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Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs

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ABSTRACT

Background: While COVID-19 outbreak has had adverse psychological effects in children with special needs, the mental state and burden on their caregivers during this pandemic has yet to be reported.

Aims: The objectives of this study were to describe the mental health status and the change in perceived strain among caregivers during the COVID-19 outbreak.

Methods and procedures: Two hundred sixty four caregivers completed an online survey that assessed demographics, use and perspective on tele-rehabilitation, homecare therapy, caregiver's strain and mental health.

Outcomes and results: The prevalence of depression, anxiety and stress symptoms were found to be 62.5 %, 20.5 % and 36.4 % respectively. A significant difference in caregiver strain ($p < 0.001$, effect size = 0.93) was observed during the outbreak compared to levels pre-outbreak (pre-outbreak strain was measured retrospectively). Caregivers not using tele-rehabilitation along with a perception of it being a poor medium for rehabilitation were at greater risks for poor mental health whereas a negative perception on homecare therapy were strongly associated with higher psychological symptoms and strain.

Conclusions and implications: This study identified a high prevalence of depression and significant change in strain displayed by caregivers during the COVID-19 outbreak. We identified several factors associated with poor mental health and perceived strain that can be used to help safeguard caregivers.

What this paper adds?

The current study provides insight into the psychological status and strain on caregivers of special needs children during the COVID-19 outbreak. The high prevalence of depressive symptoms and significant change in strain observed among caregivers demands greater attention from mental health practitioners and rehabilitation care providers. Lack of tele-rehabilitation and its negative

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perception were found to be associated with caregiver's poor mental health. Therefore, greater communication among policymakers, rehabilitation service providers and caregivers to help remove barriers associated with an unfavorable perception of tele-rehabilitation may be needed. Effective homecare therapy techniques must be learned by the caregivers and education on its positive perception should be emphasized during COVID-19 pandemic to reduce strain and provide a better mental health to caregivers. Rehabilitation strategies should have greater focus on improving self-care abilities in order to reduce depression, stress and strain in caregivers tending children with special needs.

1. Introduction

The world has been confronting an outbreak of a novel corona-virus infectious disease i.e. COVID-19 that has expeditiously spread globally from its first detection in December 2019 at Wuhan city of central Hubei province of China (Holshue et al., 2020; Wang, Pan et al., 2020; Wang, Hu et al., 2020). Due to the spread of the virus to multiple countries, on January 30, 2020 the World Health Organization (WHO) declared it as a public health emergency and on March 12, 2020 announced it as a pandemic (Organization WHO, 2020; WHO, 2020). In India, a countrywide lockdown was posed by the government on March 24, 2020 and access to all public facilities/services was prohibited (Wikipedia COVID-19 lockdown in India, 2020). Between April 29, 2020 to May 22, 2020, the number of confirmed COVID-19 cases in India was >86000 with >2500 deaths (en.wikipedia.org, COVID-19 pandemic data, 2020).

As social distancing was promoted as the best strategy to avoid transmission of COVID-19, staying at home and refraining from outdoor activities became the advised policies for children (Saxena & Saxena, 2020). In this situation, caring for children with special needs such as autism spectrum disorder (ASD), attention deficit hyperactive disorder (ADHD), cerebral palsy (CP) and chronic disability may be more challenging for caregivers (parents and other family members). In India, the estimated prevalence of CP is 2.5 % (Chauhan, Sahu et al., 2019; Chauhan, Singh et al., 2019) where as ASD and learning disability (LD) have prevalence rate of 0.11 % (Chauhan, Sahu et al., 2019; Chauhan, Singh et al., 2019) and 10.5 % (Lakhan et al., 2015) respectively. The 2011 Indian census indicates 2,042,000 0–6 year's age children suffer from chronic disability with a prevalence rate of 1.24 % (Disabled persons in India statistical profile, 2016). Often these children require rehabilitation interventions such as physiotherapy, occupational therapy, speech and language therapy, behavioral therapy and/or special education either at hospitals or clinics (Mishra & Siddharth, 2018). However, due to virus containment measures taken, children with special needs are not able to be physically supported by the rehabilitation care providers. In these circumstances, the role of caregivers of children with special needs became not only to physically care them but also to provide adequate rehabilitation at home to maintain and/or improve their physical and mental function. Due to the disruption of normal routine and social uncertainty, it is expected that children with ASD and LD will show increased frustration (The Lancet child-adolescent, 2020). Therefore, caregivers may play an important role in creating a daily schedule of rehabilitation sessions to help reduce any increase in their anxiety.

Past work demonstrated that any infectious diseases outbreak (including COVID-19) has a negative impact on the psychological state of the general population in India (Ramalingaswami, 2001; Rajkumar, 2020). Moreover, in a recent study parents reported a significant decline in behavior in 6–15 year old school going ADHD children due to the COVID-19 pandemic (Zhang et al., 2020). A direct link between parent's mood state and ADHD behavior was noted from this study. However, previous research has not assessed the prevalence of mental health problems of caregivers providing general care for the children with special needs during this pandemic.

Caregiver strain is considered as a third party disability according to The WHO Classification of Functioning, Disability and Health (ICF) (Raina et al., 2005). In addition to handling for self care and mobility, providing rehabilitation services in a home environment could be one of the major challenges faced by caregivers in this pandemic period. Moreover, previous studies identified that an individual needs physical and psychological wellbeing to reduce immune-reactivity and to defend against similar kinds of viruses (Chen et al., 2020; Severance et al., 2011). Despite the notable role played by caregivers in managing children with special needs, their perceived strain due to the COVID-19 outbreak has yet to be investigated.

