

Depression and anxiety among caregivers of children and adolescents with neurodevelopmental disorders in a government tertiary hospital during the Covid-19 pandemic

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OBJECTIVES: To determine the burden of COVID-19 related mental health problems such as anxiety and/or depression among caregivers of children and adolescents with neurodevelopmental disorders in a government tertiary hospital.

MATERIALS AND METHODS: This is a cross-sectional study conducted at the Out-patient Department of PCMC. Caregiver data sheet and HADS-P forms were given to eligible caregivers.

RESULTS: A total of 102 caregivers were included. The prevalence of significant risk for anxiety disorder among caregivers of children and adolescents with neurodevelopmental disorders is 34.31% (n=35), 1.96% (n=2) for depression and 3.92% (n=4) for both anxiety and depression. Using logistic regression, marital status of common law partner and female sex have significant association with depression and anxiety; the number of household members has a direct association to significant risk for both anxiety and depression.

CONCLUSION: Female sex and common law partnership as marital status are associated with 2-3 times of having significant risk for anxiety or depression. The number of household members is correlated with an increased significant risk of having both anxiety and depression. Screening caregivers using appropriate tests would identify caregivers at significant risk for anxiety and depression and further create intervention programs.

KEYWORDS: anxiety, depression, caregivers, neurodevelopmental disorders, COVID-19, mental health

Introduction

The coronavirus disease 2019 (COVID-19) pandemic has greatly affected the lives of all people worldwide. The stress brought about by this pandemic continues to propagate and spread, stress not only from

contacting the disease or the number of deaths reported but also the disruption of everyday lives and routine, the desire for survival, the isolation and consequently the different mental health problems that may arise¹. The mental health of parents and caregivers is explored albeit given little

attention, yet it plays a major role in a child and even in family outcomes. The care of a child with neurodevelopmental disorder is a big challenge and these parents are at increased risk of suffering from mental health disorders like anxiety and depression². Hence, with all the stress brought about by the COVID-19 pandemic and the demands of caring for a child with neurodevelopmental disorder, a timely investigation into the stress and mental health of parents is warranted. The study provides a timely screening of caregivers for depression and anxiety during the time of pandemic which can be included during clinic visits for a more holistic approach. Given the mental health problems identified, evidence-based parenting programs, training, and support can be formulated to address these mental health issues. The identified mental health problems and its consequences take time, hence long-term effective identification and intervention programs specifically for caregivers of children with neurodevelopmental disorder can be promoted during clinic visits.

Neurodevelopmental disorders are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning. Children with chronic conditions and special health care needs live at home under the direct care of their caregivers who have a direct effect and influence on the family's well-being and functioning³. These children need support in terms of their physical, social, and emotional needs

and the majority rely on their parents and families¹.

Thus, caregivers play a central role among children with neurodevelopmental disorders particularly during the rehabilitation and education processes. Hence, their well-being and health are dependent also on the whole health condition of their family in terms of the support and services received, as well as participation in social life⁸.

The different factors affecting family functioning include quality of life, treatment adherence and physical health. Alongside these factors are the key drivers of family functioning namely parents' emotional wellbeing and community/emotional support³. The mental health and wellness of caregivers are linked to family well-being. Bayer and colleagues explained in their study the association of child medical complexity with parent mental health and community support and found out that parents of children with medical complexity were at the highest risk for reporting poor or fair mental health. These parents had difficulty handling the demands of parenting and does not know where to find help in their community but on the other hand also receive emotional support from health care providers and advocacy groups³.

A cross-sectional study done in 2019 by Fatima and colleagues in India assessed the burden of depression and anxiety among mothers of children with neurodevelopmental disorder.

It was found out that depression and anxiety were common among mothers of children with neurodevelopmental disorders. Among screened mothers, 38% had depression, 43% with anxiety and 30% both depression and anxiety².

