

PARENTAL STRESS AND COPING MECHANISMS IN REARING CHILDREN WITH INTELLECTUAL DISABILITY: A STUDY CONDUCTED IN KATHMANDU

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ABSTRACT

Introduction

The birth of a child with an intellectual disability is the most traumatic event experienced by the parents and their families. The main objective of this study is to identify parental stress and coping in rearing children with intellectual disabilities in Kathmandu valley.

Methodology

A descriptive cross-sectional study was conducted among 222 parents (either mothers or fathers) of children with an intellectual disability visiting nine organizations selected through probability proportionate to size sampling. Data were collected through interview techniques using the Nepali-translated Parental Stress Scale and cope tool developed.

Result

Maximum respondents (76.1%) were mothers with an overall mean age of 46.28 years. The major stress expressed was anxiety-related to a child's future after parents' death (19.8%) and most used coping measure was sharing feelings (44.6%) respectively. The overall mean score of parental stress was 64.58 and parental coping was 106.45. Maximum respondents have a moderate level of stress (54.5%) followed by severe stress (43.2%) and a moderate level of coping (86.9%) followed by a maximum level of coping (13.1%). There was a significant association of level of stress with relationship to the child, parent's education, and presence of co-disability in the intellectually disabled child. There was a significant association of level of coping with parents' education.

Conclusion

Maximum respondents had a moderate level of stress and a moderate level of coping mechanisms. Parental stress was high in mothers, illiterate parents, and parents having an intellectually disabled child of 17 years or younger. Parental coping was high among Hindu and literate parents.

KEYWORDS

Intellectual Disability, Parental Coping, Parental Stress,



INTRODUCTION

Even the birth of a healthy baby in the family can cause a varying range of stress among the family members.¹ All children rearing involve stress and require coping to accommodate and adapt to that stress.² The delivery of an intellectually disabled child is likely to be one of the most traumatic events experienced by the parents as well as their family for which parents and the families need to go through a lot of adjustments to evolve the disabled members.³ Due to widespread discrimination toward intellectual disabilities, the stigma may place unfair regulations on the social life of the parents.⁴ Intellectual disability manifests before the age of 18.⁵ The coexistence of psychiatric disorders occurring in people with an intellectual disability is common.⁶ An intellectual disability is reported to peak at the ages of 10 to 14 years and is 1.5 times more prevalent in males than females.⁷ With a prevalence of 2% to 3% worldwide, intellectual disability represents one of the biggest medical and social challenges in society.⁸

Parenting stress is defined as immoderate tension and anxiety specially associated with parent and parent-child interactions.⁹ Parents of children with intellectual disabilities tend to report higher-than-average rates of stress, anxiety, and depression. Further, caring for an intellectually disabled is associated with an increased risk of psychological distress among parents.¹⁰ Many studies have revealed that stress is higher in parents of intellectually disabled children. So, the present study is designed to explore the stress and coping mechanisms of parents with intellectually disabled children.

METHODOLOGY

Study Design: Descriptive explorative cross-sectional design has been used.

Site: Three organizations, each from three districts of Kathmandu valley which were taking care of children with intellectual disabilities were the site of this study. These organizations were Patan Community Based Rehabilitation Organization, Sankhamul, Lalitpur; Sustamanasthiti Kalyan Vidhyalaya, Chakrabahil, Lalitpur; Mothers Group of Intellectually Disabled, Jwagal, Lalitpur; Day Care Center for Children with Multiple Disabilities, Thimi, Bhaktapur; Sustamanasthiti Kalyan Sanstha, Manav Vidhya Griha, Thimi; Bhaktapur Community Based Rehabilitation Organization, Bhaktapur; Nava Jyoti Center, Baluwatar, Kathmandu; Parent's Association of Intellectual and Multi-disability, Kirtipur, Kathmandu; and Association for the Welfare of Intellectual Handicapped, New Baneshwor, Kathmandu.

Sample size: The total population of children with intellectual disability in those organizations was 350. Sample size was calculated using Solvin's Formula [$n = N / (1 + N(e)^2)$]. The calculated sample size was 186 parents.

Sampling Method: Non-probability purposive sampling was used to select the samples. The parents meeting inclusion criteria were called at organizations for data collection. Few numbers of parents exceeded than the calculated sample

size, which could not be excluded from the study. Thus, the total number of the parents reached 222.

Ethical approval was taken from the Institutional Review Board of the Institute of Medicine, Tribhuvan University. Formal administrative approval was obtained from the authorities of selected organizations. The purpose of the study was explained and consent was taken from each respondent. The researcher had collected data through face-to-face interviews. Privacy was maintained by interviewing each respondent separately in the selected organizations.

