



# Mental Health Impact on Caretakers of Children with Neurodevelopmental Disorders in Nepal

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## ABSTRACT

### Background

The impact of neurodevelopmental disorders (NDD) on the mental well-being and overall quality of life for families with affected children is becoming increasingly recognized. The aim of the study is to see mental health impact on caretakers of children with neurodevelopmental disorder.

### Methods

This hospital based cross-sectional study was conducted in all patients who came to the hospital during three-month period at out patient's clinic of Department of Psychiatry from August to October 2024. The DASS-21 was employed for the assessment of depression, anxiety and stress. DASS has been translated into various languages, including the presently employed Nepali version. The association between psychosocial and sociodemographic characteristics were assessed using Chi-square test. All statistical analyses were performed using the SPSS version 16 and p-value <0.05 was considered as statistically significant.

### Results

The mean age of caretaker were 45 years. Minor difference was noticed in the number of caretaker belonging to nuclear 28 (59.6%) and joint families 19 (40.4%). Among the caretakers majority were educated 32 (68%), Hindu by religion 31 (66%) and were from urban area 29 (61%). In our sample, we found high level of burden; 42.6% of caretakers had depression, 55.3% had anxiety and 33% had stress.

### Conclusions

Caretakers of children with neuro developmental disorders are more prone to develop high level of burden, depression, anxiety and stress.

**Keywords:** anxiety; caretakers; depression; neurodevelopmental disorder.

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## INTRODUCTION

Neurodevelopmental disorders (NDDs) refer to conditions that influence the growth of the brain. In the United States, data released by the National Center for Health Statistics (NCHS) in 2015 indicates that an estimated 15% of children aged 3 to 17 years are impacted by NDDs.<sup>1,2</sup> A meta-analysis performed between 2014 and 2018 found a positive correlation between raising a child with NDD and experiencing symptoms of depression and anxiety.<sup>2</sup> In another research indicated that 41.8% experienced heightened psychological stress levels.<sup>3</sup> many studies revealed that caregivers tend to face considerable stress, anxiety, and depression.<sup>4,5</sup> Furthermore, they often become confined to their homes, leading to a loss of social interactions, free time, and opportunities for career advancement.<sup>6</sup> Caregivers experience significant rates of mental health issues. Various elements can indicate the likelihood of psychological issues in caregivers, particularly the degree of caregiver burden.<sup>7</sup> The objective of this study is to assess different psychological impacts (stress, anxiety, and depression) in the caregivers of children with neurodevelopmental disorders.

## METHODS

This is the Hospital based cross-sectional study conducted at Department of Psychiatry, Dhulikhel Hospital. All patients who came to the hospital during three-month period at out patient's clinics from August to October 2024. This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Ethical approval was taken from the Institutional Review Committee (IRC) of Kathmandu University School of Medicine (IRC-KUSMS Approval No. 68/23). Eligibility criteria were: voluntary written consent and primary caregivers of children aged 2-12 years with NDD and caregivers with age more than 20 years. The primary caregiver was defined as the person responsible for the day-to-day decision-making and care of the child. Socio-demographic information of the caretakers like age, sex, marital status, religion, residential area, education, occupation, monthly family income,

chronic illness and family history of psychiatric disorders, relation to children, type of family, family support, social support, and duration of care using a semi-structured questionnaire. Information about the characteristics of children like age, sex, gender, type of neuro-developmental disorder and age at diagnosis was obtained from the case records of the child.

Three dependent variables were included in the study: depression, anxiety and stress. Caretakers who scored five or more on DASS 21 were considered as screened positive for depression and similarly those who scored four or more were considered as screened positive for anxiety and those who scored eight or more were considered stressful. The DASS-21 was employed for the assessment of depression, anxiety and stress. DASS has been translated into various languages, including the presently employed Nepali version, and its psychometric properties have been found to be adequate in various populations including Nepali.<sup>8</sup> Each item is measured on a four-point Likert scale ranging from 0 ("Did not apply to me at all") to 3 ("Applied to me very much"). The total sum for DASS-21 is derived by summing the total scores of all individual items as detailed elsewhere. There are 21 questions in DASS-21, seven questions for each one of stress, anxiety, and depression. The rate was divided into normal or having symptoms of stress, anxiety, or depression.<sup>9</sup>

In addition to assessing depression, stress, and anxiety separately, the DASS-21 can also be used to measure a common factor of psychological distress that is shared by all three subscales. To do this, the total scores of the depression, anxiety, and stress subscales are summed together. This instrument has been widely used and validated in research,<sup>10</sup> making the DASS-21 one of the most established psychometric tools for assessing the overall psychological distress along with stress, depression, and anxiety.<sup>11</sup> All statistical analyses were performed using SPSS version 16 and the p-value <0.05 was considered as statistically significant. Categorical variables were expressed as proportions whereas the continuous variables were expressed as mean (SD) or median (IQR) based on normality. We summarized depression, anxiety and

stress as proportion with 95% confidence interval (CI). Association of depression, anxiety and stress with the socio-demographic characteristics was assessed using chi-square test and unadjusted prevalence ratio with 95% CI was calculated. Multivariable regression analysis was not done.