In a systematic review and meta-analysis by Scherer in 2019, there is evidence for an association between parenting a child with intellectual and developmental disability and (95%) depression and anxiety (90%) symptoms, with almost all studies reporting a positive relationship and are consistent across disability type, setting, and sample size. Other factors associated with depression include household income, socio-economic which accounts elevated risk for poor maternal well-being among mothers. For parental depression, disability severity has been implicated, a higher severity means an array of behavioral problems and more care giver demands⁵.

During the pandemic, a study by Chan and Fung in April 2021 where 129 parents participated found out that higher levels parenting stress, depressive symptoms and anxiety symptoms were seen during the pandemic among parents of children with developmental disorder compared to parents of children with typical development. One fourth of parents of children with neurodevelopmental disorders met the criteria for depression and 13.7% met the criteria for generalized anxiety disorder. Also, health

worries and parenting stress contribute to poor mental health among parent subjects¹.

Pecor and colleagues investigated the effects of COVID-19 pandemic on quality of life, all caregivers reported lower scores compared to before and even during the pandemic but more dramatically for caregivers of children with neurodevelopmental disorder. By gender, mothers experienced higher levels of parental stress and mental problems as usually they are the primary caregivers⁴. This finding consistent with a meta-analysis reportwas ing higher depression in mothers compared with fathers which may result from higher responsibility in terms of caregiving among mothers or due to response bias as men tend to disclose depressive symptoms⁵.

Looking into specific neurodevelopmental disorders, among parents of children with autism spectrum disorder, Wang and colleagues showed the relationship between COVID-19 pandemic and increase in symptoms and anxiety depression reaching 13.9% and 9.8% Compared respectively. to parents of neurotypically developing children, the parents of children with autism are more vulnerable. The psychological stress brought about by the pandemic played a key role in parental anxiety and depression scores⁴. Caregivers of children with attention-deficit/ hyperactivity disorder noted higher frequency of negative interactions with their children including increased irritability, verbal abuse

and punishment⁶. Currently there are no locally published studies.

Knowing that there is an increased prevalence of anxiety and depression among parents of children with special health care needs, how then can anxiety and depression be detected among caregivers? There are different validated tools to screen and detect depression and anxiety. Among them is the Hospital Anxiety and Depression Scale Hospital (HADS). The Anxiety and Depression Scale (HADS) was originally developed in 1983 by Zigmond and Snaith. This self-assessment scale is used reliably to detect states of depression and anxiety in the setting of hospital medical outpatient clinic⁹. This self-assessment scale is valid for screening purposes only and that diagnosis depends on clinical examination. The term hospital in the name of the tool, as explained by Snaith in 2003 suggests that it is valid in this setting however many studies have validated its use in community settings and primary care medical practice. The administration of HADS takes about 5 minutes. This can be answered by participants that are literate and able to read but in cases of illiteracy, poor vision, the tool may be read to the participants¹⁰. The HADS has undergone validation and translation in foreign languages. In a review by Bjelland and colleagues in 2002 it was found that HADS performed well in assessing severity of anxiety disorders and depression in both somatic and psychiatric cases, and in primary care patients and the general population. This tool was also validated for use in different populations such as the elderly and adolescents¹⁰. The HADS questionnaire was translated to Filipino and validated by Dr. Ma. Lourdes Rosanna E. De Guzman in 2014 and was labeled as Hospital Anxiety and Depression Scale – Pilipino (HADS-P). The cut-off score for Filipino is 11 with sensitivity of 75%, specificity of 70% and a positive predictive value of 75%¹¹.

OBJECTIVE OF THE STUDY

A. GENERAL OBJECTIVE

To determine the burden of COVID-19 related mental health problems among caregivers of children and adolescents with neurodevelopmental disorders in a government tertiary hospital.

