthly household income		
Below \$2000	17	15.9
\$2000–\$4999	27	25.2
\$5000–\$8999	25	23.4
\$9000–\$12,999	19	17.8
\$13,000 and above	19	17.8
Married	98	91.6
Employed	62	57.9
Domestic helper	36	33.6
Number of child with DD in household	1.2 (mean)	0.5 (SD)
Child/children with DD (n = 107)		
Age in years (mean, SD)	7.6	4.1
Diagnosis		
Autism spectrum disorder	61	57.0
Global developmental delay/Intellectual disability	24	22.4
Others ^a	22	20.6
Receiving therapy	72	67.3
Schooling		
Mainstream	58	54.2
Special education school	30	28.0
Not in school	19	17.8
Received home-based learning	92	86.0

^aOthers: cerebral palsy (n=5), speech delay (n=5), sensory impairment (n=6), attention deficit hyperactivity disorder (n=3), dyslexia (n=3)

hospitals or community or therapy centres) contacted them to offer support during the pandemic, even though most children were enrolled in school (82.2%) and were receiving therapy (67.3%) prior to the COVID-19 pandemic.

About half of the respondents were concerned that their child would be unable to comply with movement restriction measures and with infection control precautions (hand hygiene, mask wearing); at least a third of these felt these were major concerns.

A significant proportion (73.5%) said they felt stressed currently, with 68.2% feeling that their stress levels were higher compared to before the COVID-19 pandemic. Seventy percent (69.2%) were worried about financial stability as well.

Depression, Stress and Anxiety on the DASS-21

On the DASS-21, 52.3% of respondents had a positive screen for depression, 52.3% for anxiety, and 41.1% screened positive for stress (Table 3). Of those who screened positive for any of these sub-groups, 70.4 to 75.0% were rated in the moderate or more severe category. The most significant self-rated contributors to stress were ‘school closing and having to manage my child at home for the full day’, and ‘closure of therapy/intervention services makes me worried about disrupting therapy’.

Mean Derived Scores on the DASS-21 Compared to Non-Pandemic Times

Table 4 shows the total and mean subscale scores of depression, anxiety and stress of caregivers of all children with DD on the DASS-21 and a subset with ASD. Both were significantly higher ($p < 0.0005$) when compared to what was reported for the DASS scores in Singaporean caregivers of children with ASD during non-pandemic times. The table also referenced 2 other recent studies among Asian sites of DASS-21 scores in caregivers of children with autism during non-pandemic times and similarly, subscale scores were significantly different (Lai et al., 2015; Chan et al., 2020; Selvakumar & Panicker, 2020).

Contributors to Psychological Ill-Effects

Results of the regression analysis are as shown in Table 5.

For the DASS-D subscale, feeling stressed currently (OR = 7.8, 95% CI 2.2–27.4, $p = 0.001$), and being concerned about practising additional infection control precautions (OR = 2.5, 95% CI 0.9–6.5, $p = 0.071$), were significant predictors of having a positive DASS-D screen. The higher the caregiver’s CD-RISC-25 score, the less likely he/she would have a positive DASS-D screen (OR = 0.93, 95% CI 0.90–0.97, $p < 0.001$).

For the DASS-A subscale, factors associated with a positive DASS-A screen were: having a child with difficulty staying indoors (OR = 3.9, 95% CI 1.5–10.4, $p = 0.006$), a diagnosis of ASD (OR = 2.6, 95% CI 1.0–6.7, $p = 0.054$),

Table 2 Caregiver's perceptions of changes experienced and concerns during the pandemic, and on the support systems available