The framework for this study is based on sister Callista Roy's Adaptation Model (1988).¹¹ Parental Stress Scale¹² was used to measure parental stress. This is a Likert scale that provides a measure that considers both positive and negative stressful aspects of parenting. The respondents agree or disagree in terms of their typical relationship with their children on the 5-point scale of strongly disagree, disagree, undecided, agree and strongly agree. To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 were negative items that were reverse scored. The item scores were then summed. Overall possible scores on the scale ranged from 18 to 90. A low score signified a low level of stress, and a high score signified a high level of stress. One open-ended question developed by the researcher to identify the major stress ever experienced by the parent in rearing their children with intellectual disability was also included.

To assess coping mechanism, a Likert scale containing 52 statements was developed by the researcher based on the COPE inventory.¹³ The scale measured how people respond when they confront difficult or stressful events in their lives on a 4-point scale of I usually do not do this at all, I usually do this a little bit, I usually do this a medium amount and I usually do this a lot. To compute the parental coping score, items 8, 18, 30, 31, 32, 33, 34, 36, and 39 were reverse scored as these were maladaptive behaviors. One open-ended question developed by the researcher to identify the major coping technique used by the parents to decrease parenting stress in rearing their children with intellectual disability was also included.

The tools were translated into Nepali language and then back-translated into the English language by two independent bilingual translators.

Cronbach's alpha of the Nepali translated tool was measured to be 0.86 for the Parental Stress Scale and 0.83 for the coping scale respectively which indicated that the tools were reliable enough.

To analyze the level of stress, the range was computed from minimum and maximum scores from the Parental Stress Scale. The total minimum score was 18 and the maximum score was 90. Hence, the class interval was calculated as:

$$\text{Class Interval} = \frac{\text{Maximum score} - \text{Minimum score}}{\text{No. of level}} = \frac{90 - 18}{3} = \frac{72}{3} = 24$$



Hence, taking class interval of 24, the level of stress was categorized as follows:¹⁴

Minimum stress: score between 18–42

Moderate stress: score between 43–66

Severe stress: score between 67–90

The level of coping was also categorized as the level of stress. The total minimum score was 39 and the maximum score was 156. Hence, the class interval was calculated as:

$$\text{Class Interval} = \frac{\text{Maximum score} - \text{Minimum score}}{\text{No. of level}} = \frac{156 - 39}{3} = \frac{117}{3} = 39$$

Hence, taking class interval of 39, level of coping was categorized as follows:

Inadequate coping: score between 39–78

Moderate coping: score between 79–117

Adequate coping: score between 118–156

Statistical analysis

Data were entered in Microsoft Office Excel 2007 and analyzed by Statistical Package for Social Sciences (SPSS) version 20.¹⁵ Normality test of the data revealed a normal distribution of the data so a parametric test was used for the analysis. In descriptive statistics frequency, percentage, mean, median, and standard deviation were used. In inferential statistics, the chi-square test was used to find the relationship between parental and child-related characteristics with the levels of stress and coping and between stress and coping. An independent sample t-test was used for comparison among parents and selected characteristics.

RESULTS

During the data collection time, 222 parents were interviewed. Maximum parents have one children with intellectual disability (n=212, 95.5%) whereas less (n=10, 4.5%) have two children with intellectual disability. Further, 131 (59%) parents were employed and 91 (41%) were unemployed.

Table 1: Respondents' information on socio-demographic and children-related characteristics

Characteristics	Number	Percentage (%)
Participant's relation to the child (n=222)	Mother	169 (76.1)
	Father	53 (23.9)
Parents' age (n=222)	20-40 years	89 (40.1)
	41-60 years	102 (45.9)
	>=61 years	31 (14.0)
	Overall mean age ± SD: 46.28 ± 12.73 years	
Religion (n=222)	Hindu	185 (83.3)
	Others (Buddhist, Christian)	37 (16.7)
Parents' Education (n=222)	Illiterate	76 (34.2)
	Literate	146 (65.8)
Age of Children with Intellectual Disability (n=232^a)	Equal or below 17 years ^b	109 (49.1)
	Equal or above 18 years	113 (50.9)
Level of Children's ID	Mild to moderate	89 (40.1)
	Severe to Profound ID	133 (59.9)

Presence of Co-disability in Children with Intellectual Disability (n=232)	No co-disability	141	(60.8)
	Presence of co-disability ^c	91	(39.2)

^a10 parents have 2 children with ID

^bmedian age of children with intellectual disability: 18 years

^cphysical disability; problems with speech, hearing, and vision

Table 1 shows that the maximum respondents were mothers (76.1%) and the remaining (23.9%) were fathers. The overall mean age was 46.28 years. Majorities (65.8%) of the respondents were literate and among them, 28% can read and write only.