Because of a sudden lockdown, providing homecare therapies by caregivers would become challenging. Although homecare interventions play an important role in rehabilitation (Tinderholt et al., 2014), caregivers might not have learned the techniques in an appropriate manner to achieve the desired functional outcomes. Moreover, certain caregivers might have found them difficult to implement because of several reasons including lack of support from healthcare providers in form of communication and interaction, low self-efficacy, low level of knowledge and ability to carry out homecare therapy, poor functioning of child (Lillo-Navarro et al., 2019). The role of tele-rehabilitation in chronic conditions is extremely useful, especially during this time of pandemic (Dantas et al., 2020; Leochico, 2020). Thus, it can serve as a substitute to hands-on rehabilitation during the lock-down phase and may reduce stress and burden on caregivers. However, in a developing country like India tele-rehabilitation is in a growth stage and many potential barriers to tele-rehabilitation such as cross-cultural acceptance, poverty, accessibility and large rural populations are present (Khan et al., 2015). Furthermore, extreme patience and understanding both by the providers and caregivers will likely be required for a smooth implementation of tele-rehabilitation. A negative perception on utility of tele-rehabilitation as an alternate option may be associated with poor psychological health, strain and hence greater action may be required.

Children with intellectual and developmental disabilities are at a high risk of COVID-19 infection and the risk of transmission is further increased if already disabled (Alexander et al., 2020; Turk & McDermott, 2020). Children with chronic neuro-disabilities face additional challenges due to their functional limitations and this may further stress their caregivers (Fazzi & Galli, 2020; Schiari, 2020). Moreover, elders are also considered a high risk group for COVID-19 infections (Nicola et al., 2020). Compared to western countries, the prevalence of elders living alone in developing countries is very low (Lee & Edmonston, 2019; Sundström et al., 2009). Although a trend in increase number of nuclear elders is developing, in a national survey, it was found that only 2% Indian elders live

alone and 9% live with their spouse. About 11 % of elders live with their spouse and adult children while 55 % co-reside in multi-generational households (Samanta et al., 2015). Care of elders and the high probability of infection and/or death among elders may also adversely affect the mental health and strain of caregivers.

Thus, the first objective of this study was to describe the mental health status of caregivers tending children with special needs during the COVID-19 quarantine and to investigate the impact of the COVID-19 outbreak on the caregivers' perceived strain. The second objective was to test the demographic, social and care related factors associated with mental health status and strain of caregivers.

2. Material and methods

2.1. Study design and participants

This was a survey conducted in collaboration with rehabilitation professionals working in pediatric clinics across India. A network of physiotherapists and occupational therapists known to the investigators were contacted and the study explained in detail. The contact information of caregivers having children with special needs satisfying the inclusion criteria were collected from the professionals networks and reconfirmation on their understanding of English was done by the authors before participating in the survey. An online questionnaire was created to conduct data collection without risking participant exposure to the virus. A link containing the questionnaire was sent through emails, whatsapp and other social media to caregivers.

2.2. Data collection

Data was collected from April 29, 2020 to May 22, 2020. In this online survey participants older than 18 years of age and primary caregivers of children with special needs were allowed to participate. Other inclusion criteria included the ability to read and comprehend English along with their willingness to provide informed consent.

2.3. Ethical statement

The study and protocol was approved by the institutional ethical committee, School of Physiotherapy, Delhi Pharmaceutical Sciences and Research University (10/876/Acad/DPSRU/2018, dated 27.04.2020) and was conducted in accordance with the Declaration of Helsinki guidelines. Electronic informed consent was obtained from each participant prior to starting data collection.

2.4. Outcome measures

2.4.1. Demographics

The questionnaire was developed by the investigators and contained several sections (Appendix A). The initial section was information on demographics including child's age, relation with child, occupation of caregiver, diagnosis, and any elder (> 60 years) living at home. Then questions regarding presence of steady financial status, current workload, relationship between workload and care and whether the primary caregiver worked from home or the workplace were asked.

2.4.2. Children's functional status and perception on tele-rehabilitation

In this section, the child's independent functioning in eating, dressing, hygiene and mobility were assessed. The response for eating, dressing, hygiene function were dichotomized in to independent or dependent status where-as mobility were categorized to 5 levels. Apart from this, the caregiver's perception about homecare therapy and tele-consultation and rehabilitation were also assessed.

2.4.3. Depression, anxiety and stress levels

To assess mental health symptoms during the pandemic outbreak, Depression Anxiety Stress-21 scale (DASS-21) was used (Lovibond & Lovibond, 1995). Participants responded to a 21 item Depression anxiety stress scale (DASS-21). The scale is divided in to three subsets (stress, anxiety and depression) and each domain contains 7 items. Dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest / involvement, anhedonia and inertia were evaluated by the depression subscale. The anxiety subscale assessed autonomic arousal, skeletal muscle effects, situational anxiety, and the subjective experience of anxious affect. To assess difficulty in relaxing, nervous arousal, and being easily upset / agitated, irritable / over-reactive and impatient the stress subscale was used. The respondent scored the response on a 4 item linkert rating scale with 0 "denotes did not apply to me at all" to 3 "applied to me very much or most of the time". Scores for depression, anxiety and stress symptoms were calculated by summing the scores for the relevant items. Finally this short version DASS-21 scores were multiplied by 2 to find the severity of depression, anxiety and stress symptoms. The depression subscale is categorized as mild (10–13), moderate (14–20), severe (21–27) and extremely severe (28+). The anxiety subscale is classified in to mild (8–9), moderate (10–14), severe (15–19) and extremely severe (20+) to note the severity of anxiety symptoms. Finally, the severity of stress was assessed on mild (15–18), moderate (19–25), severe (26–33) and extremely severe (34+). The validity of this scale measuring depression, anxiety and stress symptoms was previously tested (Ng et al., 2007).

2.4.4. Caregiver strain

Caregiver's strain during and before the COVID-19 outbreak were enquired by using a validated caregiver strain index (CSI)

questionnaire (Robinson, 1983). To observe the impact of the COVID-19 outbreak on caregiver strain, participants were asked to retrospectively note the strain they perceived one month before the pandemic. This is a 13 item questionnaire measuring strain perceived by caregivers related to the childcare provided. This questionnaire contains at least one item related to domains such as employment, financial, physical, social and time. Items were dichotomized in to yes/no response and the total possible score ranges from 0 to 13 (0 - no, yes - 1). A score 7 or above indicates a greater level of strain. This scale was developed and validated to measure strain perceived due to care of children with various neurological conditions such as cerebral palsy, Duchene muscular dystrophy and other serious illnesses (Byrne et al., 2011; Pangalila et al., 2012; Sharan et al., 2012).