	N	%
Changes and concerns for self		
Are you worried about your financial stability?		
Yes	74	69.2
Do you feel that your house is more crowded than you would like for your family?		
Yes	19	17.8
How easy is it to stay largely indoors during this circuit breaker period?		
Difficult and very difficult	46	43.0
Do you feel stressed currently?		
Yes	79	73.8
Do you feel more stressed lately, compared to your normal stress levels (prior to COVID-19)?		
Yes	73	68.2
Changes and concerns for child/children with developmental disability		
Are you concerned that your child will get worse or stagnate for his/her underlying condition without the usual intervention and programs?		
Yes	85	79.4
Are you concerned that he/she cannot cope with the home-based learning curriculum?		
Yes	66	61.7
How sufficient is the guidance from teachers and therapists in helping your child with developmental needs/special educational needs during HBL?		
Very poor/poor	12	13.0
Average	46	39.1
Good/excellent	54	47.8
Are you concerned that your child will have difficulty staying at home all the time?		
Yes	51	47.7
Are you concerned that your child cannot practise the additional precautions for hand hygiene or mask wearing?		
Yes	54	50.5
Support		
Has anyone (outside of family and friends) contacted you to support you in any way (e.g. financial, emotional support) during this pandemic?		
No	69	64.5
Has any healthcare professional (doctor, nurse, therapist from a hospital/medical clinic/therapy or intervention centre) contacted you to offer support during this pandemic?		
No	76	71.0

Table 3 Prevalence of depression, anxiety and stress on the DASS-21 (n = 107)

	Depression	Anxiety	Stress
Positive screen, n (%)	56 (52.3)	56 (52.3)	44 (41.1)
Among those who screened positive			
Mild, n (%)	17 (30.4)	14 (25.0)	10 (22.7)
Moderate, n (%)	22 (39.3)	26 (46.4)	17 (38.6)
Severe, n (%)	10 (17.9)	7 (12.5)	13 (29.5)
Extremely Severe, n (%)	7 (12.5)	9 (16.1)	4 (9.1)

and a child receiving therapy (OR = 3.1, 95% CI 1.1–8.6, $p = 0.035$). Compared with caregivers who perceived good or excellent guidance from teachers/therapists for HBL, a

parent who perceived poor guidance (OR = 6.7, 95% CI 1.1–42.2, $p = 0.044$) or average guidance (OR = 3.2, 95% CI 1.1–10.4, $p = 0.028$) from teachers/therapists, were more likely to have a positive DASS-A score. Lastly, lower CD-RISC-25 scores were also associated with a positive DASS-A score (OR = 0.96, 95% CI 0.93–0.99, $p = 0.021$).

Parents who reported stress symptoms were more likely to have met stress threshold scores on DASS-S subscale (OR = 11.7, 95% CI 2.5–54.8, $p = 0.002$). Having a child with difficulty staying indoors during the CB (OR = 2.9, 95% CI 1.2–7.4, $p = 0.021$) was also significantly associated with having a positive DASS-S subscale score. Parents with a higher CD-RISC-25 score were less likely to have a positive DASS-S score (OR = 0.97, 95% CI 0.94–1.00, $p = 0.037$).

Table 4 Comparison of DASS-21 scores of parents of all children with DD and subset with ASD, to non-pandemic times locally and across 2 other asian studies

DASS-21 subscales	Current study (All with DD) (n = 107)	Current study (ASD) (n = 61)	Lai et al. (ASD) (n = 73)	Selvakumar et al. (ASD) (n = 30)	Chan et al. (ASD) (n = 121)
	Mean (SD)				
DASS- D	11.51 (10.37)*	13.25 (9.90)*#	3.18 (3.72)*	6.13 (3.82)#	7.81 (5.28)#
DASS- A	8.56 (7.53)*	10.07 (6.99)*#	2.71 (3.29)*	4.00 (3.38)#	6.93 (4.98)#
DASS- S	14.95 (9.63)*	16.43 (9.06)*#	4.98 (4.05)*	6.80 (4.12)#	9.93 (4.96)#
DASS- total	35.03 (25.02)*	39.74 (22.80)*#	10.86 (10.20)*	–	–

*A comparison t-test between means indicated that all DASS-21 subscales were significant at $p < 0.0005$ in relation to study by Lai et al.

