

Stress and Coping among Caregivers of Differently Able Children

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ABSTRACT

Background: Caring differently able children can cause stress in the caregivers. They employ a variety of coping mechanisms to deal with stress. The aim of this study is to identify stress and different coping styles among caregivers of differently able children.

Methods: A cross-sectional study was carried out in three organizations that accommodated differently abled children. A non-probability purposive sampling technique was used to recruit primary caregivers of children with developmental disabilities. This study examined caregiver stress and different coping styles by using the Parent Stress Scale and Brief COPE Inventory. Face-to-face interviews were used to collect data, which was then analyzed using SPSS.

Results: Among the total of 102 caregivers, mothers accounted for 60.8 percent, 57.8 percent child were boys whereas, 49 percent were the child with cerebral palsy. Total mean stress score was 57.17 ± 8.808 . High level of stress was reported by 58.8 percent of caregivers. Education and family income showed the statistically significant association with stress score P -value <0.05 . Total mean coping score was 67.83 ± 5.812 . Caregivers' stress had significant positive correlation with different coping styles; active coping, denial, behavioral disengagement, humor, acceptance religion and self-blame (P -value <0.05).

Conclusions: More than half of the caregivers had high level of stress. The most frequently used coping styles were self-distraction, acceptance and positive reframing. Caregivers' stress had significant positive correlation with different coping styles. Therefore, health professionals and service providers should focus on stress reduction and positive coping technique to help family adaptation.

Keywords: Caregiver; coping; differently able children; stress.

INTRODUCTION

Caring for a young child is a typical aspect of parenthood, but managing a disabled child can be exhausting for caregivers. Parents of disabled children experience more stress than typically developing children.¹⁻³ Early childhood disabilities have a wide range of effects on all developmental domains of the child's and family's lives. Parents of children with disabilities report higher stress, lower marital satisfaction, and worse levels of well-being.⁴⁻⁶ Because of the child's behavior, dependency on care, anxiety, and poor communication, mothers of children with disabilities experienced more distress.^{7,8}

Parents use a variety of coping mechanisms to cope

with stress that could be positive or negative.⁹ The challenges of rearing for child with special needs add to the stress so healthy coping is required.¹⁰ One study suggests high level of stress among caregivers and family life satisfaction is less than acceptable.¹¹ The severity of disability of the child, and inadequate health care facilities, amongst other factors. While increased stress, anxiety, and depression among such caregivers is evident globally, it is higher in low-income countries (LICs). Still, there is a deficit of research in assessing the stress level and coping strategies among caregivers of children with disabilities in Nepal. Thus, the study aims to assess the stress and coping styles among the caregivers of differently able children.

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METHODS

Cross-sectional analytical design was used to assess the level of stress and coping strategies among caregivers with differently able child. There were three organizations working with learning and other developmental disabilities in kaski: Autism care Nepal Society, Sewa Kendra and Sathi Sansar Nepal. Autism care Nepal society is a parent network group which was established with the aim to provide day care facility and vocational training for caregivers. Sewa Kendra is a day care center established to manage the intellectual disable children. Likewise, Sathi Sansar Nepal is organization working with learning and developmental disabilities including functional limitations.

There was total 159 cases in three organizations among them 114 were children; Autism care Nepal society 10, Sewa Kendra 23 and Sathi Sansar Nepal 81. All the caregivers with differently able children from Autism Care Nepal as well as Sewa Kendra and 69 from Sathi sansar were selected because 12 were excluded for the pretesting thus 102 eligible caregivers from three organizations were selected purposively for the study. The caregivers were selected with the criteria those who: (i) are primary caregivers; (ii) have a child with the diagnosis of autism, cerebral palsy and other intellectual disabilities and (iii) aged above 20 years old.

The data were collected using interviewer administered questionnaire from 102 caregivers of differently able children. For the better understanding of the instrument, English questionnaire was translated into Nepali language. Two stage back translation of research instrument was done by linguistic professional and pre tested among 12 caregivers of Sathi Sansar which were not included in the study sample. The instrument is divided into three parts: Part I consist of background information of the child: age, sex, type of disability and caregiver information: age, gender, marital status, educational level, type of family, income and relation with the child.