2.5. Data analysis

Data were analysed with SPSS version 26.0. Descriptive statistics were used to find the prevalence of depression, anxiety, stress symptoms and demographics of factors. The impact of COVID-19 outbreak on CSI was analysed using a paired *t*-test. Bivariate Pearson correlation testing was conducted to find the relationship among depression, anxiety, stress symptoms and CSI. Multivariate ANOVA (MANOVA) was conducted to analyse the demographic, social and care related factors associated with DASS indices (depression, anxiety and stress symptoms). To test the demographic, social and care related factors associated with CSI, analysis of covariance (ANCOVA) was used where the CSI score one month before the pandemic outbreak (retrospective data) was considered as a covariate.

3. Results

3.1. General characteristics

Contact information of 307 caregivers of children with special needs satisfying the inclusion criteria were received from the rehabilitation professional network and then participants were reconfirmed by the authors for knowledge in reading, understanding English and access to internet. Five caregivers denied participating because of various reasons and two were excluded because of lack of understanding English. The 300 participants fitting study criterion were asked to complete the online form. Finally, data from 264 respondents were recorded (response rate 88 %, no missing data) and analysed. All respondents had a minimum bachelor degree qualification and 85 % of our sample had above bachelor level education. Approximately, 80 % of caregivers were the mother, 16 %

Table 1
Demographics and general characteristics (N = 264).

Characteristics	N (%)
Primary caregiver	
Mother	210(79.5)
Father	42(15.9)
Other family member	12(4.5)
Age of child	
<6 years	120(45.45)
≥ 6 years	144(54.55)
Diagnosis	
Cerebral palsy	132(50)
Autism spectrum disorder	66(25)
Attention deficit hyperactive disorder	21(8)
Learning disability	12(4.5)
Global developmental delay	9(3.4)
Down's syndrome	6(2.3)
spina bifida	10(3.8)
Gullian barre syndrome	4(1.5)
Hereditary spastic paraplegia	4(1.5)
Steady financial status	
Yes	201(76.14)
No	63(23.86)
Elder living at home	
Yes	129(48.9)
No	135(51.18)
Working from home	
Yes	84(31.8)
No	63(23.9)
Not applicable	117(44.3)
Work load increased	
Yes	135(51.1)
No	33(12.5)
Not applicable	96(36.4)
Increase workload affects care	
Yes	132(50.0)
No	54(20.5)
Not applicable	78(29.5)

were the father and only 4% provided care as other family member (Table 1). The mean age of children was 6.20 ± 3.05 (mean \pm SD) years and participants were from 9 major cities of India.

3.2. Prevalence of depression, anxiety, stress symptoms and CSI among caregivers

Overall, the prevalence of depressive symptoms was 62.5 % whereas prevalence of anxiety and stress symptoms were 20.5 % and 36.4 % respectively. The prevalence of psychological symptoms with their severity is presented in Table 2 and Fig. 1.

3.3. Impact of COVID-19 outbreak on CSI

To evaluate the impact of COVID-19 on CSI, the CSI during the outbreak was compared with the retrospectively reported CSI score 1 month before the outbreak by a paired *t*-test. Table 3 and Fig. 2 indicates there was a statistical significant change ($p < 0.001$) with large effect size (0.93) from before to during the outbreak and a mean difference of 2.98 ± 3.83 .

3.4. Correlation among depression, anxiety, stress symptoms and CSI among participants

The results of correlation analysis are shown in Table 4. Bivariate correlation testing was done among depression, anxiety, stress symptoms and CSI. The results showed a weak but statistically significant correlation between depression ($r = 0.25$, $P < 0.001$) and anxiety symptoms ($r = 0.21$, $P < 0.001$) with CSI, while a moderate, statistical significant correlation ($r = 0.40$, $P < 0.001$) was found between CSI and stress symptoms. Moreover, a statistical significant and strong correlation were observed between depression, anxiety symptoms ($r = 0.64$, $P < 0.001$), depression, stress symptoms ($r = 0.61$, $P < 0.001$) and anxiety, stress symptoms ($r = 0.73$, $P < 0.001$).

3.5. Factors associated with depression, anxiety and stress symptoms among caregivers of children with special needs

To explore the demographic, social and care related factors associated with DASS indices (depression, anxiety and stress symptoms), MANOVA was used. The assumptions for MANOVA such as absence of outliers, linear relationship between each dependent variables and each group of independent variable, multivariate normality and absence of multi-collinearity (correlation coefficient 0.2 to 0.9 between each dependent variables) were met and the independent factors satisfying the assumptions were selected to be tested.

One way MANOVA analysis with Wilk's lambda (Λ), *p* value and effect sizes (partial Eta squared) are presented in Table 5, which shows the difference across levels in various factors when depression, anxiety and stress symptoms considered together as a dependent variable.

Analysis of variance (ANOVA) was conducted to test association of each independent factor on depression, anxiety and stress symptoms separately (Table 6). The mean and standard deviation score of all psychological symptoms of each independent factor across levels is presented in Appendix B. To estimate the strength of associations estimates (B) is used. Finally, a series of post-hoc analyses (Scheffe's test used because of unequal sample sizes) were performed to examine differences across three levels of perception on difficulty of home care therapy, five levels of mobility and three levels of work from home pattern during lock-down. The mean differences and *p* value are presented in Table 7.

Table 2
Prevalence of depression, anxiety and stress symptoms with severity level among caregivers of children with special needs (N = 264).