## RESULTS

A total of 47 parents of children with NDDs completed the study questionnaire. Table 1 shows that Parents' ages ranged from 20 to more than 60 years, with a mean age (SD) of caretakers were 45(9±2) years. Out of the 47 caretakers of children with NDD included; 26(55.3%) belonged to the age group up to 45 years and below and 21(44.7%) belonged to age group 45 years and less. The number of caretakers belonging to nuclear family type was 28(59.6%) and joint family's type was 19 (40.4%). Among the caretakers, majority were educated 32 (68.1%) and 15(31.9%) were not educated, Hindu by religion were 31(66%) and non-Hindu were 16(34%). More than half were from urban

<b>Table 1. Socio-demographic variables of caretakers. (n=47)</b>	
<b>Variables</b>	<b>Frequency (%)</b>
<b>Age</b>	
Up to 45	26(55.3)
≥ 46	21(44.7)
<b>Sex</b>	
Male	24(51.1)
Female	23(48.9)
<b>Marital status</b>	
Single	8(17.0)
Married	39(83.0)
<b>Religion</b>	
Hindu	31(66.0)
Non-Hindu	16(34.0)
<b>Occupation</b>	
Unemployed	17(36.2)
Employed	30(63.8)
<b>Education</b>	
No formal	15(31.9)
Formal	32(68.1)
<b>Demography</b>	
Rural	18(38.3)
Urban	29(61.7)

area 29 (61%) and 18(38.3%) were from rural areas. Two third of participants 39(83%) were married and only 8(17%) were single (Table 1).

As shown in Table 2, caretakers were equally distributed among father 24 (51.1%) and mother 23 (48.9%), and most of the children, almost 60% lived in the nuclear family. Half of the caretakers reported receiving support from their families, while an equal number stated they did not receive any family support. Family support, family type, occupation and family history of psychiatry illness are the variables that were associated with depression, anxiety and stress (Table 3).

<b>Table 2. Psychosocial variables impacting caretakers mental health. (n=47)</b>	
<b>Variables</b>	<b>Frequency (%)</b>
<b>Relationship to child</b>	
Father	24(51.1)
Mother	23(48.9)
<b>Family type</b>	
Nuclear	28(59.6)
Extended	19(40.4)
<b>Duration of Care</b>	
18 years	25(53.2)
≥18 years	22(46.8)
<b>Social support</b>	
Yes	23(48.9)
No	24(51.1)
<b>Family support</b>	
Yes	26(55.3)
No	21(44.7)
<b>Perceived stress</b>	
Yes	30(63.8)
No	17(38.2)
<b>Number of children</b>	
Single	7(14.9)
More	40(85.1)

## DISCUSSION

Our study sought to assess the mental health burden of depression, anxiety and stress amongst the caretakers of children with common NDD attending a mental health facility in tertiary care center in Nepal. In our sample, we found high level of burden; 42.6% of caretakers had depression, 55.3% had anxiety

Table 3. Psychosocial variables and their association with depression, anxiety and stress. (n=47)									
Variables	Depression (Yes) n(%)	$\chi^2$	p-value	Anxiety (Yes) n(%)	$\chi^2$	p-value	Stress (Yes) n(%)	$\chi^2$	p-value
Family support									
Yes	15(75)	5.4	0.02	17(65.4)	2.3	0.1	11(68.8)	2	0.1
No	5(25)			9(34.6)			5(31.2)		
Family type									
Nuclear	12(60)	0.003	0.9	16(61.5)	0.1	0.7	13(81.2)	5	0.03
Extended	8(40)			10(38.5)			3(18.8)		
Occupation									
Employed	12(60)	0.72	0.39	16(61.5)	0.1	0.7	7(43.8)	4	0.04
Unemployed	8(40)			10(38.5)			9(56.2)		
Family history of psychiatry illness									
Up to 15 years	4(20)	1.6	0.2	6(23.1)	5.5	0.01	4(25)	3	0.07
16 years & above	16(80)			20(76.9)			12(75)		
Subjective feeling of stress									
No	11(55)	1.7	0.2	13(50)	4.8	0.02	6 (37.5)	7	0
Yes	9(45)			13(50)			10(62.5)		
Social support									
Yes	13(65)	3.5	0.05	18(69.2)	9.5	0.002	10(62.5)	2	0.1
No	7(35)			8(29.8)			6(37.5)		

and 33% had stress. The caretakers identified with depression and anxiety were informed about their mental health condition and were treated by the department of psychiatry. Our estimates were much higher compared to that of Nepal National Mental Health Survey 2020; the prevalence of depression among age group of 40-49 years was (4%) and lifetime prevalence of anxiety was 17%.<sup>12</sup> The finding of a high level of distress in caregivers of NDD children is in line with previous studies of caregivers of children with intellectual disability in Nepal<sup>13</sup> and other studies of children with disabilities in India.<sup>14</sup> One study from India among mothers of different type of neurodevelopmental disorders reported that 46% were diagnosed depression, 52% were diagnosed anxiety disorder and 36% were diagnosed both anxiety and depression.<sup>15</sup>