#A comparison t-test between means indicated that all DASS-21 subscales for the ASD group were also significant at $p < 0.001$ in relation to the other 2 ASD studies respectively

Table 5 Logistic regression or factors affecting scores on the DASS-21

Variables	OR (95% CI)	p value
Depression		
Do you feel stressed currently?		0.001
Yes	7.76 (2.20–27.38)	
No	1	
Are you concerned that he/she (your child) cannot practise the additional precautions for hand hygiene or mask wearing?		
Yes	2.45 (0.93–6.50)	0.071
No	1	
CDRISC25 total score	0.93 (0.90–0.97)	<0.001
Anxiety		
How easy is it to stay largely indoors during this circuit breaker period?		0.006
Very easy, easy, neutral	1	
Difficult and very difficult	3.94 (1.49–10.43)	
Child having a diagnosis of autism spectrum disorder (ASD)	2.57 (0.99–6.71)	0.054
Child receiving any therapy		
Yes	3.05 (1.08–8.63)	0.035
No	1	
How sufficient is the guidance from teachers and therapists in helping your child with developmental needs/special educational needs during HBL?		
Very poor and poor	6.65 (1.05–42.23)	0.044
Average	3.44 (1.14–10.35)	0.028
Good and excellent	1	
No HBL	1.50 (0.37–6.15)	0.571
CDRISC25 total score	0.96 (0.93–0.99)	0.021
Stress		
How easy is it to stay largely indoors during this circuit breaker period?		0.021
Very easy, easy, neutral	1	
Difficult and very difficult	2.95 (1.18–7.35)	
Do you feel stressed currently?		0.002
Yes	11.65 (2.48–54.78)	
No	1	
CDRISC25 total score	0.97 (0.94–1.00)	0.037

Resilience and Contributors to Resilience

Mean resilience score on the CD-RISC-25 was 63.7 (SD 17.2). Factors associated with higher resilience in caregivers included being of male gender. Males in this study had higher resilience score compared with females (mean difference = 9.0, 95% CI 1.4–16.5, $p=0.02$). Caregivers whose spouses were essential workers or were working from the workplace had higher resilience scores compared to those whose spouses had other work statuses (mean difference = 7.7, 95% CI 1.5–13.9, $p=0.02$). Caregivers with no concerns about HBL had higher resilience scores compared to those with extreme concerns about HBL (mean difference = 9.4, 95% CI 2.2–16.6, $p=0.01$). Caregivers reporting poor guidance during HBL were more likely to have lower resilience scores (mean difference = - 15.1, 95% CI - 24.7 to - 5.5, $p=0.002$), compared to those reporting good or excellent guidance during HBL. We observed that parents with less than three children at home would score 7.04 units lower in the CD-RISC-25 resilience measure as compared to parents with equal or more than three children at home. Moreover, parents who felt that their house was more crowded as a result of the pandemic also had 6.89 units lower resilience scores than caregivers who did not feel so. Furthermore, caregivers who reported receiving an average amount of guidance from form teachers/therapist during HBL had a lower level of resilience than parents who stated that they received excellent guidance, since they scored 5.85 units lower on the CD-RISC-25 resilience measure. Lastly, the results also showed that parents with children who were not receiving any therapy have higher resilience (5.31 units higher on CD-RISC-25) than those with children who were

receiving therapy. The detailed results are summarized in Table 6.

Discussion

Our findings highlighted that during the lockdown, parents of children with DD suffered much higher rates of depression, anxiety and stress symptoms than the general population. A higher prevalence of symptoms of depression (52.3%), anxiety (52.3%) and stress (41.1%) were found, compared to the overall prevalence of depression (33.7%), anxiety (31.9%) and stress (29.6%) in the general population during the COVID-19 pandemic derived from meta-analysis of studies (Salari et al., 2020). Furthermore, subgroup analysis in Salari's paper revealed the prevalence of depression (35.3%) and anxiety (32.9%) in Asian countries to be higher than in European countries, and our study conducted in Southeast Asia revealed an even higher prevalence than quoted. It is of additional concern that three-quarters of these parents indicated that their stress was at least of moderate to extreme severity.