Variables	Prevalence No (%)
Depression	
Normal	99(37.5)
Mild	84(31.8)
Moderate	54(20.5)
Severe	21(7.9)
Extremely severe	6(2.3)
Anxiety	
Normal	210(79.5)
Mild	21(8)
Moderate	15(5.7)
Severe	6(2.3)
Extremely severe	12(4.5)
Stress	
Normal	168(63.6)
Mild	45(17.1)
Moderate	36(13.6)
Severe	6(2.3)
Extremely severe	9(3.4)

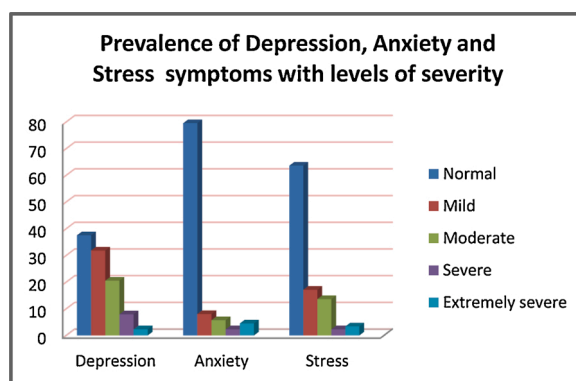


Fig. 1. Graph showing prevalence of depression, anxiety and stress symptoms with levels of severity among caregivers tending children with special needs ($n = 264$).

Table 3

Impact of COVID-19 outbreak on caregiver strain index analysed by paired t -test.

Variable	Before outbreak (mean \pm SD)	During outbreak (mean \pm SD)	Mean change	95 % CI	T	p	Effect size
Care giver strain index (CSI)	4.30 \pm 3.04	7.29 \pm 3.38	-2.98 \pm 3.83	-3.45 – -2.52	-12.664	< 0.001*	0.93

*Significance kept at $p < 0.05$, Effect size = Cohen's d .

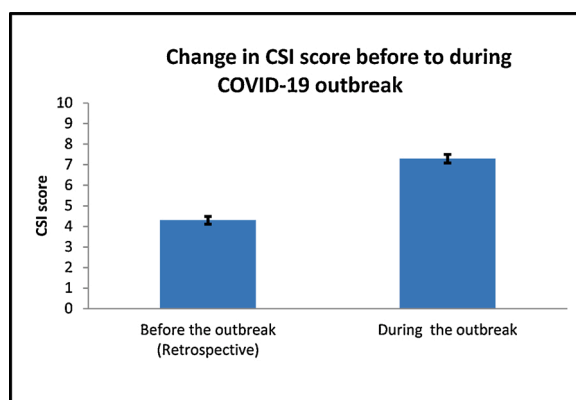


Fig. 2. Graph showing mean change in CSI score before the outbreak (retrospectively reported) to during the outbreak.

Table 4

Bivariate correlation analysis among depression, anxiety, stress symptoms and CSI.

	Depression	Anxiety	Stress	CSI
Depression	1			
Anxiety	0.64**	1		
Stress	0.61**	0.73**	1	
CSI	0.25**	0.21**	0.40**	1

** Correlation is significant at 0.01 level (2 tailed).

3.6. Factors associated with CSI among caregivers of children with special needs

Univariate ANCOVA was performed to test the demographic, social and care related factors associated with CSI during the outbreak among caregivers tending children with special needs. After meeting the assumptions, CSI score before the pandemic outbreak was considered as a covariate in the model. The mean and standard deviation score of CSI during the outbreak of each independent factor across levels is presented in Appendix B. The ANCOVA results including estimates (B), p value and effect sizes (partial Eta squared)

Table 5
MANOVAs – Differences in depression, anxiety and stress symptoms interaction levels of demographic, social and care related factors.

Factors	Value	F	Df	P	η_p^2
Child's age	0.917	7.868	3	<0.001***	0.083
Continuing tele-rehabilitation	0.886	11.184	3	<0.001***	0.114
Caregiver's perception on tele- consultation as alternate option	0.909	8.705	3	<0.001***	0.091
Learned homecare therapy	0.960	3.614	3	0.014*	0.040
Perception on difficulty of homecare therapy	0.907	4.928	6	<0.001***	0.047
Independence in eating	0.935	6.052	3	0.001**	0.065
Independence in dressing	0.858	14.296	3	<0.001***	0.142
Independence in Hygiene	0.875	12.376	3	<0.001***	0.125
Independence in mobility	0.870	3.061	12	<0.001***	0.045
Working from home	0.903	4.517	6	<0.001***	0.050
Elder living at home	0.986	1.252	3	0.291	0.014
Steady financial income	0.961	2.558	3	0.015*	0.039

Note: $p \leq 0.05^*$, $p \leq 0.01^{**}$, $p \leq 0.001^{***}$.
 η_p^2 : Partial Eta squared.

Table 6
ANOVA tests between the groups differences in depression, anxiety and stress symptoms (N = 264).

Factors	No.	Depression			Anxiety			Stress		
		B	p	η_p^2	B	P	η_p^2	B	p	η_p^2
Child's age				0.054			0.033			0.073
<6 ^a	120									
≥6	144	-2.917	<0.001***		-2.217	0.003**		-3.967	<0.001***	
Continuing tele-rehabilitation				0.000			0.028			
Yes ^a	189									0.006
No	75	0.250	0.771		2.250	0.007**		-1.262	0.208	
Caregiver's perception on tele-rehabilitation as alternate option				0.057			0.083			
Yes ^a	162									0.035
No	102	3.599	<0.001***		3.599	<0.001***		2.810	0.002**	
Learned homecare therapy				0.016			0.001			
Yes ^a	210									0.002
No	54	1.946	0.042*		0.533	0.568		-0.806	0.472	
Perception on difficulty of homecare therapy				0.001			0.012			
Easy	25	0.737			-2.747			-7.063		0.050
Moderate ^a	104									
Difficult	135	0.070			0.230			0.004		
Independence in eating				0.044			0.055			
Dependent	165	2.727	0.001**		2.958	<0.001***		2.206	0.018*	0.021
Independent ^a	99									
Independence in dressing				0.060			0.141			
Dependent	174	3.248	<0.001***		4.818	<0.001***		4.547	<0.001***	0.087
Independent ^a	90									
Independence in Hygiene				0.103			0.101			
Dependent	186	4.414	<0.001***		4.238	<0.001***		4.392	<0.001***	0.075
Independent ^a	78\									
Independence in mobility				0.063			0.073			
Level 1	72	2.475			0.399			0.377		
Level 2	42	2.248			1.565			0.615		
Level 3	21	0.534			-2.435			-3.242	<0.001***	0.083
Level 4	60	-1.509			-3.035			-4.557		
Level 5 ^a	69									
Working from home during lockdown				0.033			0.042			<0.001***
Yes ^s	84									
Not applicable (N/A) being homemaker	63	-2.487			-2.793			-3.711		0.057
No	117	-2.333			-0.881			-3.857		
Elder living at home				0.000			0.000			
Yes ^a	129									0.006
No	135	0.075	0.923		-0.087	0.908		-1.176	0.193	
Steady financial income				0.026			0.002			
Yes ^a	201									0.015
No	63	-2.387	0.008**		-0.631	0.475		-2.072	0.051	

