

Mental Health Status of Mothers Having Children with and without Disability: A Comparative Study of Women in Nepal

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ABSTRACT

Introduction

Childhood disabilities pose a significant risk to maternal mental health. This study aims to compare the mental health of mothers raising children with autism spectrum disorder (ASD) and developmental delays (DD), comparing their stress levels including anxiety and depression with those of mothers of neurotypical (NT) children.

Method

A cross-sectional survey of mothers attending Pediatric outpatient Department of TU Teaching Hospital in Kathmandu was conducted immediately post-pandemic. The Hopkins Symptom Checklist-25 (HSCL-25) was used to measure stress including anxiety and depression. Mothers of children with ASD, DD, and NT children, without other comorbid health conditions were included in the study.

Results

Of the total 150 participant mothers, 34 (22.6%) were mothers of children with ASD, 32 (21.3%) were mothers of children with DD, and 84 (54.6%) were mothers of NT children. More than half of the mothers with children with ASD and DD were found to have stress including anxiety and depression, as compared to 9.5% of the mothers with NT children. Mothers of children with ASD had significantly higher odds of stress (OR 15.7; 95% CI: 5.6–44.1; $p < 0.01$). Similarly, mothers of children with DD also showed higher odds of stress (OR 11; 95% CI: 3.9–31.1; $p < 0.01$). Maternal education was identified as an important predictor of stress. Higher stress level was observed among mothers of children with ASD who had education below the 10th grade, with an odds ratio of 7 (95% CI: 0.75–65.2).

Conclusion

There is high level of anxiety and depression in mothers with children with ASD and DD as compared to mothers with NT children.

Keywords

Autism spectrum disorder; development delay; maternal mental health; neuro-typical

INTRODUCTION

Women in Nepal experience discrimination in the form of social, political and economic exclusion, and gender-based violence.¹ With out-migration of men for economic opportunities, more women experience mental health problems.² However, it is grossly overlooked.³ Women experience added stress due to challenges of fulfilling their role as a mother⁴ which is exacerbated when children have disability.⁵ Almost 40% of the caregivers of children with disabilities experience some psychological distress.⁶ A parental stress can be predicted by child behavioral problems and parents' coping strategies.⁷ Parents with a child with a disability can experience personal, social, and financial burdens. Evidence suggests that mothers often curtail working hours or stop working outside of the home⁸ and avoid social activities.⁹ Parental stress increases parental hostility and reduces child responsiveness.¹⁰ Depressed mothers may have negative views of themselves as parents.¹² Mental illness also poses stigmatization¹³ contributing to delayed identification.¹⁴ Timely identification and intervention of maternal mental health issues improve maternal sensitivity and infant attachment.¹⁵ Therefore, incorporating routine screening for parental mental health in childhood intervention programs is crucial.

In Nepal, about 3/1000 children have autism.¹⁶ Studies from rural Nepal found high level of stress among caregivers of children with neurodevelopmental disorders with significant relationship with degree of disability.¹⁷ The current study aims to compare the stress including anxiety and depression levels among mothers of children with ASD and DD with mothers of NT children.

METHODS

In this cross-sectional, observational study, mothers of children below 16 years of age attending the pediatric outpatient department at Tribhuvan University Teaching Hospital (TUTH), Nepal were enrolled. The sample size was calculated using Epi Info computer software for comparing proportions between the groups. A confidence level of 95% and power of 80% were used. Mothers of children with autism spectrum disorder (ASD), developmental delay (DD), and neurotypical children were included in the study. Mothers whose children were diagnosed with ASD or DD for less than

six months were excluded. The period of six months was considered, taking into account the extent of stress immediately after the diagnosis. Mothers of critically ill children or any other acute illnesses requiring immediate interventions and other comorbid conditions requiring continuous medical care, like asthma, epilepsy, and chronic renal diseases, were also excluded from the study. After obtaining written consent, the investigator interviewed the mothers and gathered information regarding their demographic information, children's age, sex, and type of disabilities, if any, were also recorded.