Various literature comparing ASD/DD with TD children have highlighted the plight of parents in their caregiving stress during usual times. A systemic review and meta-analysis involving studies from multiple countries highlighted that as high as one third (31%) of parents of children with intellectual and developmental disabilities reach cut-off score for moderate depression and moderate anxiety, compared to parents of TD children at only 7% and 14% respectively (Scherer et al., 2019). Further, in another large US national database study, mothers and fathers of ASD children were

Table 6 Linear regression factors associated with resilience of caregivers

Parameter	Sig	B	95% Confidence Interval	
			Lower bound	Upper bound
Male caregiver	0.020	9.009	1.447	16.572
Spouse who were not working from workplace or essential worker	0.015	7.736	1.529	13.943
House feels 'too crowded'	0.076	- 6.887	- 14.509	0.735
With child without receiving any therapy	0.086	5.311	- 0.770	11.392
Caregiver report that the guidance received during HBL				
Poor/Very poor	0.002	- 15.095	- 24.716	- 5.474
Average	0.085	- 5.853	- 12.540	0.833
Good/excellent	-	-		
No HBL	0.879	0.697	- 8.352	9.746
Concern about their child's HBL				
No concern at all	0.011	9.432	2.232	16.631
Concern level 1–4	0.211	4.821	- 2.817	12.459
Concern level 5	-	-		
Number of children at home < 3	0.058	- 7.038	- 14.318	0.242

2.95 and 2.41 times more likely to experience depression (Cohrs & Leslie, 2017). During the COVID-19 pandemic, these differences are similar. Caregivers of children with DD experienced significantly higher caregiver burden, depression, anxiety and stress than those of TD children (Chafouleas & Iovino, 2020). In particular, parents of children with ASD reported higher levels of anxiety and depression than parents of TD children (Wang et al., 2021). Similarly, we adopted the DASS-21 scale to provide comparisons to baseline reported locally and across two Asian studies using similar scales. The severity of psychological ill-effects in our study was higher than reported before COVID-19, with significantly much higher scores across all subscales on the DASS-21. In fact, the subset with ASD had higher mean scores than the DD group overall.

Common themes of factors contributing to parental stress have emerged from reports from various countries. For example, in the American Psychological Association Stress in America poll 2020 conducted in a cohort of parents (not specifically parents of children with DD) during the pandemic, their stress was related to worries of themselves or their family members getting COVID-19, online learning, disrupted education and lack of access to healthcare services (American Psychological Association (APA) 2020). The UK Co-Space study published various site reports on parental stress during the pandemic. These UK sites share common factors: parental stress over their work, the child's screen time, child's education and child's wellbeing (Waite et al., 2020). Very few published reports have examined the specific causes of parental stress, anxiety and depression in children with DD. In the Co-Space Irish report, parents of children with DD (ASD, ADHD) reported the child's behaviors and concerns over the child's future as additional stress sources than stated above. In India, lack of telerehabilitation services or its negative perception; not having any home-care therapy in children with DD (mostly children receiving neurorehabilitation) caused more anxiety and depression respectively.

In our study, we found unique and specific factors associated with depression, anxiety and stress in parents of children with DD—in a developed nation-state with high educational and health standards. Half of the parents in this study were worried that their children cannot practise the required infection control measures; those with such concerns were 2.5 times more likely to have depressive symptoms. Difficulties in keeping children indoors so that they do not get infected with COVID-19 correlated with anxiety and stress in caregivers. Singapore is a dense urban city. The size of the average household in Singapore is about 1000 square feet (four-room public housing apartment). The space limitation and lack of outdoor space in the apartments likely add to the challenges of remaining indoors for a prolonged period of time (Department of Statistics Singapore, 2019).

Having a diagnosis of ASD in the child is associated with a higher risk of anxiety in caregivers (Zhou et al., 2019), compared to other diagnostic groups, as children with ASD may have higher behavioral and more complex developmental challenges. This heightened risk is also seen in various studies as mentioned, both before and during pandemic times, but is especially noticeable among mothers (Wang et al., 2020). Having children who were receiving therapy was associated with higher symptoms of anxiety in the caregivers; this could reflect a subgroup of children with more severe developmental issues. In addition, the sudden and prolonged disruption to therapy may have contributed to caregiver concerns about interrupted developmental gains or even regression. Furthermore, parental perception of poor guidance from therapists and teachers for HBL was associated with increased risk for parental anxiety. This is likely to arise from parents feeling inadequate to take on the role of the therapist or teacher during HBL, which added to their anxiety. This may be compounded by lack of resources and preparedness during a sudden announcement of lock-down. The inherent educational and behavioral difficulties of children with DD, also make it more challenging for them to participate in HBL effectively.