Note: $p \leq 0.05^*$, $p \leq 0.01^{**}$, $p \leq 0.001^{***}$; a - Referent factor; B = Estimates; η_p^2 : Partial Eta squared.

Table 7
Scheffe's post-hoc analysis for multiple comparisons.

Factors	Depression		Anxiety		Stress	
	MD	p	MD	p	MD	p
Perception on difficulty of homecare therapy						
Easy vs. moderate	0.73	0.914	-2.74	0.261	-7.07	0.002**
Easy vs. difficult	0.66	0.927	-2.97	0.201	-7.06	0.002**
Moderate vs. difficult	-0.07	0.996	-0.23	0.957	-0.003	1.000
Independence in mobility						
1 vs. 2	0.22	1.000	-1.16	0.905	-0.23	1.000
1 vs. 3	1.94	0.803	2.83	0.446	3.61	0.375
1 vs. 4	3.98	0.009**	3.43	0.029*	4.93	0.004**
1 vs. 5	2.47	0.223	0.39	0.997	0.37	0.999
2 vs. 3	1.71	0.895	4.00	0.175	3.85	0.386
2 vs. 4	3.75	0.057	4.60	0.006**	5.17	0.012*
2 vs. 5	2.24	0.477	1.56	0.768	0.61	0.995
3 vs. 4	2.04	0.785	0.60	0.997	1.31	0.970
3 vs. 5	0.53	0.998	-2.43	0.606	-3.24	0.497
4 vs. 5	-1.50	0.746	-3.03	0.080	-4.55	0.011*
Working from home						
Yes vs. N/A being home maker	2.48	0.021*	2.79	0.006**	3.71	0.002**
Yes vs. No	2.33	0.080	0.88	0.678	3.85	0.006**
N/A vs. No	-0.15	0.987	-1.91	0.127	0.14	0.991

Note: $p \leq 0.05^*$, $p \leq 0.01^{**}$, $p \leq 0.001^{***}$.

MD: mean difference.

after controlling CSI score before the outbreak, is presented in [Table 8](#).

4. Discussion

The overall result of the study shows a high prevalence of depressive symptoms among caregivers tending children with special needs during the COVID-19 pandemic outbreak. A significant difference in caregiver strain was observed during the outbreak when the strain was retrospectively noted one month before the pandemic. Apart from it, we found several demographic, social factors and services related to care of child are associated with depression, stress, anxiety symptoms and perceived strain.

The study observed a high prevalence of depressive symptoms (62.5 %) among caregivers whereas 20.5 % and 36.4 % were indicated for anxiety and stress symptoms respectively. Our study reported a significantly high prevalence of depressive symptoms among caregivers in contrast to 37.1 % and 20.1 % reported by two Chinese studies conducted during the initial period of lockdown among the general population ([Ahmed et al., 2020](#); [Huang & Zhao, 2020](#)). It was also noted that an extended period of outbreak was not associated with a change in depression score among the general population ([Wang, Pan et al., 2020](#); [Wang, Hu et al., 2020](#)). Caregivers of children with special needs face unique challenges in family, social life and are stigmatized in society because of their children's disability. Behavioral issues are also very common in this population ([Martin et al., 2019](#); [Vadivelan et al., 2020](#)). However, in comparison to a low prevalence of depression reported by previous studies among caregivers of ASD (43 %), CP (26 %), intellectual and developmental disabilities (IDD) (29 %) children, a higher prevalence in our study was possibly because of the added burdens after the outbreak ([Al-Farsi et al., 2016](#); [Sajedi et al., 2010](#); [Singer, 2006](#)). Thus, we assume the high prevalence in our sample may be due to the combined effect of lock-down and the particular nature of their occupation. Moreover, the impact of the increase in death rate in India and the amount of pandemic media coverage during the time of data collection may have contributed to increased depression level.

The low prevalence of anxiety symptoms in the present study is similar to the data reported by past research on parents of intellectual disabled (18.33 %) and IDD (31 %) ([Tak et al., 2018](#); [Scherer et al., 2019](#)). Although the Chinese and Iranian general population observed a high prevalence of anxiety during the pandemic, the lower prevalence in our caregivers might be related to the timing of the individual studies ([Ahmed et al., 2020](#); [Moghanibashi-Mansourieh, 2020](#)). Fear of disease contagiousness, knowledge on safety measures are usually the main causes of anxiety apart from financial and social issues ([Roy et al., 2020](#)). By the time this study was conducted, caregivers may have been more aware and better informed about the disease, the precautionary measures to be followed, and had partially adapted to the situation. Furthermore, during the lockdown, living with the family members and increased interpersonal communication might have had a direct effect on anxiety scoring. The same factors probably attributed to stress levels unlike to the previous study results ([Al-Farsi et al., 2016](#); [Masulani-Mwale et al., 2018](#)). Recent research also identified a strong relationship between psychological and physical symptoms in the general population and among health workers during the COVID-19 pandemic ([Chew et al., 2020](#); [Wang, Pan et al., 2020](#); [Wang, Hu et al., 2020](#)). These common symptoms such as throat pain, headache, migraine and fatigue are often confused with associated symptoms of viral infection and may further aid in deteriorating mental health.