Table 2: Major stress and coping measures expressed by the respondents (n = 222)

Major Stresses	Number	Percent (%)
Anxiety-related to intellectually disabled child's future after parent's death	44	(19.8)
Child's illness	43	(19.4)
When known about child's condition	32	(14.4)
Child's disturbing behavior	25	(11.3)
Socialization problem that includes neglect of others, social embarrassment, and altered social life	19	(8.6)
The child is a female; hence, fear to leave alone and need care during menstruation	16	(7.2)
Extra inputs of care	15	(6.8)
Financial problem	11	(5)
Intellectual disability not diagnosed in time	10	(4.5)
Difficulty in school admission due to unknown about a special school for intellectual disability.	5	(2.3)
Intellectual disability diagnosed in another child	2	(0.9)
Major Coping Measures		
Sharing feelings with friends, relatives, and/or organization	99	(44.6)
Involving in religious activities	32	(14.4)
Engaging in substitute work	27	(12.2)
Seeking support from family/friends/ organization	22	(9.9)
Expecting government or other organizations for rearing child with intellectual disability	14	(6.3)
Listening to music or watching TV	7	(3.2)
Solving problems by self through planning	7	(3.2)
Being with a child with an intellectual disability	6	(2.7)

Table 2 shows maximum (19.8%) respondents expressed their anxiety about the intellectually disabled child's future after parents' death followed by child illness (19.4%) and least (0.9%) expressed the diagnosis of intellectual disability in another child was a major stress. Further, sharing feelings with friends, relatives, and/or organization (44.6%) followed by involving in religious activities (14.4%) were the major coping measures used by the parents.

Table 3: Level of stress and coping mechanisms of the respondents (n=222)

Variables		Numbers	Percent (%)	Mean
Level of stress	Minimum stress	5	2.3	Parental stress: 64.58 ± 9.22 Fathers' stress: 62.09 ± 8.16 Mothers' stress: 65.36 ± 9.42
	Moderate stress	121	54.5	
	Severe stress	96	43.2	
Level of coping	Moderate coping	193	86.9	Parental coping: 106.45 ± 9.72 Fathers' coping: 108.57 ± 10.19 Mothers' coping: 105.80 ± 9.50
	Maximum coping	29	13.1	

Table 3 depicts that maximum (54.5%) respondents have a moderate level of stress in rearing their children with intellectual disability followed by a severe level of stress (43.2%). The mean score of stress in fathers was 62.09±8.16 and in mothers was 65.36 with the overall mean score of parental stress 64.58 Likewise, maximum respondents (86.9%) have a moderate level of coping followed by a maximum level of coping (13.1%) and none had the minimum level of coping. The mean score of coping in fathers was 108.57±10.19 and in mothers was 105.80± 9.50 with the overall mean score of parental coping 106.45 ±9.72.

Table 4 shows a significant association of the level of stress with the relationship with the child ($p=0.028$), parents' education ($p=0.009$), level of children's intellectual disability ($p=0.038$), and presence of co-disability in children with intellectual disability ($p=0.019$) respectively. Similarly, there was a significant association between the level of coping and parents' education ($p=0.002$). However, there was no significant association between stress and coping ($p=0.853$).

Table 4: Association between the selected socio-demographic variable with level of stress and coping (n=222)

Characteristics	Level of Stress		χ^2 Value	p-Value	Level of Coping Mechanisms		χ^2 Value	p-Value				
	Minimum and Moderate Stress Level	Severe Stress Level			Moderate Coping Level	Severe Coping Level						
Relation to the child												
Mother	89	(52.7)	80	(47.3)	4.834	0.028*	149	(88.2)	20	(11.8)	0.941	0.332
Father	37	(69.8)	16	(30.2)			44	(83.0)	9	(17.0)		
Parents' Education												
Illiterate	34	(44.7)	42	(55.3)	6.803	0.009*	74	(97.4)	2	(2.6)	9.720*	0.002*
Literate	92	(63.0)	54	(37.0)			119	(81.5)	27	(18.5)		
Level of Children's Intellectual Disability												
Mild to moderate	58	(65.2)	31	(34.8)			76	(85.4)	13	(14.6)		
Severe to Profound	68	(51.1)	65	(48.9)	4.283	0.038*	117	(88.0)	16	(12)	0.312	0.577
Presence of Co-disability in Children with Intellectual Disability												
No co-disability	84	(63.2)	49	(36.8)	5.539	0.019*	118	(88.7)	15	(11.3)	0.931	0.335
Presence of co disability	42	(47.2)	47	(52.8)			75	(84.3)	14	(15.7)		

Test statistics: chi-square *indicates significant p-value at <0.05 Yate's corrected c^2 value