Resilience in our study population was lower when compared with resilience scores of a large US population study during the pandemic (Killgore et al., 2020) and even lower compared to the published normative data for this scale (Connor & Davidson, 2003). Protective factors of caregivers included being of male gender than female gender. It is possible that females are generally less resilient as they struggle to cope with multiple roles, which may include working from home and caregiving duties (King et al., 2020). It may also be possible that gender itself poses particular risks to being more susceptible to stress (Hirani et al., 2016). However it was also interesting that having a spouse who was not working from home, was associated with higher resilience scores—highlighting possibly more stress in a crowded home with possibility of spousal conflicts (Pietromonaco & Overall, 2020). In fact, our study is consistent with that of another local study reporting marital conflicts and parenting stress with mothers doing poorly on work-family balance during this lockdown period (Chung et al., 2020). Additionally, as mentioned, guidance and support rendered during HBL rendered evident effects on whether parents with DD children felt they could psychologically weather the lock-down. Resilience can be actively developed in individuals and is thus potentially modifiable if we know how to render targeted assistance especially in a prolonged pandemic setting.

With these findings, there is a need for specific guidance to clinicians and professionals working with children with DD so that they can better support these families in these stressful times. In addition to UNICEF and WHO's

parenting guidance for parents of children with disabilities (United Nations Children’s Fund (UNICEF) 2020), our study has found specific risk factors associated with poorer mental health and lower resilience in caregivers, and seeks to recommend more specific and targeted strategies to help parents with DD, so that providers, systems and policies can also support their emotional wellbeing.

Given that caregiver report of feeling stressed was a significant predictor of having a positive screen for depression and stress on the DASS-21, we recommend that healthcare, educational and social service providers working with caregivers of children with DD adopt a proactive approach towards screening the mental health of caregivers at any touchpoint, or reaching out to them actively through telemedicine. Providers can promote mental health by advocating self-care, mindfulness, self-compassion and other stress-management strategies. Ensuring caregiver access to the multitude of networks of resources can potentially reduce stress and increase a sense of parental mastery when resources and guidance are lean during the pandemic. To mitigate caregiver concerns about children with DD losing developmental gains and regressing, providers can place greater emphasis on adopting caregiver training-based methods for virtually-delivered therapy—this can help to empower caregivers and equip them to better support their children.

Regulations and systems surrounding children with DD can be optimised, for example to give special consideration and flexibility in applying regulations like mask-wearing to children with DD. In addition, videos and visual supports for caregivers on how to help children with DD comply to infection control measures can be adapted and widely shared within DD communities. Government and global responses during the pandemic should be mindful that as attention is shifted to the frontlines, national social safety net programs should include caregivers with DD. Families who are facing financial difficulties are likely to prioritize their basic needs over the child’s therapy. Governing bodies should actively identify the needy and provide various types of financial support during the COVID-19 pandemic.

Our study has its limitations. First, the data was obtained from self-reported questionnaires and hence has inherent responder-bias. This cohort may not be representative of all parents with children with DD as we adopted a snowball sampling methodology, which likely reached a higher proportion of parents who were technology-enabled and social-media savvy. Potentially, this group of parents might have greater social support and hence more protective factors for resilience. Furthermore, the number of respondents is relatively small. As such, the findings from this study may underestimate the true psychological impact of the pandemic on parents of children with DD. Another limitation is that given the cross-sectional nature of our study, we do not have

information on the functioning of our caregivers and families prior to the pandemic. We did attempt to compare our findings to past research on caregivers of children with DD. Also, we could not capture the changes in psychological distress over time. This study was performed in Singapore, a developed city state, which might limit the generalizability of our findings to nations with similar social, health and educational restrictions. Additionally, the DASS-21 seeks to look at psychological wellbeing of caregivers and establish symptoms of depression, anxiety and stress. While it had good internal reliability in our study cohort, it was not possible to corroborate with actual clinical diagnoses of depression and anxiety in these parents.

