

Coping Styles among Parents of Children with Autism Spectrum Disorders

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ABSTRACT

Introduction: Autism falls under the most common category of Pervasive Developmental Disorders (PDD). It is a lifelong neurodevelopmental disability characterized by persistent and pervasive impairments that include challenges with social understanding and communication, difficulty adapting to new situations, and exhibiting repetitive behaviors or interests. Caring for children diagnosed with Autism Spectrum Disorder (ASD) can be an arduous task for caregivers all around the globe. To tide through the various phases of development, certain coping mechanisms are applied by the parents of children with ASD. An impact on the level of parental distress can be evaluated being based on parental coping styles concerning developmental disabilities **Objective:** To assess the coping among the parents of children with autism spectrum disorder and to measure the association of coping styles with selected background variables. **Methods:** A descriptive cross-sectional, questionnaire-based survey was carried out among 174 parents of children with ASD in selected autism care centers in Kathmandu, Nepal. The data was collected using a questionnaire developed by taking the reference from the Brief COPE questionnaire to evaluate the coping styles used by parents. Descriptive (mean and standard deviation) and inferential statistics (independent sample t-test) were used to analyze data in SPSS vs20. **Results:** The findings of the study revealed, the majority of the respondents were below 35 years of age (70.1%), female (55.2%), belonged to the Brahmin/Chhetri (63.2%) ethnic group, had a single child (62.1%), belonged to nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically (66.7%) and having a graduate or higher education (71.3%). Similarly, the majority of autistic children were aged between 1 to 5 years (93.1%), and were males (71.3%). In terms of birth order, the majority of children with autism were firstborns (72.4%), did not have any other illnesses (96.6%), and were diagnosed at the age of less than 3 years (62.1%). Overall, the majority of the parents used a problem-focused coping style with a mean of 3.2 ± 0.3 , followed by avoidant coping style (2.7 ± 0.4) and emotion-focused coping style (2.5 ± 0.5). Likewise, there was there was a significant association of avoidant coping style with the age of respondents and the number of children they have, emotion-focused coping with ethnicity, and occupation of respondents. Again, the sex of respondents, level of education of spouse, and level of autism of children of respondents were found to have a significant association with both avoidant and emotion-focused coping styles. Overall,

the level of education of respondents was associated with overall coping strategies. **Conclusion:** Based on the findings of the present study, the study concludes that the majority of the respondents used problem-focused coping style, followed by avoidant and emotion-focused coping styles. Significant associations were found between various coping styles and demographic attributes such as age, gender, ethnicity, occupation, level of education of respondents as well as their spouse, and the level of ASD of their children. Understanding the coping styles is central to supporting the parents' coping efforts. Providing parents with effective techniques to manage their emotions can greatly influence how they view their situation, the intensity of the symptoms of their children, and the psychological distress associated with it.

KEYWORDS

Autism Spectrum Disorder, Coping Styles, Nepal, Parents

INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that persists throughout a person's life. It is characterized by persistent and pervasive impairments that include challenges with social understanding and communication, difficulty adapting to new situations, and exhibiting repetitive behaviors or interests (American Psychiatric Association [APA], 2013). Autism falls under the most common category of Pervasive Developmental Disorders (PDD). Autism can affect any child of any family irrespective of racial, ethnic, or social boundaries; economic status; lifestyle choices or educational levels. The authentic estimation of the autistic person's population in Nepal is still a challenge as many people are unaware of it with very weak diagnoses. About 250000-300000 persons are estimated to be diagnosed with Autism (PWAs) in Nepal of which the number of severely affected ones ranges between 60,000-90,000 (Autism Care Nepal Society [ACNS], 2022). Parenting is a challenging job and can be stressful as well. Then, the intensity of that stress is aggravated when it comes to parenting children with special needs. (Brazier, 2016). An impact on the level of parental distress can be evaluated being based on parental coping styles and the presence of social support concerning developmental disabilities.

To tide through the various phases of development, certain coping mechanisms are applied by the parents of children with ASD (Dabrowska & Pisula, 2010). Additional physical, emotional, social, and financial resources are needed in the caregiving process (Murphy, Christian, Caplin, & Young, 2007). An impact on the level of parental distress can be evaluated based on parental coping styles and the presence of social support concerning developmental disabilities (Dabrowska & Pisula, 2010). The tendency to consider family as a highly integrated and joined unit was seen among the parents who preferred positive coping styles (Altiere & Von Kluge, 2009). Better maternal well-being regardless of the level of symptomatology of the children with ASD has a close association with higher levels of problem-focused coping and lower levels of emotion-focused coping (Smith et al., 2007). However, depression among the parents of children with ASD was found to be correlated with avoidant coping styles, such as distancing and escape (Dunn, 2001).