B. SPECIFIC OBJECTIVES

- To describe the demographics of caregivers of children and adolescents with neurodevelopmental disorders
- 2. To determine the prevalence of depression and anxiety among caregivers of children and adolescents with neurodevelopmental disorders
- 3. To determine the association of having anxiety and/or depression with sociodemographic factors, child characteristics and neurodevelopmental disabilities

METHODOLOGY

This was a cross-sectional study that was conducted as face-to-face session with the participants during the clinic visit and evaluation of their children with neurodevelopmental disorders at the Philippine Children's Medical Center, Quezon City.

The study's inclusion criteria are as follows:

- Caregivers of children and adolescents
 with neurodevelopmental disorders
 who are seen at the Out-Patient
 Department of the Section of
 Neurodevelopmental Pediatrics
- 2. Caregivers of admitted children and adolescents with neurodevelopmental disorders
- 3. All caregivers in the family present during the time of consultation

The study's exclusion criteria are as follows:

1. Caregivers who are diagnosed with anxiety and depression, currently being managed by a health professional.

In a study by Fatima and colleagues, the assumption of proportion of anxiety and depression among mothers is 43.3% and

37.5% respectively and with relative precision of 20%, alpha error of 5% (95% confidence level)². Using the Power Analysis and Sample Size (PASS) 2008 Output, the calculated sample size for depression is 98 and 102 for anxiety. Therefore, this study enrolled 102 eligible participants.

Permission from the author of HADS-P was obtained prior to using the questionnaire. A caregiver data sheet and HADS-P form was given to eligible caregivers by the principal investigator. An Adult Psychiatrist was on board for any crisis management.

on-going COVID-19 Due to the pandemic, standard health protocols were observed to prevent spread of the virus. The primary investigator secured informed consent and explained the objectives and methodology of the study. The administration of HADS-P was done on a face-to-face basis and took about 5-10 minutes. All participants were able to read and answer the questionnaire without any assistance from the investigator.

The participants were informed of HADS-P results immediately. Caregivers with remarkable screening test results were referred to Adult Psychiatry service in other government institutions with OPD services for adult patients for further evaluation and management.

During the data collection there was no need for crisis management and debriefing. The study was presented to the Institutional Research Ethics Committee of Philippine Children's Medical Center and commenced with the approval of the Ethics Committee.

Using statistical software (SPSS version 26), specific statistical analysis tools were employed in the analysis and interpretation of data. Descriptive statistics such as frequency count, percentage, mean, median and standard deviation were also used. Linear regression was done to predict the value of a variable based on the value of another variable while logistic regression was done for analyzing the relationship between one or more existing independent variables. Dummy coding was employed to incorporate categorical variables into regression analysis.

RESULTS

A total of 102 caregivers were included in this study. Table I shows the distribution of the caregivers according to demographic profile. Majority of the participants were from the age group of 31–40 years old (52.94%). Most participants were females (89.22%) and mothers (84.31%). As to civil status, 60.78% of the caregivers were married while 26.47% were common law partners. Almost half of the participants (44.12%) reached college levels and the majority of the caregivers were unemployed (63.73%).

Table I. Demographic Profile of Caregivers of Children and Adolescents with Neurodevelopmental Disorders

Demographic Profile Age	No./n=102	Percent	
30 and below	17	16.67	
31-40	54	52.94	
41 and above	31	30.39	
Mean	37.27 years (SD ± 0.68)		
Median	36 years old		
Range (min, max)	24, 60 years old		
Gender			
Male	11	10.78	
Female	91 89.22		
Marital Status			
Common law Partner	27	26.47	
Married	62	60.78	
Single Parent/Widow	13	12.75	

Demographic Profile Age	No./n=102	Percent				
Educational Attainment						
Elementary	6	5.88				
High School	40	39.22				
College	45	44.12				
Vocational	11	10.78				
Occupation						
Employed	29	28.43				
Self-Employed	8	7.84				
Unemployed	65	63.73				
Relation to Child with Neurodevelop	mental Disorder					
Father	11	10.78				
Mother	86	84.31				
Other Relative	5	4.90				

In terms of family monthly income, majority of the participants have monthly income falling under the low-income class (Php 12,082-24,164) to lower middle-income class (Php 24,164 – Php 48,328) based on the Philippine Statistics Authority classification¹³. The majority of the caregivers have one child and 5 to 6 household members.