Caregivers not continuing tele-rehabilitation during the lockdown are associated with a high anxiety level and a strong association was found between a caregiver's perception on tele-consultation as an alternate medium for rehabilitation and psychological symptoms. We found that subjects who responded with a perception against tele-consultation were at greater risk for depression, anxiety

Table 8
ANCOVA tests between the groups differences in CSI during outbreak (N = 264).

Factors	df	F	B	T	p	η_p^2
Child's age	1	4.514				
<6 ^a			-0.859	-2.125	0.035*	0.017
≥6						
Continuing tele-rehabilitation	1	4.37				0.016
Yes ^a			-0.921	-2.092	0.037*	
No						
Caregiver's perception on tele-rehabilitation as an alternate option	1	12.598				0.046
Yes ^a			-1.521	-3.549	<0.001***	
No						
Learned homecare therapy	1	8.015				0.030
Yes ^a			-1.383	-2.831	0.005**	
No						
Perception on difficulty of homecare therapy	2	22.101				0.145
Easy			-4.402	-5.226	<0.001***	
Moderate ^a						
Difficult			1.045	2.727	0.007**	
Independence in eating	1	3.786				0.014
Dependent			0.799	1.946	0.053	
Independent ^a						
Independence in dressing	1	8.935				0.033
Dependent			-1.291	-2.989	0.003**	
Independent ^a						
Independence in Hygiene	1	3.245				0.012
Dependent			-0.801	-1.801	0.073	
Independent ^a						
Independence in mobility	4	10.630				0.141
Level 1			-2.126	-4.085	<0.001***	
Level 2			-1.613	-2.718	0.007**	
Level 3			0.595	0.787	0.432	
Level 4			-2.888	-5.401	<0.001***	
Level 5 ^a						
Working from home during lockdown	2	17.968				0.121
Yes ^a			-1.421	-3.202	0.002**	
Not applicable being homemaker			-3.073	-5.992	<0.001***	
No						
Elder living at home	1	4.742				0.018
Yes ^a			-0.865	-2.178	0.030*	
No						
Steady financial income	1	0.649				0.002
Yes ^a			-0.378	-0.805	0.421	
No						

*CSI before the outbreak (retrospective) as co-variate in the model.

Note: $p \leq 0.05^*$, $p \leq 0.01^{**}$, $p \leq 0.001^{***}$; a - referent factor.

B = Estimates; η_p^2 Partial Eta squared.

Mobility level 1: Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces.

Level 2: Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces.

Level 3: Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes, etc.).

Level 4: Can sit on their own but does not stand or walk without significant support and adult supervision.

Level 5: Has difficulty sitting on their own and controlling their head and body posture in most position.

and stress symptoms. With the advancement in technology, tele-rehabilitation is considered as an alternative medium in health care. Moreover, to provide solutions to global disease and to better battle against this current pandemic, tele-rehabilitation should have a greater emphasis wherever feasible. Poor utilization and acceptance of tele-health service was also observed in another Indian study (Khanna et al., 2018). The overlooked barriers in a developing country such as poverty, confidentiality, privacy and cross-cultural acceptance of tele-rehabilitation strategies are the probable factors for the negative perception of tele-rehabilitation warrant future exploration (Khan et al., 2015). Moreover, caregiver's knowledge on the importance of tele-rehabilitation, patient and therapist bonding, communication between participants play a major role in creating acceptance of tele-rehabilitation and a positive perception in caregivers (Kairy et al., 2013; Mair et al., 2005). Thus, the present work encourages greater urgency for policy makers and care providers to implement and strengthen greater use of tele-rehabilitation approaches and to provide better education on the benefits of tele-rehabilitation as a means to reduce depression, stress and anxiety symptoms among caregivers tending children with special needs.

Parents/caregivers participation and engagement are major components in rehabilitation of children with disability as they spend more time with them (Phoenix et al., 2020). Thus, it is advisable that the caregivers should strive to learn homecare treatment techniques from the therapists to enhance their overall functional ability. However, due to a sudden declaration of lockdown many

caregivers were unable to learn homecare techniques in an appropriate manner that might have resulted in wrong perception about difficulties encountered during homecare therapy. Caregivers who did not learn homecare therapy were associated with depression and who held a perception that homecare therapy is moderate to difficult was strongly associated with stress symptoms. These findings indicate either lack of education on the importance of homecare therapy or ineffective home care training was provided to caregivers deserves greater consideration. We also found that certain immediate non-modifiable factors such as dependency in eating, dressing and hygiene were risk factors for depression, anxiety and stress symptoms similar to that reported in a previous study (Batool & Khurshid, 2015). We observed that both caregivers of children who could walk long outdoor distances without difficulty (mobility level 1) and with difficulty (level 2) were associated with poor mental health compared to those caregivers with children having only independent sitting ability (level 4). Most of the participants in level 1 and 2 were ASD and LD while in level 4 CP were the majority. Therefore, we can assume that sensory and behavioral issues of children are the main contributors to poor psychological health in their caregivers. Working from home during the lockdown is also found to be a risk factor for poor mental health. The reason could be by being at home they have to care the child in addition to their job schedule at home. Caregivers of older children were less prone for depression, anxiety and stress symptoms because they are likely to be more autonomous, independent in function and less demanding for caregivers. This data was confirmed by the positive association between dependency in eating, dressing, hygiene and higher depression, anxiety and stress symptoms. Moreover, coping strategies learnt by parents over time might have aided in reducing the poor psychology associated with the children's disability.