Despite the limitations, we believe that our findings are important for bringing attention to an important but neglected sector of our community during the pandemic. The pandemic has taught us that the experiences of our patients and their family are fluid and at the mercy of the circumstances surrounding them. Though countries and adaptations to COVID-19 may differ, collectively understanding the struggles of caregivers of DD and what contributes to their psychological ill-health or resilience in communities around the world, allows us to note our blind spots, be nimble and agile in responding to the swift changes, and calibrate our support.

In conclusion, this study highlights the high rates of depression, anxiety and stress symptoms encountered by caregivers of children with DD during a nationwide lock-down amidst the COVID-19 pandemic. These rates are at least 3–4 times higher compared to local non-pandemic baseline, and significantly higher than other Asian countries during non-pandemic times, especially impacting caregivers of children with ASD. Overall, rates of psychological ill-effects in these caregivers are also higher than rates in the general population based on pandemic reports, paired likewise with concomitant lower resilience scores. These findings likely reflect the caregivers’ continued suffering in this long-drawn pandemic, with repeated cycles of school closures and social restrictions. Additionally, various challenges of infection control, difficulties keeping children with DD indoors, feeling lost with need for guidance about HBL—all point to additional burdens and worries that these caregivers have, especially affecting female caregivers (e.g., mothers). These findings add weight to the proposition that the pandemic has disproportionately impacted caregivers and children with DD significantly. However, more importantly, understanding the specific contributing factors to psychological ill-effects allows us the opportunity to provide targeted support for specific caregivers and to address specific caregiver concerns. It is imperative to improve existing social-health-education partnerships to support caregivers of children with DD—for the caregivers’ mental health and enhancing their psychological resilience in their caregiving efforts. Cooperation

between health, social and education systems, and organisations needs to be enhanced, effective and efficient. It is also timely to have a humble rethink about what is “essential” and “non-essential” services to these families during a lockdown, which may be very different from the families with TD children or the general population.

Acknowledgments The authors would like to acknowledge all government and private early intervention centers and special schools, Lien Foundation and SG Enable for their efforts in sharing the study link. The authors would like to thank Dr. Dimple Rajgor and Winnie Wee for their help in editing and formatting of the manuscript and all caregivers who gave their time participating in this study.

Authors Contribution TSHL conception and design of the study, revising the manuscript critically for important intellectual content and final approval of the version to be submitted. MYT acquisition, analysis and interpretation of data, drafting the article, and final approval of the version to be submitted. RA analysis and interpretation of data, revising the manuscript critically for important intellectual content and final approval of the version to be submitted. YQK conception and design of the study, revising the manuscript critically for important intellectual content and final approval of the version to be submitted. MYK conception and design of the study, drafting the article, and final approval of the version to be submitted. LS-analysis and interpretation of data, revising the manuscript critically for important intellectual content and final approval of the version to be submitted. SCC conception and design of the study, revising the manuscript critically for important intellectual content and final approval of the version to be submitted. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding The authors did not receive support from any organization for the submitted work.

Declarations

Conflict of interest The authors have no relevant financial or non-financial interests to disclose.

Ethical Approval Ethics approval was obtained from the National Healthcare Group Domain Specific Review Board, Singapore prior to the commencement of this study.

Informed Consent This was an anonymised survey and explanation of the study aims was provided, with implied consent for all who returned the survey results.