For the ASD and DD groups, communication ability was categorized as non-verbal, sign language, or verbal. The severity of the condition was categorized into three levels: Level I (minimal help required), Level II (moderate help required), and Level III (substantial help required). The ASD and DD group was then compared with NT group.

Data collection began in January 2020 but was paused from mid-March until end of 2022 due to COVID-19 pandemic. Data collection resumed from January till May, 2023. After initial interview, participants were asked to fill out the Hopkins Symptom Checklist – 25 (HSCL-25) questionnaire themselves so as to maintain privacy and to prevent the influence of family members or companions. Participants who reported suicidal ideation (Question 20) were referred to professional counselors and the hospital's psychiatry department. Ethical clearance was obtained from the Institutional Review Board of Institute of Medicine.

Measures

ASD and DD were assessed by obtaining a detail medical history and clinical examinations. Hopkins Symptom Checklist-25 (HSCL-25)

The HSCL-25 is a measure of symptoms of anxiety and depression. The tool was initially developed to assist clinicians in assessing the mental health of English-speaking patients in primary care settings (Hesbacher et al., 1980). The HSCL-25 instrument consists of two parts: Part I has 10 items for anxiety symptoms; and Part II has 15 items for depression symptoms. The scale for each question includes four response categories ("Not at all = 1," "A little = 2," "Quite a bit = 3," and "Extremely = 4"). Across diverse populations, the instrument has consistently demonstrated, that higher scores on Part I and

Part II are strongly linked to severe emotional distress, without giving a specific diagnosis. Additionally, the depression score (Part II) is associated with major depression, as defined by the Diagnostic and Statistical Manual of the American Psychiatric Association.¹⁸ This instrument has been translated into over 30 languages and found to be reliable and valid in a variety of cultural groups and languages.¹⁹ In Nepal, it has been translated and validated and used to identify the mental health status of people after a major earthquake, and also in Bhutanese refugees.^{20,21}

The responses are summed and divided by the number of answered items. There are three scores: The anxiety score is derived by adding items 1 through 10 and dividing this number by 10. The depression score is obtained by adding items 11 through 25 and dividing by 15. The total score is obtained by adding all 25 items and dividing by 25. Individuals with scores on anxiety and/ or depression and/or total > 1.75 was considered symptomatic.

Statistical Analysis

The demographic data of children and parents are expressed in mean, standard deviation, median, and interquartile range. Total HCSSL score, including anxiety and depression among the mothers were calculated. The chi-square test, Odd's Ratio, and logistic regression were used be used for analyses. The predictors considered for maternal stress were duration of diagnosis, gender, severity, language, maternal and paternal education, residence, and family type. Analysis was performed in SPSS 20.

RESULTS

Of the 150 participant mothers, 34 had children with ASD, 32 had children with DD, and 84 had NT children without any co-morbidities. The median age (IQR) of the children at the time of presentation in the ASD, DD, and NT groups was M = 40 (24-192) months, M= 60 (8-180) months and M=72(6-192) months, respectively. The median age of diagnosis was M = 26 (14-144) months in the Measurements of the thyroid gland were taken using a digital Vernier calliper and a digital weighing machine. Length, breadth, and thickness of the right and left lobes, isthmus, and pyramidal lobe (if present) were measured. The weight of the thyroid gland was also recorded. The length of

the cadaver was measured using a measuring tape. The gland was cleaned and prepared for measurement after removal, ensuring accuracy and consistency. Measurements were taken as outlined in Figure ASD and M=6 (1-36) months in the DD group. The results showed that there were more significantly higher number of male children than female, with almost two-thirds in the ASD group. In ASD group, 7 (20%) were nonverbal and 18 (50%) of the children were using some sign language and 30 (88.2%) children required substantial help. In DD group, 20 (62.5%) were nonverbal, 8 (25%) of the children were using some sign language and 27 (84.4%) required substantial help. The children of severity grade III in the DD group were bed-bound. Two-thirds of the mothers belonged to the nuclear family and were from Kathmandu Valley. In the developmental delay group, about half of the mothers were from outside the valley (Table 1).