Part II consists of Parental Stress Scale developed by Berry & Jones Which is used to describe the stress, feelings and perception about the experience of being a parent.¹² Study demonstrates that it is a reliable and valid basis for measuring stress in parents of children with attention deficit hyperactive disorder.¹³ It consist of 5-point Likert scale compromises 18 questions 1 = strongly disagree and 5 = strongly agree with total score ranging from 18 to 90, with higher scores indicating higher stress. To compute the score, 8 positive items (item no.1, 2, 5, 6, 7, 8, 17 & 18) has reversed scored. The item scores are then summed. Furthermore, the

total score is classified as: high level 57-90 and low level 18-56. PSS was chosen for this study because it has a better application, is shorter and easier to comprehend, and can focus on the stress caused by the parenting role. Cronbach's alpha for items was 0.83 and test-retest reliability was 0.81.¹⁴

Part III consists of Brief COPE inventory tool developed by carver et al, that is multi-dimensional questionnaire designed to evaluate the many coping techniques people employ in reaction to stress.¹⁵ and also used to assess the coping among Nepalese parents of intellectual disable children.¹⁰ It consists of 28 questions on a four-point scale ranging from 1= I haven't been doing this at all, to 4= I've been doing this a lot. Self-distraction, active coping, denial, drug use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame are the 14 subscales of coping styles. High scores on the scale suggest that specific coping mechanisms are used more frequently. Internal reliabilities were reported to be adequate on average (α ranging from 0.50 to 0.90).¹⁶

All caregivers were pre informed by the organizations that they get a call from the researcher to manage the time for interview. Informed consent was taken from the caregivers by explaining the objectives of study to ensure their right. Confidentiality was maintained by not disclosing collected information to others and used only for research purpose. Caregivers were assured that they were free to withdraw from the study at any time if they desire. Then data was collected using face-to-face interview technique with 6-7 caregivers each day for 20-25 minutes each. Considering all the public health measures to prevent risk of COVID-19, interview was conducted in quiet and separate room in the organization where the caregivers feel comfortable at the time when they drop and receive their children. Study period was Nov 2020 to Oct 2021. This study was approved by the institutional review committee, Institute of Medicine, Tribhuvan University, Nepal. The data was analyzed with SPSS software and summarized using descriptive statistics such as frequency, percentage, mean, and standard deviation. Inferential statistics chi square test was used to see if there were any association between level of stress with child and caregivers' characteristics. To determine the relationship between the stress and different coping styles, Pearson's correlation coefficient test was used. In all the inferential statistical procedures, $p \leq 0.05$ was considered statistically significant.

RESULTS

In this study, a total of 102 caregivers of differently

able children were participated. The mean age of caregivers was 40.44 (SD=9.094) ranged from 24-70 Years. The majorities of the participants were the children's mother (60.8%), married with partner (88.2%) and had secondary level education¹⁷ (47.1%) followed by 4.9% caregivers was low (having no formal) level education. Their family type (63.7%) was nuclear and 38.2% was not sufficient yearly household income. The background information of caregivers in the study is presented in Table 1.

Table 1. Background information of caregivers of differently able children.n=102

Variables	Number	Percent
Age in Years		
20-40	52	51.0
41-70	50	49.0
Mean \pm SD (40.44\pm9.094), Range 24-70 Years		
Gender		
Female	72	70.6
Male	30	29.4
Educational status		
No education	5	4.9
Primary not completed Primary completed	28	27.5
Secondary completed	16	15.7
More than secondary	48	47.1
	5	4.9
Marital status		
Married with partner	90	88.2
Unmarried	2	2.0
Separated	2	2.0
Divorced	3	2.9
Widowed	5	4.9
Relation with Child		
Mother	62	60.8
Father	31	30.4
Other than parents	9	8.8
Yearly Family income		
Not Sufficient	39	38.2
Sufficient	51	50.0
Surplus	12	11.8
Family type		
Nuclear	65	63.7
Joint	35	34.3
Extended	2	2.0

The children with different ability had a mean age of 12.94 (SD =4.72) years age ranged from 2- 18 years. A majority were boys (57.8%). Forty-nine (49%) had cerebral palsy followed by autism (26.5%) and other intellectual disability (24.5%). Table 2 shows background variables of the children.