Autism is also common in Nepal. However, studies related to autism are scant. According to the first paper on autism released, parents and professionals in Nepal are not well-informed or aware of autism (Shrestha & Santangelo, 2014). Nepal is among the low-income nations with inadequate infrastructure for both health and education. There are very less organizations in Nepal that support and assist parents and children with autism. So it can be inferred that there is a significant requirement for sharing and comprehending the perspective of parents with autistic children to address the inadequacies in health,

education, and social systems (Yousafzai et al., 2014). There has been relatively less research conducted in Nepal regarding coping among parents of children with autism spectrum disorder, therefore the objective of this study is to assess the coping among those parents in Kathmandu, Nepal.

MATERIALS AND METHODS

The study followed a descriptive cross-sectional approach in its design. The study was carried out among the parents of children diagnosed with autism spectrum disorders from autism care centers in Kathmandu, Nepal, selected using a non-probability convenience sampling method. The sample size for the study was calculated by using the formula for the infinite population as no reliable estimates mention the statistics of people with autism in Nepal with the following assumptions: z being 1.96, p being 50%, a 5% margin of error. The sample size was 422 after adding a 10 percent non-response rate. However, considering the exclusion criteria, the data was collected from only 174 respondents. The study was conducted after obtaining ethical approval from the ethical review board of Nepal i.e. Nepal Health Research Council (NHRC) (Ref. No. 2771). Written informed consent was obtained from the participants before the administration of the questionnaire. Data was collected from May 2023 to August 2023 by using a self-administered questionnaire which consisted of 2 sections, prepared after the review of relevant works of literature.

Section 1: consisted of Demographic proforma which assessed the demographical characteristics of parents: age, sex, ethnicity, education of parents, occupation of parents, economic status, type of family, number of children, and number of children with autism. It also assessed child characteristics: current age, gender, birth order, age at diagnosis, ASD spectrum, comorbidity, and duration of training in autism centers.

Section 2: consisted of questions related to coping that was developed taking the reference from the Brief COPE questionnaire to evaluate the coping styles used by parents. The scores for the three main coping styles are displayed as average scores, which are obtained by dividing the sum of all item scores by the total number of items indicating the degree to which the respondent has been engaging in that coping style: 1 = I haven't been doing this at all, 2 = A little bit, 3 = A medium amount, 4 = I've been doing this a lot. The three overarching coping styles are outlined as Problem-Focused Coping (Items 3, 5, 6, 11, and 13), Emotion-Focused Coping (Items 9, 10, 12, 14, and 15), and Avoidant Coping (Items 1, 2, 4, 7 and 8)

The collected data were coded, entered, and analyzed in SPSS (Statistical Package for Social Sciences) version 20. Descriptive statistics such as mean and standard deviation were used for the analysis of data, and the association of coping with socio-demographic characteristics was assessed by using an independent sample t-test, one-way ANOVA.

RESULTS

Table 1. Socio-demographic Characteristics of Respondents

Indicators	n=174	
	Frequency (N=174)	Percent (%)
Age category		
< 35 years	122	70.1
≥35 years	52	29.9
Sex		
Male	78	44.8
Female	96	55.2
Ethnicity		
Dalit	4	2.3
Janajati	48	27.6
Madhesi	8	4.6
Muslim	4	2.3
Brahmin/Chhetri	110	63.2
Number of Children		
1	108	62.1
>1	66	37.9
Family Type		
Nuclear	92	52.9
Joint	82	47.1
Occupation		
Homemaker	60	34.5
Self employed	56	32.2
Government employee	20	11.5
Private employee	32	18.4
Agriculture	6	3.4
Education Level		
Read & write only	2	1.1
Secondary level	10	5.7
Higher secondary level	38	21.8
Graduate and above	124	71.3
Economic Status		
Sufficient to spend	116	66.7

Insufficient to spend	44	25.3
Sufficient to save	14	8.0

Table 1 presents the socio-demographic details of 174 respondents of autistic children. Among them, the majority of them were below 35 years of age (70.1%), female (55.2%), and belonged from the Brahmin/Chhetri (63.2%) ethnic group. In addition, most of the respondents had a single child (62.1%), belonged to a nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically (66.7%), and were highly educated with 71.3% having a graduate or higher education.