References

- American Psychological Association (APA) (2020). Stress in America 2020. Stress in the time of COVID-19: volume one. <https://www.apa.org/news/press/releases/stress/2020/stress-in-america-covid.pdf>. Accessed 21 Sept 2020.
- Antony, M. M., Bieling, P. J., & Cox, B. J. (1998). Psychometric properties of the 42-item and 21-item versions of the depression anxiety stress scales in clinical groups and a community sample. *Psychol Assess*, *10*(2), 176–181. <https://doi.org/10.1037/1040-3590.10.2.176>
- Barrero-Castillero, A., Morton, S. U., Nelson, C. A., & Smith, V. C. (2019). Psychosocial stress and adversity: Effects from the perinatal period to adulthood. *NeoReviews*, *20*(12), e686–e696. <https://doi.org/10.1542/neo.20-12-e686>
- Bryant, D. J., Oo, M., & Damian, A. J. (2020). The rise of adverse childhood experiences during the COVID-19 pandemic. *Psychological Trauma*, *12*(S1), S193–s194. <https://doi.org/10.1037/tra000711>
- Chafouleas, S. M., & Iovino, E. A. (2020). Initial Impact of COVID-19 on the Well-being of Caregivers of Children with and without Disabilities. Storrs, CT: UConn Collaboratory on School and Child Health. <https://csch.uconn.edu/wp-content/uploads/sites/2206/2020/07/CSCH-Brief-COVID-19-Impact-on-Caregivers-July-2020.pdf>. Accessed 19 March 2021.
- Chan, B. S. M., Deng, J., Li, Y., Li, T., Shen, Y., Wang, Y., et al. (2020). The role of self-compassion in the relationship between post-traumatic growth and psychological distress in caregivers of children with autism. *Journal of Child and Family Studies*, *29*(6), 1692–1700. <https://doi.org/10.1007/s10826-019-01694-0>
- Chung, S. K. G., Chan, X. W., Lanier, P., & Wong, P. (2020). Associations between work-family balance, parenting stress, and marital conflicts during COVID-19 pandemic in Singapore. *OSF Preprints*. <https://doi.org/10.31219/osf.io/nz9s8>
- Cohrs, A. C., & Leslie, D. L. (2017). Depression in parents of children diagnosed with autism spectrum disorder: A claims-based analysis. *Journal of Autism and Developmental Disorders*, *47*(5), 1416–1422.
- Connor, K. M., & Davidson, J. R. (2003). Development of a new resilience scale: The connor-davidson resilience scale (CD-RISC). *Depression and Anxiety*, *18*(2), 76–82. <https://doi.org/10.1002/da.10113>
- Department of statistics Singapore (2019). Household - Latest Data. <https://www.singstat.gov.sg/find-data/search-by-theme/households/households/latest-data>. Accessed 6 Oct 2020.
- Fontanesi, L., Marchetti, D., Mazza, C., Di Giandomenico, S., Roma, P., & Verrocchio, M. C. (2020). The effect of the COVID-19 lockdown on parents: A call to adopt urgent measures. *Psychological Trauma: Theory, Research, Practice, and Policy*, *12*(S1), S79–S81. <https://doi.org/10.1037/tra0000672>
- Griffith, A. K. (2020). Parental burnout and child maltreatment during the COVID-19 pandemic. *J Fam Violence*. <https://doi.org/10.1007/s10896-020-00172-2>
- Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(3), 629–642. <https://doi.org/10.1007/s10803-012-1604-y>
- Hirani, S., Lasiuk, G., & Hegadoren, K. (2016). The intersection of gender and resilience. *Journal of Psychiatric and Mental Health Nursing*, *23*(6–7), 455–467. <https://doi.org/10.1111/jpm.12313>
- Idele, P., Anthony, D., Mofenson, L. M., Requejo, J., You, D., Luo, C., et al. (2020). The Evolving Epidemiologic and Clinical Picture of SARS-CoV-2 and COVID-19 Disease in Children and Young People. (pp. 1–43). UNICEF Innocenti Research Brief.
- Killgore, W. D. S., Taylor, E. C., Cloonan, S. A., & Dailey, N. S. (2020). Psychological resilience during the COVID-19 lockdown. *Psychiatry Research*, *291*, 113216. <https://doi.org/10.1016/j.psychres.2020.113216>
- King, T., Hewitt, B., Crammond, B., Sutherland, G., Maheen, H., & Kavanagh, A. (2020). Reordering gender systems: Can COVID-19 lead to improved gender equality and health? *The Lancet*, *396*(10244), 80–81.
- Lai, W. W., Goh, T. J., Oei, T. P., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, *45*(8), 2582–2593. <https://doi.org/10.1007/s10803-015-2430-9>

- Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the depression anxiety stress scales (DASS) with the beck depression and anxiety inventories. *Behaviour Research and Therapy*, 33(3), 335–343. [https://doi.org/10.1016/0005-7967\(94\)00075-U](https://doi.org/10.1016/0005-7967(94)00075-U)
- Oei, T. P., Sawang, S., Goh, Y. W., & Mukhtar, F. (2013). Using the depression anxiety stress scale 21 (DASS-21) across cultures. *International Journal of Psychology*, 48(6), 1018–1029. <https://doi.org/10.1080/00207594.2012.755535>
- Ong, H. L., Vaingankar, J. A., Abdin, E., Sambasivam, R., Fauziana, R., Tan, M.-E., et al. (2018). Resilience and burden in caregivers of older adults: Moderating and mediating effects of perceived social support. *BMC Psychiatry*, 18(1), 1–9. <https://doi.org/10.1186/s12888-018-1616-z>
- Pietromonaco, P. R., & Overall, N. C. (2020). Applying relationship science to evaluate how the COVID-19 pandemic may impact couples' relationships. *The American Psychologist*. <https://doi.org/10.1037/amp0000714>
- Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 44(7), 1609–1620. <https://doi.org/10.1007/s10803-013-2028-z>
- Russell, B., Hutchison, M., Tambling, R., Tomkunas, A., & Horton, A. (2020). Initial challenges of caregiving during COVID-19: Caregiver burden, mental health, and the parent–child relationship. *Child Psychiatry & Human Development*, 51(5), 671–682. <https://doi.org/10.1007/s10578-020-01037-x>
- Salari, N., Hosseini-Far, A., Jalali, R., Vaisi-Raygani, A., Rasoulpoor, S., Mohammadi, M., et al. (2020). Prevalence of stress, anxiety, depression among the general population during the COVID-19 pandemic: A systematic review and meta-analysis. *Globalization and Health*, 16(1), 1–11. <https://doi.org/10.1186/s12992-020-00589-w>
- Sanders, L. M. (2020). Is COVID-19 an adverse childhood experience (ACE): Implications for screening for primary care. *The Journal of Pediatrics*, 222, 4–6. <https://doi.org/10.1016/j.jpeds.2020.05.064>
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS one*, 14(7), e0219888.
- Selvakumar, N., & Panicker, A. S. (2020). Stress and coping styles in mothers of children with autism spectrum disorder. *Indian Journal of Psychological Medicine*, 42(3), 225–232.
- United Nations Children's Fund (UNICEF) (2020). Coronavirus (COVID-19) parenting tips. <https://www.unicef.org/coronavirus/covid-19-parenting-tips#13>. Accessed 21 Sept 2020.
- United nations educational scientific and cultural organization (UNESCO) (2020). Adverse consequences of school closures. <https://en.unesco.org/covid19/educationresponse/consequences>. Accessed 1 Oct 2020.
- Waite, P., Patalay, P., Moltrecht, B., McElroy, E., & Creswell, C. (2020). COVID-19 worries, parent/carer stress and support needs, by child special educational needs and parent/carer work status. https://emergingminds.org.uk/wp-content/uploads/2020/05/CoSPACE-report-02_03-05-20.pdf. Accessed 1 Oct 2020.
- Wang, C., Pan, R., Wan, X., Tan, Y., Xu, L., Ho, C. S., et al. (2020). Immediate psychological responses and associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the general population in China. *International Journal of Environmental Research and Public Health*, 17(5), 1729. <https://doi.org/10.3390/ijerph17051729>
- Wang, L., Li, D., Pan, S., Zhai, J., Xia, W., Sun, C., et al. (2021). The relationship between 2019-nCoV and psychological distress among parents of children with autism spectrum disorder. *Globalization and Health*, 17(1), 1–14.
- Yoshikawa, H., Wuermli, A. J., Britto, P. R., Dreyer, B., Leckman, J. F., Lye, S. J., et al. (2020). Effects of the global coronavirus disease-2019 pandemic on early childhood development: short- and long-term risks and mitigating program and policy actions. *The Journal of Pediatrics*, 223, 188–193. <https://doi.org/10.1016/j.jpeds.2020.05.020>
- Zhou, W., Liu, D., Xiong, X., & Xu, H. (2019). Emotional problems in mothers of autistic children and their correlation with socioeconomic status and the children's core symptoms. *Medicine*, 98(32), e16794–e16794. <https://doi.org/10.1097/MD.00000000000016794>

Publisher's Note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.