Table 2. Background information of the Children. n=102

Variables	Number	Percent
Age in Years		
2-10	32	31.37
11-18	70	68.62
Mean ± SD (12.94±4.72)		
Age range 2-18 years		
Gender		
Boys	59	57.8
Girls	43	42.2
Type of developmental disability		
Cerebral Palsy	50	49.0
Autism	27	26.5
Intellectual disability	25	24.5

Table 3 presents descriptive statistics of perceived stress of the caregivers. More than half (58.8%) of caregivers had high level of stress. The mean total stress score was 57.17 ± 8.808 , with a minimum score of 34 and maximum score of 77.

Table 3. Level of stress among caregivers of differently able children. n=102

Level of Stress	Number	Percent
High stress (57-90)	60	58.8
Low stress (18- 56)	42	41.2
Mean ± SD (57.17± 8.808)		
Minimum score 34, maximum score 77.		

Total mean coping score was 67.83 ± 5.812 . The most frequently used coping styles were self-distraction (mean ± SD = 6.76 ± 1.15), acceptance (mean ± SD = 6.92 ± 0.93) and positive reframing (mean ± SD =

6.531 ± 1.19). Substance use (mean ± SD = 3.87 ± 1.096), denial (mean ± SD = 3.18 ± 0.88) and humor (mean ± SD = 2.35 ± 0.556) were less frequently used by the caregivers (Table 4).

Table 4. Mean score of coping styles among caregivers of differently able children. n = 102

Coping Styles	Mean	Std. Deviation
Total Coping Score	67.83	5.812
Coping Styles		
Self-distraction	6.76	1.153
Active coping	5.94	1.257
Denial	3.18	.886
Substance use	3.87	1.096
Emotional support	5.29	1.190
Use of informational support	5.84	1.340
Behavioral disengagement	3.90	1.726
Venting	4.79	1.180
Positive reframing	6.53	1.191
Planning	5.34	1.331
Humor	2.35	.556
Acceptance	6.92	.930
Religion	4.51	1.166
Self-blame	3.91	1.235

The Pearson chi-square test was used to identify the association; education and family income showed the statistical significant association $\chi^2 = 8.351$ and P -value = .004 and $\chi^2 = 14.065$ and P -value = .000 respectively. There are no significant association in the stress score for the child's characteristics and other caregiver's characteristics (Table 5).

Table 5. Association between stress score with child's and caregiver's characteristics.

Variable	Level of Stress		x ²	P-value
	High n(%)	Low n(%)		
Child characteristics				
Age group in Years				
2-10	20 (19.6)	12 (11.7)	0.260	.610
11-18	40 (39.2)	30 (29.4)		
Sex				
Boy	34 (33.3)	25 (24.5)	0.083	.774
Girl	26 (25.5)	17 (16.6)		
Type of disability				
Autism	12 (11.7)	15 (14.7)	3.134	.209
Intellectual disability	16 (15.6)	9 (8.8)		
Cerebral palsy	32 (31.4)	18 (17.6)		
Caregiver's characteristics				
Age group in Years				
20-40	26 (25.5)	26 (25.5)	3.410	.065
41-70	34 (33.3)	16 (15.6)		
Gender				
Male	20 (19.6)	10 (9.8)	1.079	.299
Female	40 (39.2)	32 (31.4)		
Marital Status				
Single	10 (9.8)	2 (1.9)	3.373	.066
Married with partner	50 (49.0)	40 (39.2)		
Education				
Up to primary level	36 (35.3)	13 (12.7)	8.351	.004*
Secondary & above	24 (23.5)	29 (28.4)		
Relation with child				
Parents	54 (52.9)	39 (38.2)	.251	.617
Other than parents	6 (5.8)	3 (2.9)		
Family type				
Nuclear	22 (21.5)	15 (14.7)	.010	.922
Joint & extended	38 (37.2)	27 (26.4)		
Family income				
Insufficient	32 (31.4)	7 (6.8)	14.065	.000*
Sufficient	28 (27.4)	35 (34.3)		

Test statistics: Pearson's chi-square * p value significant at <0.05, df =1

Pearson's correlation analysis showed that caregivers' stress had significant positive correlation with different coping styles; active coping, denial, substance use, behavioral disengagement, positive reframing, planning, humor, acceptance religion and self-blame (P -value<0.05). Self-distraction, venting, emotional and informational support did not show any significant results. Results of correlation analysis are presented in Table 6.

Table 6. Correlation between stress and different coping styles.