Health is defined as a state of complete physical, mental and social well-being and to observe all the three dimensions of caregiver's health, the CSI questionnaire was used (WHO definition of health, 2020). One month before the COVID-19 pandemic lockdown a mean perceived strain of 4.30 was observed in our sample (when asked to score it retrospectively) which significantly increased to 7.29 post-lockdown. This level of increase demands that greater attention to be paid to effectively alleviate this added strain. Relationship between caregiver strain and functional limitation of the child remain inconclusive. We noticed children with indoor mobility with orthotic devices and lack of independent sitting ability groups were strongly associated with increased caregiver strain. This finding is corroborated by the previously published Indian study (Prakash et al., 2017). On the other hand, a lower level of strain among caregiver's of children with dependency in dressing indicates it should not be an immediate primary goal by care providers to reduce strain in the caregivers during this pandemic. Caregivers continuing tele-rehabilitation and homecare therapy scored these types of therapies to be physically strained and confining in CSI questionnaire. This was supported by the findings that the strain was more in caregivers whose perception of homecare therapy was moderate to difficult. Thus, better communication between rehabilitation professionals and caregivers is needed to teach the strategies in an efficient manner to reduce strain. Furthermore, there should be a call for greater attention among rehabilitation care providers and policy makers for increasing education in this area. Family adjustments, keeping a fixed work schedule and simulating office conditions may help to decrease strain associated with care giving as a strong association was noted between working from home and perceived strain similar to mental health. Beside this, a higher strain in caregivers living with elder may be due to the burden related to additional care to them.

4.1. Limitations

This study has several limitations. First of all, to ensure safety of participants, psychological testing and caregiver strain were self administered, and not recorded by health professionals. Second, a causal relationship between COVID-19 and psychological outcome is difficult to obtain because of the cross-sectional nature of study. Moreover, COVID-19 for some participants in itself may have contributed to levels of mental health symptoms, and this was not controlled for. Third, because of the online nature questionnaire structure, and location of rehabilitation centres, the study was limited to participants in major cities who had adequate English comprehension skills. Thus, the results may not be generalizable to all caregivers tending children with special needs. Fourth, the study had not scrutinized the severity of the illness of the child and past history of mental symptoms in caregivers which likely contribute to the strain and mental health of caregivers. This aspect should be addressed in future studies. Finally, due to the time-constraint of pandemic outbreak, user involvement in instrument development was not solicited but this could be incorporated in future studies. The study represented the initial use of an on-line questionnaire that could possibly be further refined and used in future pandemics. Future investigations should longitudinally assess the mental health and strain on caregivers whenever an outbreak persists for a sufficient duration of time.

5. Conclusion

This study identifies a high prevalence of depressive symptoms displayed by caregivers tending children with special needs. The COVID-19 outbreak has had a significant impact on caregiver strain when the perceived strain one month before the outbreak was measured retrospectively. Lack of tele-rehabilitation and its negative perception were found to be associated with caregiver's anxiety symptoms and poor mental health respectively whereas continuing tele-rehabilitation added more strain to the caregivers. Caregivers who had not learned homecare therapy were more depressed, while those who learned homecare therapy methods experienced more strain. Moreover, a perception of homecare therapy as being moderate to difficult medium were significantly associated with higher stress and strain compared to those who perceived it as easy. Older children (≥ 6 years), with better self-care abilities were protective factors against caregiver's poor mental health. Finally, working from home during the lockdown was associated with poor psychological health and elder living at home poses greater stress to the caregivers. Therefore, greater communication among service providers and caregivers regarding removal of barriers associated with an unfavorable perception of tele-rehabilitation, increasing education on the homecare therapy, and provision of psychological interventions/services may help to diminish mental health issues

and strain associated with care-giving. Ultimately, by these caregiver implementations, children with special needs can receive better care during current (COVID-19) and future outbreaks.

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Data sharing

All data relevant to the study are included in the article and appendix. .

CRediT authorship contribution statement

Sapna Dhiman: Conceptualization, Methodology, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Pradeep Kumar Sahu:** Conceptualization, Methodology, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **William R. Reed:** Formal analysis, Data curation, Writing - review & editing. **G. Shankar Ganesh:** Data curation, Writing - review & editing. **Ramesh K. Goyal:** Project administration, Data curation, Writing - review & editing. **Shilpa Jain:** Data curation, Writing - review & editing.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A

Questionnaire

During Covid-19 parents/caregivers of children with special needs are facing unique challenges. Though social distancing has been widely promoted as the best strategy to avoid transmission that advice may not be realistic for people who care for children and youth with special needs and who may require therapy or assistance with daily tasks. Parents/Caregivers are struggling to balance work, child care and self-care while keeping worries of both children's and own under control, which further adding to parents/caregiver stress.

Hence this survey intends to find out Impact of COVID-19 on Parents/Caregivers mental health and caregiver strain. Participation is totally voluntary. Information provided by the participant shall be kept confidential and will be used only by the researcher for research purpose.

Consent: I have understood the details of the study. I allow using information provided by me for research purpose by Researchers.
Agree to participate in the study
Disagree

1 Name:

2 Are you the primary caregiver?

a Mother

b Father

c If Other, Specify

3 Age of the Child-

4 What is the diagnosis of the child? (e.g., Cerebral palsy, Autism, ADHD, Attention Deficit Hyperactive Disorder, Learning disability, Spina Bifida etc.)

5 Detail address of caregiver

6 Do you have a steady financial income after the COVID19 outbreak?- Yes/No

7 Do any elderly member (above 60) live with you in your family- Yes/No

8 Occupation:

9 Are you working from home during COVID-19 outbreak? Yes/No/Not applicable

10 If Yes, Does working from home affects the care you provide to your child? Yes/No

11 What are your child's functioning abilities in the following areas?

a Eating: Dependent/Independent

b Dressing: Dependent/Independent

c Hygiene: Dependent/Independent

- 12 Please read the following and mark only one box beside the description that best represents your child’s movement abilities.
 - a Has difficulty sitting on their own and controlling their head and body posture in most positions
 - b Can sit on their own but does not stand or walk without significant support and adult supervision
 - c Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes, etc.)
 - d Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces
 - e Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces
- 13 Have you learned homecare therapy of your child? Yes/No
- 14 If yes, how you find homecare therapy? Easy / moderate / difficult.
- 15 Are you able to do tele-rehabilitation with your rehabilitation service provider during this lockdown? Yes/No
- 16 Do you find tele-rehabilitation as an alternate option for rehabilitation? Yes/No

CAREGIVER STRAIN INDEX:

Two caregiver strain index questionnaire are attached. Answer the following questions according to your experience one month before and during the COVID-19 pandemic outbreak in Yes or No format.