Table II. Distribution of caregivers according to household information

Household Information	No./n=102	Percent		
Php 10,000 and below	41	40.20		
Php 10,001 – Php 20,000	49	48.04		
Above Php 20,000	12	11.76		
Mean	Php 15,858.82 (SD [±] Php	12,458.89)		
Median	Php 12,000.00			
Range (min, max)	Php 3,000, Php 70,000.00			
Number of Children				
1	33	32.35		
2	27	26.47		
3	23	22.55		
More than 3	19	18.63		
Median	2			
Range (min, max)	1, 6			

Number of Household Members				
4 and less	36	35.29		
5 to 6	43	42.16		
More than 6	23	22.55		
Median	5			
Range (min, max)	2,17			

Looking into the demographic profile of children of caregivers in this study, majority were from the age group of 4–17 years old (44.12%) and first born (46.08%), As to neurodevelopmental diagnosis, majority have Autism Spectrum Disorder (34.31%), followed by those who have Intellectual Disability (21.57%), with Global Developmental Delay (20.59%), Cerebral Palsy (17.65%) and those with ADHD and down syndrome (both 1.96%). For intervention, most children have no intervention (therapies) yet and are not yet enrolled in schools (59.80%). A co-morbid diagnosis of Epilepsy was seen among 35.29% of these children and are maintained on anti-seizure medications.

Table III. Demographic Profile of Caregivers' Children

Demographic Profile	No./n=102	Percent
3 yrs old and below	26	25.49
4 – 7 years old	45	44.12
8 years old and above	31	30.39
Mean	6.40 years (SD [±] 0.40)	
Median	6 years old	
Range (min, max)	0.42, 17 years old	
Birth Order		
1 st	47	46.08
2 nd	24	23.53
3 rd	20	19.61
4 th onwards	11	10.78
Diagnosis		
ADHD	2	1.96
Autism Spectrum Disorder	35	34.31
Cerebral Palsy	18	17.65
Down Syndrome	2	1.96
Global Developmental Delay	21	20.59
Infant at High Risk for Developmen-	2	1.96
Intellectual Disability	22	21.57

Intervention					
none	41	40.20			
OT alone	12	11.76			
PT alone	15	14.71			
OT and PT	11	10.78			
OT and ST	20	19.61			
PT and ST	1	0.98			
OT, PT, ST	2	1.96			
Education					
none	61	59.80			
SPED	24	23.53			
Nursery – Grade 6	17	16.67			
Maintenance Medication					
none	66	64.71			
Taking medications	36	35.29			

While majority of the caregivers did not display a significant risk for anxiety and depression, the prevalence of significant risk for anxiety disorder among caregivers and adolescents with neurodevelopmental disorders is 34.31% while significant risk of depression is seen in only 1.96%. Almost 4% (4 caregivers) showed a significant risk for having both anxiety and depression.

Table IV. Prevalence of risk for depression and anxiety among caregivers of children and adolescents with neurodevelopmental disorders

Risk for Depression and	No.	Percent
Normal	61	59.8
Anxiety	35	34.31
Depression	2	1.96
Depression and Anxiety	4	3.92
Total	102	100%

Caregivers of children with autism spectrum disorder showed higher risk of anxiety and depression than in the other neurodevelopmental diagnosis followed by caregivers of children with intellectual disability and global developmental delay.