Variable	Pearson's correlation coefficient (r)	P-value
Self-distraction	.042	.674
Active coping	.443**	.000
Denial	.269**	.006
Substance use	-.289**	.003
Emotional support	-.153	.124
Informational support	-.077	.440
Behavioral disengagement	.335**	.001
Venting	.147	.139
Positive reframing	-.277**	.005
Planning	-.247*	.012
Humor	.276**	.005
Acceptance	.339**	.000
Religion	.400**	.000
Self-blame	.276**	.005

Test statistics: Pearson's correlation

***. Correlation is significant at the 0.01 level (2-tailed).* **. Correlation is significant at the 0.05 level (2-tailed).*

DISCUSSION

The study provides the information on caregivers' stress and different coping styles. The results show that more than half (58.8%) of caregivers had high level of stress. The mean total stress score was 57.17 ± 8.808 , with a minimum 34 and maximum score of 77 which is lower than the previous study¹⁸ and higher than the study done in Nepal and Malasia.^{10,19,20} The findings of another study done in Nepal revealed that mothers of children with intellectual disabilities suffer from high levels of anxiety and depression, which has a negative impact on their children's quality of life.²⁰ Many studies reveal more differences than similarities regarding the parental stress this might be due to the study was conducted during a COVID 19 pandemic situation.

With regard to the caregivers' demographic variables, education and family income were significantly associated with stress but in the previous study, number of children in the family was associated with caregivers' perceived stress²¹ and age was associated

with stress.⁴ Likewise, in present study, there was no significant association between other caregivers' and child characteristics (age, sex and type of disability) with stress which is similar to previous studies.^{4,21} By marital status, there was a substantial variation in mean parental stress. When compared to married mothers, divorced or bereaved mothers had more parenting stress.¹⁹ The disparities can be related to variances in healthcare systems, culture, instrumentation and data collection methods.

Total mean coping score was 67.83 ± 5.812 in this study. The most frequently used coping styles were self-distraction, acceptance and positive reframing. Substance use, denial and humor were less frequently used by the caregivers. The caregivers also utilized positive coping skills, which can help them adapt to caring for a disable child more efficiently. This conclusion supported prior findings showing that parents of children with Down syndrome and hearing loss chose active coping and acceptance as coping techniques.¹⁹ Similarly, religion, acceptance, and positive reframing

were the most commonly utilized coping mechanisms among caregivers, whereas substance use and behavioral disengagement was the least frequently used.^{21,22} The main coping style used by the caregivers was Active emotional coping.²²

Furthermore, mothers reported more frequent use of active avoidance coping strategies than fathers and mothers whose school age children living at home reported more frequent use of positive coping and less frequent use of active avoidance coping. Study showed the associations between coping and stress. It suggests on reducing the parents use of avoidant coping strategies and increasing the use of positive coping.²³ Coping in parents of children with autism varied from parents of usually developing children. In parents of children with autism and Down syndrome, emotion-oriented coping was a predictor of parental stress, while task-oriented coping was a predictor of parental stress in parents of generally developing children. There is association between parenting stress and coping techniques.³

In the current study, Pearson's correlation analysis showed that caregivers' stress had significant positive correlation with different coping styles; active coping, denial, substance use, behavioral disengagement, positive reframing, planning, humor, acceptance religion and self-blame (P -value<0.05). Self-distraction, venting, emotional and informational support did not show any significant results. Likewise, the caregivers with higher use of informational support and behavioral disengagement coping styles had higher perceived stress. Caregivers with more children and those using higher emotional support and religion coping demonstrated a lower level of perceived stress.²¹

In this study, all the caregivers are from the same district. To validate the conclusions of this study, we'll need a large sample size with wider coverage. To better comprehend the relationship between various variables, more variables could be incorporated. Thus, all these issues need to be investigated further.

CONCLUSIONS

More than half the caregivers have high level of stress. The most frequently used coping styles were self-distraction, acceptance and positive reframing. Education and family income showed the statistically significant association with caregivers' stress. Caregivers' stress had significant positive correlation with different coping styles; active coping, denial, behavioral disengagement, humor, acceptance, religion and self-blame. Likewise, stress had negative correlation with substance use, positive reframing, and planning. Therefore, professionals

and service providers should focus on appropriate approaches to help family adaptation by recognizing the stress and coping strategies utilized by caregivers of differently able children.

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CONFLICT OF INTEREST

None

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