Table 2 provides the demographic information of the parents in all three groups. The mean age of mother in the ASD, DD and NT group is M =35.4 (SD = 6), M = 33 (SD = 5.4) and M = 31.6 (SD = 5.2), respectively. Similarly, the mean age of father in the ASD, DD and NT group is M = 39 (SD = 6.6), M =37.8(SD = 6.6) and M = 35.7 (SD = 6), respectively. Regarding education level, two-thirds of ASD and NT groups had an educational level above 10th grade. About half of the mothers in DD were educated above 10th grade. Similarly, about half of the fathers in ASD and DD and one-third of the fathers in the NT group, respectively, had an education level above 10th grade. In ASD, DD and NT group, 18 (53%), 23 (71.9%) and 56 (66.7%) mothers were homemakers.

Table 3 shows the total HSCL, anxiety, and depression level in mothers. Out of 34 mothers in ASD group, 20 (58.8%); in DD group, out of 32 mothers, 16 (50%) and in NT group, out of 84 mothers, 8 (9.5%) had total HSCL score of more than 1.7. Three mothers in ASD and 6 mothers in the DD group scored high for the critical question (Q20) on suicidal thoughts . The odds of having maternal stress were 15.7 and 11 times in the ASD and DD groups respectively shown in Table 4.

Among the different predictors of stress, maternal education below tenth grade predicted higher stress in mothers in ASD group shown in Table 5.

Table 1. Demographic characteristic of children with DD and NT children

		ASD (n=34)	DD (n=32)	NT (n=84)
Median (IQR) Age at time of visit in months		40 (24-192)	60 (8-180)	72 (6-192)
Median (IQR) Age of Diagnosis in months		26 (14-144)	6 (1-36)	
Gender				
	Male	24(70.6)	22(68.7)	49 (58.3)
	Female	10(29.4)	10(31.3)	
Address				
	From Kathmandu Valley	25 (73.5)	18 (56.2)	67(79.8)
	Out of Kathmandu Valley	9 (26.5)	14 (43.8)	17(20.2)
Family structure				
	Nuclear	25 (73.5)	22 (68.7)	54(64.3)
	Joint	9 (26.5)	10(31.3)	30(35.7)
Birth Order				
	First	25 (73.5)	21(65.6)	61 (72.6)
	Second	6(17.6)	8(25)	21 (25)
	Third	3 (8.8)	2(6.2)	3 (2.4)
	Fourth		1 (3.1)	
Child's communication ability				
	Not verbal	7 (20.6)	20 (62.5)	
	Sign Language	18(50)	8 (25)	
	Verbal	9(29.4)	4 (12.5)	
Severity				
	Level I	4 (11.7)	5 (15.6)	
	Level II	22 (64.7)	9 (28.1)	
	Level III	8 (23.5)	18 (56.3) bedbound	

Table 2. Demographic characteristics of participant parents of children with ASD, DD and NT

		ASD (n =34) (%)		DD (n =32) (%)		NT (n = 84) (%)	
		Mother	Father	Mother	Father	Mother	Father
Mean Age in years (SD)		35.4 (6.0)	39(6.6)	33(5.4)	37.8(6.6)	31.6 (5.2)	35.7(6)
Education							
	Illiterate			5 (15.6)	1 (3.1)	4 (4.8)	1 (1.2)
	Upto Grade 5	1 (2.9)		2 (6.3)	4 (12.5)	7 (8.3)	7 (8.3)
	6-10	7 (20.6)	9 (26.5)	9 (28.1)	8 (25.0)	16 (19.0)	18 (21.4)
	Intermediate	15 (44.2)	2 (5.8)	8 (25.0)	6 (18.8)	31 (36.9)	20 (23.8)
	Bachelor	5 (14.7)	14 (41.2)	8 (25.0)	8 (25.0)	17 (20.2)	27 (32.2)
	Master and above	6 (17.6)	9 (26.5)		5 (15.6)	9 (10.8)	11 (13.1)
Occupation							
	No work	18 (53.0)	2 (5.9)	23 (71.9)	3 (9.4)	56 (66.7)	3(3.6)
	Agriculture	1 (2.9)		1 (3.1)			
	Daily wage earner		2 (5.9)		2 (6.3)	6 (7.1)	10 (11.9)
	Self employed	7 (20.6)	11 (32.3)	2 (6.3)	12 (37.5)	2 (2.4)	22(26.2)
	Service	7 (20.6)	14 (41.2)	5 (15.6)	9 (28.1)	20 (23.8)	35(41.6)
	Migrant worker	1 (2.9)	5 (14.7)	1 (3.1)	6 (18.7)		14(16.7)