Table V. Cross tabulation of prevalence of significant risk for depression and anxiety according to neurodevelopmental disorders

Diagnosis	То	tal	Nor	mal	Depre	ession	Anx	ciety		ession nxiety
g	No.	%	No.	%	No.	%	No.	%	No.	%
Autism Spectrum Disorder Level 3	35	34.3	21	60	1	3	11	31	2	6
Intellectual Disability	22	21.6	13	59	-	-	9	41	-	-
Global Developmental Delay	21	20.6	12	57	1	5	7	33	1	5
Cerebral Palsy	18	17.6	13	72	-	-	5	28	-	-
ADHD moderate	2	2	-	-	-	-	1	50	1	50
Down Syndrome	2	2	2	100	-	-	-	-	-	-
Infant at High Risk for Developmental Delay	2	2	-	-	-	-	2	100	-	-

Logistic regression showed that caregivers with marital status of common law partner has 2.558 higher likelihood of anxiety disorder while 1.760 likelihood in depression than the other caregivers with different status. It may mean that caregivers with marital status of common law partner are more likely to have anxiety or depression disorder than caregivers with different status. As to sex, female caregivers have a higher score for anxiety disorder and depression than male caregivers. It may mean that female caregivers are more likely to have anxiety or depression disorder than male caregivers. In Table VI, using stepwise regression, there are two variables with a significant risk for anxiety and depression. The excluded variables have p-values greater than 0.05 level of significance which indicates that there is not enough evidence to conclude that these variables are associated with significant risk for anxiety and depression.

Table VI: Linear Regression analysis of independent variables correlated to scores of significant risk for anxiety and depression

	Anxie	ety	Depression		
Significant variables	Coefficients	P-value	Coefficients Beta	P-value	
Caregivers Marital Status (Dummy coding: CLP=1)	2.558	.004	1.760	.023	
Caregiver's Sex	3.642	.004	2.333	.034	

Excluded Variables	Coefficients Beta	P-value	Coefficients Beta	P-value	
Caregiver's Age	.052	.611	023	.832	
Caregivers Marital Status (Dummy coding: M=1)	.214	.130	.009	.954	
Caregivers Marital Status (Dummy coding: Others=1)	146	.130	006	.954	
Family Monthly Income	017	.860	114	.253	
Number of Children	.020	.831	.008	.935	
Number of Household Members	126	.184	022	.825	
Child's Age	105	.284	080	.431	
Child Diagnosis	.089	.344	.063	.516	
Child Diagnosis	080	.395	070	.469	
Child Diagnosis	008	.936	.057	.560	
Child Diagnosis	009	.920	087	.370	
Child Diagnosis	022	.819	.041	.672	
R square	.139		.085		

Among the four participants at risk for both anxiety and depression, the number of household members has a direct association with risk for both anxiety and depression. The more household members there are, the higher the tendency to have significant risk for both anxiety and depression.

Table VII. Logistic Regression analysis of independent variables association of significant risk for both anxiety and depression

	Anxiety and Depression			
Significant variables	Coefficients Beta	P-value		
Number of Household Members	.220	.051		
Excluded Variables	Coefficients Beta	P-value		
Caregiver's Age	.003	.956		
Caregiver's Sex	.399	.528		
Caregivers Marital Status (Dummy coding: M=1)	.140	.709		
Caregivers Marital Status (Dummy coding: CLP=1)	.005	.946		
Caregivers Marital Status (Dummy coding: Others=1)	.179	.673		
Family Monthly Income	.631	.427		
Number of Children	.195	.659		
Child's Age	.046	.830		

Child Diagnosis	1.014	.314	
Child Diagnosis (Dummy coding: CP=1)	.597	.440	
Child Diagnosis (Dummy coding: GDD=1)	.025	.874	
Child Diagnosis (Dummy coding: ID=1)	2.050	.152	
Child Diagnosis (Dummy coding: Others=1)	1.539	.215	
R square	.106		

DISCUSSIONS

The present study showed the burden of COVID-19 related mental health problems among 102 caregivers of children and with neurodevelopmental adolescents disorders. Using the HADS-P, 35 caregivers (34.31%) were identified to have significant risk for anxiety, two were identified to have significant risk for depression and four caregivers for both anxiety and depression. These caregivers were informed of the screening results and subsequently referred to Adult Psychiatry service in other government institutions for further evaluation management.