Table 5: Mean difference in the respondents' stress and coping mechanisms according to selected characteristics (n=222)

Characteristics	Number	Level of stress				Level of coping			
		Mean	SD ^a	t value	p-value	Mean	SD	t value	p-value
Relation to the child									
Mother	169	65.3609	9.42545	2.270	0.024*	105.80	9.507	-1.817	0.071
Father	53	62.0943	8.16009			108.57	10.197		
Religion									
Hindu	185	64.5189	9.01514	-0.224	0.823	107.14	9.767	2.338	0.020*
Others	37	64.8919	10.35424			103.08	8.883		
Education									
Illiterate	76	66.8158	8.39795	2.638	0.009*	103.38	8.638	-3.487	0.001*
Literate	146	63.4178	9.45097			108.06	9.899		
Age of Children with intellectual disability									
≤17 years	109	65.8624	9.70153	2.047	0.042*	106.23	9.952	-0.346	0.730
≥18 years	113	63.3451	8.60935			106.68	9.539		

^aSD: Standard Deviation



Table 5 shows there is variation in stress score among mothers and fathers ($p=0.024$) concluding high parental stress in mothers ($p=0.024$). Likewise, parental stress is high among illiterate parents ($p=0.009$) and in parents of 17 years or younger children with intellectual disability ($p=0.042$) respectively. Similarly, parental coping is high among Hindu ($p=0.020$) and literate ($p=0.001$) parents.

DISCUSSION

Regarding major stresses felt by the parents in rearing children with intellectual disabilities, maximum (19.8%) of respondents expressed anxiety about the children with an intellectual disability after their parents' death which was identified as a significant factor associated with families of mentally retarded.¹⁶

Likewise, parents have also expressed disturbed behavior of the children has caused parental stress which correlates with the finding of the inappropriate behavior of children with an intellectual disability as a major stressor.¹⁷

This study result showed the mean score for the level of stress of fathers was 62.09 ± 8.16 and mothers was 65.36 ± 9.42 highlighting a significant difference with high stress in mothers ($p=0.024$). In contrast, the mean psychological stress score of male parents was 111.47, and female parents was 125.27 which were statistically equal.³

This study showed there was an association between children's level of intellectual disability with the level of stress ($p=0.038$) and presence of co-disability in children with intellectual disability ($p=0.019$) which was supported by the study that found the parents of profoundly to moderately mentally retarded children had a significantly higher frequency of stressors as compared to those of mild to borderline mentally retarded children.¹⁸

This study showed the variation in the mean score of parental stress and age of intellectually disabled children which revealed parental stress was high among parents of intellectually disabled children of age 17 years or less. This is consistent with the finding that identified the stress of parenting to be most intense in small children with developmental disabilities.¹⁹

The mean coping score of mothers in this study was 105.80 ± 9.50 and fathers was 108.57 ± 10.19 with no mean variation. Another study also has the consistent finding in which the mean coping score of male parents was 6.84 and female parents was 6.73 with no variation.³

In this study, sharing feelings with friends, relatives, and the organization involved was the most expressed coping used by the parents (44.6%). But, information and acceptance, good family cooperation, and social support were the factors that helped parents to cope with stress.²⁰

This study showed an association between the respondents' education level and parental coping score. On the basis of the mean score, this study showed that coping was high in literate respondents which were consistent with the other

study.²¹ Most of the mothers who are educated seek professional help for coping. Educated parents are also able to provide appropriate and timely treatment for various problems of their child. The educated parents may be aware of attending meetings to enhance their coping strategies and to deal with the problems of the child successfully. Further, the educated parents are more exposed to the prevailing facilities that will improve their child's condition and enhance the strategies that they can adapt to cope effectively with the psychological stress and they have frequent contacts with experts and professionals.

CONCLUSION

More than half of parents have a moderate level of stress and more than four-fifths of parents have a moderate level of coping abilities. Parental stress and coping are not significantly associated as every parent is individually different and has been using different strategies to cope with stress. There is no single best way to cope for all people and in all situations. Parental stress was high in illiterate parents whereas coping was found to be high in literate resulting in less stress. Thus, the higher the parental educational level, the lower was the parental stress.

RECOMMENDATION

Organizations working for an intellectual disability should institute healthy coping strategies in parents of children with intellectual disabilities. Parents of children with intellectual disabilities should be encouraged to get united to work in the welfare of children with intellectual disabilities to strengthen their future. A separate counseling service with a professional counselor should be established in their own organizations as well as in health care settings. A study using both qualitative and quantitative methods can be done to explore more precise findings.

LIMITATIONS OF THE STUDY

The children had heterogeneous causes of intellectual disability (such as autism, Down's syndrome) which were not assessed in the study.

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CONFLICT OF INTEREST

None

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None



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