Table 3. Total HSCL and anxiety and depression scores of mothers in ASD, DD and NT group

	Total HSCL Score			Anxiety Score			Depression Score		
	ASD (n=34)	DD (n=32)	NT (n=84)	ASD (n=34)	DD (n=32)	NT (n=84)	ASD (n=34)	DD (n=32)	NT (n=84)
Mean (SD)	1.93 (0.7)	1.87(0.7)	1.3(0.3)	1.74(0.6)	1.75(0.6)	1.23(0.2)	1.96(0.8)	1.8(0.7)	1.28(0.3)
Symptomatic(>1.7)	20	16	8	20	19	5	20	16	7
(%)	(58.8)	(50.0)	(9.5)	(58.8)	(59.3)	(5.9)	(58.8)	(50)	(8.3)

Table 4. Odd's ratio of Stress in mothers with children with ASD and DD when compared with mothers with NT children

	Stress	No Stress	Odd's ratio	CI (95%)	
NT (n=84)	7	77			
ASD (n=34)	20	14	15.7	5.6-44.1	P < 0.0001
DD (n=32)	16	16	11.0	3.9-31.1	

Table 5. Predictors of stress in mothers with children with ASD and DD

		ASD					DD				
		Stress Yes (20)	No (14)	Odd	CI	P	Stress Yes (16)	No (16)	Odd	CI	P
Diagnosed for more than 2 years	Yes (20)	10	6	1.33	0.34-5.27	0.68	12	13	0.69	0.13-3.75	0.66
	No (14)	10	8				4	3			
Gender	F	4	6	0.33	0.07-1.52	0.15	5	5	1.0	0.22-4.46	1.0
	M	16	8				11	11			
Severity	Minimal help	1	3	0.19	0.02-2.08	0.14	1	3	0.28	0.02-3.13	0.31
	Substantial / very substantial help	19	11				15	13			
Language	Non verbal/sign language	14	11	0.63	0.13-3.13	0.57	12	11	1.3	0.29-6.4	0.69
	Verbal	6	3				4	5			
Maternal Education	Below 10 th grade	7	1	7.0	0.75-65.2	0.06	10	6	2.78	0.66-11.62	0.16
	Intermediate and above	13	13				6	10			
Paternal Education	Below 10 th grade	7	3	1.97	0.41-9.51	0.39	9	4	3.8	0.86-17.32	0.07
	Intermediate and above	13	11				7	12			
Residence	Inside Kathmandu valley	14	11	0.64	0.13-3.13	0.58	10	8	1.67	0.41-6.81	0.48
	Out of Kathmandu Valley	6	3				6	8			
Family Type	Nuclear	14	11	0.64	0.13-1.4	0.58	12	10	1.8	0.39-8.21	0.45
	Joint	6	3				4	6			

CI = Confidence Interval; P= p value (significance when <0.05)

DISCUSSION

The current study explores the mental health of Nepali mothers, with a specific focus on mothers raising children with ASD and DD and compares mothers with neurotypical children. The study found depression in about 6% and anxiety in about 8% of mothers with neuro-typical children. The finding is contrary to the findings of the National survey where they have found anxiety in 22% and depression in 5% of women in the reproductive age group. This may be because we have included women with children only and the national survey has included all the women of reproductive age irrespective of whether they have a child or not. Also, we have used HSCL and the survey has used the PHQ-9 questionnaire. When compared with mothers with children with autism and developmental delay were compared, the odds of having stress (both depression and anxiety) were 15 times and 11 times, respectively. The findings shed light on the prevalence of stress and its potential impact on the well-being of mothers in the context of caring for children with diverse needs. Similar studies also found that about 50 to 60 % of the caregivers of neurodevelopmental disorders have high level of distress.²² These studies align with other similar studies that highlight the challenges faced by mothers raising children with special needs.²³