Among those with significant risk for anxiety, 31% have children with autism spectrum disorder. This finding is consistent with the study of Ersoy and colleagues in 2020 showing a higher level of anxiety on chronic diseases in mothers of children with autism compared to mothers with normal children during the time of pandemic¹⁴. A study by Purpura in 2021 showed that higher

levels of stress are evident in caregivers of children with a primary diagnosis of autism spectrum disorder and intellectual disability than caregivers of children with other neurodevelopmental disorders. This was attributed to the intrinsic and pervasive characteristics of these two disorders⁸. Given the present situation, parents of children with experience autism mav more stress aggravated by new or increased behavioral problems¹⁵.

Before the pandemic, a study by Fatima and colleagues showed that depression and anxiety were common among mothers of children with neurodevelopmental disorders. It screened positive for 91 mothers and diagnosed 52 with generalized anxiety disorder which was consistent with the screening results of the present study². During the pandemic it is expected that there would be higher prevalence of anxiety and depression, corollary to a study by Chan and Fung showing higher levels parenting stress,

depressive symptoms and anxiety symptoms among parents of children with developmental disorder compared to parents of children with typical development¹. Hence, there is an increased risk of having anxiety and/ or depression among caregivers of children with neurodevelopmental disorders with or without the pandemic compared to their counterparts.

One of the objectives is to determine the association of having significant risk for anxiety and/or depression with sociodemographic child factors, characteristics and neurodevelopmental disabilities. Interestingly, female sex and marital status of common law partnership are associated to 2-3 times of having significant risk for anxiety or depression. This may be due to the fact the most participants are mothers (84%), mostly unemployed and the ones assigned as primary caregivers who are with their children for most of the day. Often, they must care for their children on top of other household chores and family responsibilities. Looking at the gender per se, a study by Amendola and colleagues in 2021 found that females reported higher symptoms of depression, anxiety, and circadian rhythm dysregulation than males. However, one important note is that lockdowns are a new type of situation and that the mental health of men and women may be affected both in similar and differing ways¹⁷.

In terms of marital status, a study by Grundstrom investigated associations between

relationship status and mental well-being. It revealed that cohabiting tended not to differ from marriage in terms of having better mental well-being. The risk factors for depressive symptoms and lower self-esteem are being single or being divorced¹⁸. This contradicts the findings of the present study. Another interesting finding in this study worth pursuing in the future is the finding that the number of household members correlated with having an increased significant risk for having both anxiety and depression. We can only surmise that more household members mean more responsibilities.

The nature of the study limits the researcher to use causal inferences to determine the association of having anxiety and/or depression with different factors; longitudinal research may be used for this one.

Conclusion

This study focused on the mental health of caregivers of children and adolescents with neurodevelopmental disorders. Thirty-five caregivers (34.31%) were identified to have significant risk for anxiety, two were identified to have significant risk for depression and four caregivers for both anxiety and depression. Female sex and marital status of common law partnership are associated to 2-3 times of having significant risk for anxiety or depression. Further, the number of household members is correlated with having increased significant risk of

having both anxiety and depression. The caregiver's age and sex, family income, number of children, child's neurodevelopmental diagnosis had no enough evidence to conclude that these variables have significant association to significant risk for both anxiety and depression. Screening of caregivers in clinical settings using appropriate tests would yield to identifying caregivers at significant risk for anxiety and depression and further create intervention programs both preventive and rehabilitative.

Screening for anxiety and depression of caregivers using appropriate tests should be part of the holistic care of children with neurodevelopmental disabilities since caregivers have a significant role in the success of these interventions. Timely checks on the mental health status of the caregivers are of paramount importance. identified, prompt referrals to appropriate services need to be made. Parent training and parental education as well as psychosocial support groups for parents can promote positive parenting and help address the mental health issues of parents especially during the time of COVID-19 pandemic.

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