Below is a list of things which other people have found to have difficulty with when helping care for a relative /friend. Please answer yes or no by Yes No placing a ✓ in the appropriate column

1. Sleep is disturbed because *is in and out of bed or wanders around at night*
 2. It is inconvenient because *(e.g. helping takes so much time or its long drive over to help.)*
 3. It is a physical strain *(e.g. because helping in and out of a chair, effort or concentration required)*
 4. It is confining *(e.g. helping restricts free time or cannot go visiting)*
 5. There have been family adjustments *(e.g. because helping has disrupted routine, there has been no privacy)*
 6. There have been changes in personal plans *(e.g. had to turn down a job; could not go on vacation)*
 7. There have been other demands on my time *(e.g. from other family members)*
 8. There have been other emotional adjustments *(e.g. because of severe arguments)*
 9. Some behaviour is upsetting *(e.g. because of incontinence; has trouble remembering things; or accuses people of taking things)*
 10. It is upsetting to find *has changed so much from his/her formal self (e.g. he/she is a different person than he/she used to be)*
 11. There have been work adjustments *(e.g. having to take time off)*
 12. It is a financial strain
 13. Feeling completely overwhelmed *(e.g. because of worry about: concerns about how you will manage.)*
-

DEPRESSION ANXIETY STRESS SCALE -21(DASS-21):

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 - Did not apply to me at all

1 - Applied to me to some degree, or some of the time

2 - Applied to me to a considerable degree or a good part of time

3 - Applied to me very much or most of the time

1. Are you not experience any positive feeling
 - a.

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3

(continued on next page)

(continued)

4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

Appendix B. Mean \pm SD of depression, anxiety, stress symptoms and CSI score across levels of various independent factors

Factors	Mean \pm SD			
	Depression	Anxiety	Stress	CSI
Child's age				
<6 ^a	12.67 \pm 5.84	4.92 \pm 3.08	15.67 \pm 7.02	7.02 \pm 3.64
\geq 6	9.75 \pm 6.35	2.70 \pm 2.39	11.70 \pm 7.14	7.52 \pm 3.14
Continuing tele-rehabilitation				
Yes ^a	11.27 \pm 5.27	3.27 \pm 2.00	14.22 \pm 6.06	7.53 \pm 3.27
No	11.52 \pm 8.35	5.52 \pm 3.06	12.96 \pm 9.82	6.68 \pm 3.58
Caregiver's perception on tele-rehabilitation as alternate option				
Yes ^a	10.15 \pm 4.91	2.52 \pm 1.42	12.78 \pm 5.52	7.53 \pm 3.48
No	13.23 \pm 7.64	6.12 \pm 4.69	15.59 \pm 9.29	6.91 \pm 3.19
Learned homecare therapy				
Yes ^a	10.94 \pm 5.84	3.80 \pm 2.92	14.02 \pm 6.83	7.57 \pm 3.47
No	12.89 \pm 7.65	4.33 \pm 3.80	13.22 \pm 9.06	6.22 \pm 2.76
Perception on difficulty of homecare therapy				
Easy	12.00 \pm 7.05	1.20 \pm 0.66	7.20 \pm 3.83	2.00 \pm 1.61
Moderate ^a	11.26 \pm 4.95	3.94 \pm 2.92	14.26 \pm 5.97	7.02 \pm 3.23
Difficult	11.33 \pm 7.18	4.17 \pm 3.99	14.27 \pm 8.27	7.29 \pm 3.38
Independence in eating				
Dependent	12.36 \pm 6.82	5.02 \pm 3.19	14.69 \pm 7.76	7.63 \pm 3.33
Independent ^a	9.64 \pm 4.83	2.06 \pm 1.78	12.48 \pm 6.36	6.72 \pm 3.41
Independence in dressing				
Dependent	12.45 \pm 6.76	5.55 \pm 3.88	15.41 \pm 8.03	7.08 \pm 3.23
Independent ^a	9.20 \pm 4.57	0.73 \pm 0.51	10.86 \pm 4.42	7.70 \pm 3.63
Independence in Hygiene				
Dependent	12.64 \pm 6.65	5.16 \pm 3.80	15.16 \pm 7.82	7.19 \pm 3.21
Independent ^a	8.23 \pm 3.84	0.92 \pm 0.78	10.76 \pm 4.77	7.53 \pm 3.76
Independence in mobility				
Level 1	13.08 \pm 6.49	4.83 \pm 3.72	15.33 \pm 6.96	6.29 \pm 3.85
Level 2	12.85 \pm 6.87	6.00 \pm 3.27	15.57 \pm 9.59	7.14 \pm 2.90
Level 3	11.14 \pm 3.07	2.00 \pm 1.63	11.71 \pm 5.30	9.28 \pm 2.61
Level 4	9.10 \pm 5.31	1.40 \pm 1.39	10.40 \pm 5.76	6.05 \pm 3.24
Level 5 ^a	10.60 \pm 6.57	4.43 \pm 3.74	14.95 \pm 6.87	8.91 \pm 2.50
Working from home during lockdown				
Yes ^a	13.00 \pm 7.30	5.35 \pm 3.27	16.42 \pm 6.70	8.35 \pm 3.09
Not applicable (N/A) being homemaker	10.66 \pm 6.47	4.47 \pm 3.54	12.57 \pm 8.28	7.41 \pm 3.21
No	10.51 \pm 5.10	2.56 \pm 1.72	12.71 \pm 6.78	5.66 \pm 3.49
Elder living at home				
Yes ^a	11.30 \pm 6.34	3.95 \pm 2.02	14.46 \pm 7.80	6.93 \pm 3.32
No	11.37 \pm 6.24	3.86 \pm 2.99	13.28 \pm 6.82	7.67 \pm 3.42
Steady financial income				
Yes ^a	11.91 \pm 6.23	4.05 \pm 3.83	14.35 \pm 6.85	7.04 \pm 3.62
No	9.52 \pm 6.12	3.42 \pm 2.90	12.28 \pm 8.35	7.37 \pm 3.31

Note: SD = Standard deviation.

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