When comparing maternal education and their stress, the study showed that the level of education in all the groups is similar. Even with higher education, maternal stress levels are found to be high. These findings prompt further exploration into the factors contributing to stress among mothers, irrespective of their educational background. Additionally, it underscores the importance of tailored support mechanisms targeting stress management strategies for mothers, regardless of their educational attainment, within the context of caring for children with neurodevelopmental disorders.

A similar finding was seen in the study done by Singer.²³ They found that mothers of children with chronic physical problems who have college degrees experience more stress than mothers of the same groups with lower levels of education. It can be assumed that it may be because of a better understanding of challenges and awareness leading to higher expectations for their child, more access to information,

including treatment options, leading to decision-making stress, difficulty in work-life balance and professional demands, societal demands with educational level, and financial burden that cannot be guaranteed by educational level. Thus, recognizing the complexity of the relationship between maternal education and stress cannot be undermined while developing support programs that address the unique needs of diverse families raising children with developmental challenges. When mothers themselves are in stress, it may affect the mother's ability to respond consistently and sensitively to her child's needs, impacting the overall parent-child relationship.

Emotional availability is crucial for the social and emotional development of children with developmental delays. It is seen that higher parenting stress was associated with less optimal emotional availability.²⁴ Children with ASD and DD themselves are at risk of anxiety and when parents have psychopathology-like anxiety, it may increase the problematic negative behavior in children²⁵ as well as also increase the risk of children reflecting moderate and high levels of anxiety disorders.²⁶ When stressors are too intense, or last for a long period of time, individuals may not manage to cope with them, i.e. the stress response system may remain activated and there can be important negative consequences on individual health.²⁷

In the context of Nepal, mental health problems are highly stigmatized with cultural beliefs of spiritual punishment, family dishonor and personal weakness. When stigma against mental health disorder was conceptualized, the primary concerns of people living with mental disorders were acceptance, privacy, productivity, social prestige.²⁸ It is found that people with mental disorders experience rejection from families and colleagues.²⁹ However, the study underscores the additional challenges faced by families due to societal perceptions. In this context, the current study underscores the need for improved mental health services and increased awareness to address the mental health needs of parents raising children with developmental challenges.

Thus, the findings of this study make a compelling case for the importance of incorporating routine screening for maternal or caregiver mental health problems in childhood

intervention programs that are focused on ASD and different childhood disabilities. While the study provides valuable insights, there are limitations to consider. The cross-sectional nature of the study restricts the establishment of causal relationships. Longitudinal studies could offer a more in-depth understanding of the dynamic interplay between maternal mental health and the challenges associated with raising children with developmental delays and autism. In addition, different coping strategies of parents and the emergence of challenges in taking care of children with disabilities, this study is unable to find out whether the duration of disabilities can elevate or decrease mental health problems in caretakers. Additionally, we also had a small sample size due to the data collection period, which was during the pandemic. Given the challenge of lockdown, the research staff were able to collect data from 150 participants. Future research should recruit a larger sample for more power.

CONCLUSION

The current study shows high level of anxiety and depression among the mothers with children with disabilities like autism spectrum disorder and developmental delays as compared to mothers with neurotypical children.

Hence, it demands a comprehensive support system and early intervention for mental health issues in the context of raising children with disabilities. Further research and collaborative efforts between healthcare providers, policymakers, and communities are essential to create a more inclusive and supportive environment for families navigating children with developmental challenges.

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CONFLICT OF INTEREST

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AUTHOR CONTRIBUTIONS

Shrestha M. : planning, data collection, data analysis, manuscript preparation

Ranjit S.Y. : data analysis, manuscript preparation

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