Table 2: Respondents' Child Characteristics

Indicators	n=174	
	Frequency	Percent (%)
Age(in years)		
1 to 5	162	93.1
6 to 10	12	6.9
Sex		
Male	124	71.3
Female	50	28.7
Birth Order		
1st child	126	72.4
2nd child	46	26.4
4th child	2	1.1
Other Illness		
Yes	6	3.4
No	168	96.6
Diagnosed Age		
<3 Years	108	62.1
3 to 5 years	66	37.9

Table 2 displays the socio-demographic distribution of children with autism. The majority of autistic children were aged between 1 to 5 years (93.1%) and were male (71.3%). In terms of birth order, the majority of them were the first-born (72.4%), did not have any other illnesses (96.6%) and were diagnosed at the age of less than 3 years (62.1%).

Table 3: Coping Styles Used by Respondents

Indicators	Mean±SD
Coping Overall	2.8±0.3
<i>Problem-Focused</i>	3.2±0.3
<i>Emotion-Focused</i>	2.5±0.5
<i>Avoidant Coping</i>	2.7±0.4

As presented in Table 3, the majority of the parents used problem problem-focused coping strategy with a mean of 3.2±0.3, followed by avoidant coping strategy (2.7±0.4) and emotion emotion-focused coping strategy (2.5±0.5).

Table 4: Association of Coping Styles with Socio-demographic Characteristics

Indicators	Coping Strategies								
	Problem Focused			Emotion Focused			Avoidant		
	Mea n	Std.Devi ation	P- value	Mea n	Std.Devi ation	P- value	Mea n	Std.Devi ation	P- value
Age			0.789			0.448			0.000
< 35 years	3.2	0.3		2.5	0.5		2.8	0.3	
≥35 years	3.2	0.4		2.4	0.5		2.5	0.4	
Sex			0.541			0.002			0.029
<i>Male</i>	3.2	0.3		2.3	0.5		2.7	0.4	
<i>Female</i>	3.3	0.3		2.6	0.5		2.8	0.3	
Ethnicity*			0.075			0.004			0.079
<i>Dalit</i>	3.1	0.5		3.2	0.0		3.0	0.2	
<i>Janajati</i>	3.3	0.3		2.5	0.6		2.7	0.4	
<i>Madhesi</i>	3.4	0.3		2.6	0.4		3.1	0.4	
<i>Muslim</i>	3.7	0.1		2.3	0.0		2.7	0.5	
<i>Brahmin/Chhetri</i>	3.2	0.3		2.4	0.5		2.7	0.4	
Number of Children			0.486			0.209			0.002
1	3.3	0.3		2.4	0.5		2.8	0.4	
>1	3.2	0.2		2.5	0.5		2.6	0.3	
Education level*			0.030			0.038			0.021
<i>Able to read and write</i>	3.0	0.0		3.0	0		2.2	0.0	
<i>Secondary</i>	3.5	0.2		2.9	0.3		3.0	0.2	
<i>Higher Secondary</i>	3.3	0.2		2.5	0.4		2.7	0.4	
<i>Graduate and Above</i>	3.2	0.3		2.4	0.5		2.7	0.4	

Education level of spouse*			0.153		0.028		0.029
<i>Primary level</i>	3.6	0.0		2.7	0.0	2.7	0.0
<i>Secondary level</i>	3.2	0.2		2.4	0.7	2.7	0.4
<i>Higher secondary level</i>	3.3	0.3		2.6	0.4	2.9	0.4
<i>Graduate and above</i>	3.2	0.3		2.4	0.5	2.7	0.30.153
Type of family			0.304		0.592		0.707
<i>Nuclear</i>	3.2	0.3		2.5	0.5	2.5	0.4
<i>Joint</i>	3.3	0.3		2.5	0.5	2.5	0.4
Occupation of Respondent*			0.089		0.001		0.786
<i>Homemaker</i>	3.3	0.3		2.6	0.4	2.8	0.3
<i>Self Employed</i>	3.2	0.2		2.3	0.6	2.7	0.4
<i>Government employee</i>	3.3	0.3		2.6	0.4	2.8	0.5
<i>Private Employee</i>	3.2	0.3		2.5	0.4	2.7	0.3
<i>Agriculture</i>	3.0	0.2		2.3	0.3	2.7	0.4
Occupation of Spouse*			0.936		0.563		0.352
<i>Homemaker</i>	3.2	0.3		2.4	0.5	2.7	0.3
<i>Self-employed</i>	3.2	0.3		2.5	0.5	2.8	0.3
<i>Government employee</i>	3.2	0.3		2.5	0.6	2.8	0.5
<i>Private employee</i>	3.3	0.3		2.6	0.4	2.7	0.2
<i>Agriculture</i>	3.3	0.3		2.4	0.4	2.5	0.4
<i>Foreign Employment</i>	3.4	0.3		2.6	0.3	2.9	0.6
Economic Status*			0.722		0.323		0.418
<i>Sufficient to Spend</i>	3.2	0.3		2.5	0.5	2.7	0.3
<i>Insufficient to spend</i>	3.3	0.3		2.6	0.4	2.7	0.4
<i>Sufficient to save</i>	3.2	0.3		2.4	0.6	2.9	0.4
Level of Autism*			0.004		0.000		0.278
<i>Mild</i>	3.2	0.3		2.4	0.5	2.7	0.4
<i>Moderate</i>	3.3	0.3		2.7	0.4	2.7	0.3
<i>Severe</i>	2.9	0.1		3.2	0.0	3.1	0.1
Family History of Autism			0.007		0.727		0.108
<i>No</i>	3.3	0.3		2.5	0.5	2.7	0.4
<i>Yes</i>	3.0	0.3		2.4	0.7	2.9	0.1