Likewise, study from Pakistan also reported high level of mental health issues among caretakers. In this study, a total of 76.3% of informal caregivers were suffered from mild depression, 59.3% were moderately depressed and 76.5% were severely depressed. When it comes to anxiety, it was even higher compared to depression. Among caretakers

72.4% had mild anxiety, 68.2% had moderate anxiety, and 50.5% had severe anxiety. In addition, 75.0% demonstrated mild, 71.1% moderate, 85.7% severe, and 95.0% extremely severe stress.<sup>16</sup>

Study from Saudi Arabia found that, most of the parents had depression, 21.5% mild, 25.5% moderate, and moderate to severe among 38%. Furthermore, anxiety was also present among most parents, mild among 26.7%, moderate among 27.4%, and severe among 31.7%. Most importantly, most parents were found to have both depression and anxiety, while only 8.9% were free of these conditions.<sup>17</sup> Similar findings were reported from African continent. Ocansey P M et.al finds that, about 56.2%, 66.2% and 78% of the caregivers experienced severe anxiety, severe depression and moderate to severe stress symptoms respectively.<sup>18</sup>

In our study age of the caregivers was not associated with depression, anxiety and stress. In the literature, the evidence on the relationship between care takers age and depression is mixed. While some reported increased in depression with older age.<sup>2</sup> While others studies found that younger caregivers to be more depressed.<sup>19</sup> Hodapp et al.<sup>20</sup> and Dabrowska

et al.<sup>21</sup> reported that, mothers of autistic children experienced more depression, anxiety and stress as compared to fathers. The literature globally, is divided on this matter. In multiple studies, similar results have demonstrated that mothers and fathers of children with NDDs express anxiety, depression, and stress at similar rates.<sup>22</sup> Researchers from Oman also found that the mothers and fathers of children with ADHD and intellectual disabilities demonstrated that both parents have similar rates of depression and anxiety. On the other hand, a study in Kuwait suggested that mothers of children with autism have higher rates of depression than fathers.<sup>23</sup> Even though it anticipated that females, particularly mothers, would experience more distress, there was no notable correlation between mental health issues and the gender of caregivers in our study. A possible explanation for this finding is that it could be due to multiple factors that can contribute the mental health of caretakers like social support, family dynamics, economic conditions, resilience of individual parents and comorbidities.

In our study the level of education of parents of neurodevelopmental disorders was not significantly associated with depression, anxiety and stress. Previous studies showed that the educational level was not significantly associated with stress but found that depression and anxiety were higher among more educated caregivers.<sup>24</sup> This may be because educated parents are more aware about the condition and are more worried about the child's condition. Family history of psychiatric disorders is an established risk factor and, we found this was associated with anxiety in our study. However, we did not find depression and stress were associated with family history of psychiatry disorders.<sup>25</sup> Family history may have been under reported due to stigma. Review of Ribeiro (2013) found that, feeling satisfied with social support, having a positive view of the parental role, maintaining a strong family connection and an emotional bond between parent and child, receiving support from your partner, all contributes to lowering stress levels.<sup>26</sup> Our finding is in line with these studies. One study revealed that parents of children with

autism spectrum disorder or ADHD have a higher rate of parenting distress compared with parents of children with other NDDs. however, due to small sample size we have not evaluated the association of depression, anxiety and stress with different type of neurodevelopmental disorders.<sup>27</sup>

There was no correlation between the number of family support and psychological stress and anxiety in our study, however depression was significantly associated with family support. Maridal HK et.al study from Nepal found that the only help source that was significantly correlated with lower psychological distress was advice and help from health workers, indicating that health workers might have an important role in reducing stress in caregivers.<sup>28</sup> Providing target family support to meet the needs of family caregivers may alleviate their anxiety and depression as well as improve mental wellbeing.

### Limitations

Most significant limitation is sample size, and statistical interpretation should be made with caution. It could be that parents of a child with a neurodevelopmental disorder do not reach out to a psychiatrist for assistance. Since the study concentrated on caregivers, it admits the constraint of not taking comprehensive clinical data on the children which could be potential factors influencing the study results.

### CONCLUSIONS

This study findings support the evidence that caretakers of children with neuro developmental disorders are more prone to develop depression, anxiety and stress. These vulnerable group needs special emotional and psychosocial support. These facts should be taken into consideration while planning the care interventions for caretakers.

**Conflict of interest:** None

**Funding:** None



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**Citation:** Kunwar D, Shrestha B, Risal A. Mental Health Impact on Caretakers of Children with Neurodevelopmental Disorders in Nepal. *JCMS Nepal*. 2025; 21(3): 307-313.