*Individual Samples T-Test, *One-way ANOVA*

Data presented in Table 4 showed that there was a significant association of avoidant coping style with age of respondents and number of children they have. Meanwhile, emotion focused coping was found to be significantly associated with ethnicity and occupation of respondents. Furthermore, sex of respondents, level of education of spouse, and level of autism of children of respondents were found to have a significant association with both avoidant and emotion-focused coping styles used by respondents. In addition, the level of education of respondents was associated with overall coping strategies.

DISCUSSION

Of the total 174 respondents, the findings revealed that the majority of them were below 35 years of age (70.1%), female (55.2%), and belonged from the Brahmin/Chhetri (63.2%) ethnic group. Also, most of the respondents had a single child (62.1%), belonged to nuclear family (52.9%), were homemakers (34.5%), able to spend sufficiently economically (66.7%) and were highly educated with 71.3% having a graduate or higher education. In general, it was noted that most of the surveyed individuals used problem problem-focused coping style, followed by avoidant and emotion-focused coping styles. These findings are in line with the findings of a study (Luong et al., 2009) which showed that Asian parents of children with ASD engage more frequently in problem-focused coping strategies. However, these findings are contradictory to findings of a study by (Lai et al., 2015) which suggested that parents of children with ASD engaged in active avoidance coping more frequently than parents of typically developing children. In addition, findings of a review highlighted the use of both problem-focused (e.g., treatments/interventions for child, reappraisal, and reframing) and emotion-focused (e.g., social support, spirituality, and respite) coping strategies in parents of children with ASD (Lai & Oei, 2014).

Likewise, the findings of the present study suggest a significant association of avoidant coping style with the age of respondents and the number of children they have. These findings are further supported by a study (Gray, 2006) which revealed that, in consideration of parents' age, younger parents of ASD children use more problem-focused coping strategies than older parents, whereas older parents use more emotion-focused coping strategies than younger parents.

Moreover, as per the present study, emotion-focused coping was found to be significantly associated with the ethnicity and occupation of respondents. Additionally, the sex of respondents, level of education of spouse, and level of autism of children of respondents were found to have a significant association with both avoidant and emotion-focused coping styles used by respondents. In addition, the level of education of respondents was associated with overall coping strategies. All these findings are similar to the findings of the review (Lai & Oei, 2014) according to which parents' and caregivers' use of coping strategies is influenced by demographical characteristics (i.e., gender, age, education) of respondents, and child characteristics (i.e., age, gender, medical conditions). However, the review has opposed the findings of the present study by indicating that income too makes a significant difference in the use of coping strategies by parents.

CONCLUSION

After analyzing the results of the current research, it can be inferred that the majority of participating parents used problem problem-focused coping style, followed by avoidant and emotion-focused coping styles,

which indicates that parents need to be made aware of the negative impacts of avoidant coping in their life. Additionally, the findings suggest a significant association of avoidant coping style with the age of respondents and the number of children they have. Emotion-focused coping was found to be significantly associated with the ethnicity and occupation of respondents. Meanwhile, the sex of respondents, level of education of spouse, and level of autism of children of respondents were found to have a significant association with both avoidant and emotion-focused coping styles used by respondents. In addition, the level of education of respondents was associated with overall coping strategies. It is important to note that emotion, problem, and avoidance styles of coping can each be maladaptive & ineffective or adaptive & effective, depending on the outcome. Problem-focused coping is said to be the most effective way to tackle life's problems; however, it is only effective if the individual has control over the outcome. Avoidant coping involves withdrawing or disconnecting self from a stressful situation, however, these strategies are related to an individual's negative functioning. Understanding the coping styles is central to supporting the parents' coping efforts. Teaching parents appropriate coping skills can have a significant impact on the way they perceive their condition, the severity of the symptoms of their children, and the psychological distress associated with it. Further research is necessary to evaluate the effectiveness of various programs that help parents adopt healthy ways of coping with the challenges and distress associated with day-to-day living.

CONFLICT OF INTEREST

None

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