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Comparison Of Parental Stress, Family Burden And Coping Among Parents Of Children With Intellectual Disability And Autism Spectrum Disorder Seeking Treatment In Child And Adolescent Psychiatry Opd Of Tertiary Care Hospital, Odisha

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ABSTRACT

Background: Raising a child with disability presents a lifelong challenge for both the parents and other family members and adapting to the nature of the illness can lead to disturbances within the family across multiple aspects.

Aim: This study aims to compare parental stress, family burden and coping among parents of children with Intellectual Disability (ID) and Autism Spectrum Disorder (ASD).

Materials and Methods: The current study was an observational study with a descriptive correlational design. It included 106 parents of children with ID (n=54) and ASD (n=52). Assessments of parental stress, family burden and coping were conducted using Parental Stress Scale, Family Burden Interview Schedule, Coping Checklist and Multidimensional Scale of Perceived Social Support respectively, through telephonic interviews, conducted by Master of Science (M.Sc.) Nursing student, during COVID-19 period.

Results: There was a significant difference in overall parental stress (p=0.04) and overall perceived social support (p=0.01) between both groups. Parents of children with ID experienced greater parental stress, whereas, parents of children with ASD perceived high social support. Moreover, in this study, after performing bivariate analysis, there was difference in correlates of parental stress, family burden and coping between the two groups.

Conclusion: Parents of children with ID often experiences high levels of parental stress. Nurses can play an important role in identifying stress, burden and maladaptive coping, and hence introducing positive coping skills, forming and encouraging family support groups to increase their social support, potentially reducing parental stress.

Keywords: Autism Spectrum Disorder; Burden; Coping; Intellectual Disability and Stress.

I. INTRODUCTION

Children with mental illnesses significantly impact the well-being of parents and families across physical, psychological, societal and behavioural dimensions. The global prevalence of childhood mental disorders is 6.7%, encompassing Anxiety (3.2%), Attention Deficit Hyperactivity Disorder (ADHD) (5.5%), ASD (16.1%), Conduct disorder (5.0%), Depression (6.2%) and Emotional disorder (4.4%).[1] In India, prevalence rates vary between school-based and community-based studies i.e. (23.33%) and (6.46%),[2] with the National Mental Health Survey (NMHS) indicating rates of 13.5% in urban and 6.9% in rural areas.[3]

Neurodevelopmental Disorders (NDDs) such as ID and ASD are prevalent, affecting personal, social, and academic functioning.[4] ID is characterized by aberrations and abnormalities in brain development, resulting in permanent deficiencies and co-morbid behavioural problems.[5] ASD, a pervasive neurodevelopmental disorder, manifests in abnormal behaviour, deficits in social communication and interests. Parents of children with ID and ASD face substantial burdens, including financial challenges, family disputes, and emotional strain.[6,7] The stress experienced by parents is intensified for younger children, impacting tasks like teaching social interaction and basic life skills, leading to feelings of guilt and self-blame.[8,9] During the COVID-19 pandemic, parental stress heightened due to disruptions in routine, financial strains, unavailability of medical services and fear of the virus. The families of children with special needs are confronted with an even bigger problem with the sudden appearance of the COVID-19 pandemic.[10]

Understanding parents' family burden in ID and ASD is crucial for providing them good and effective professional support by nurse, which can be helpful for the parents to identify the best coping behaviour and strategies to know their abilities to fight against stressful situations and ensure that they can spend their lives in relatively less stress and burden.

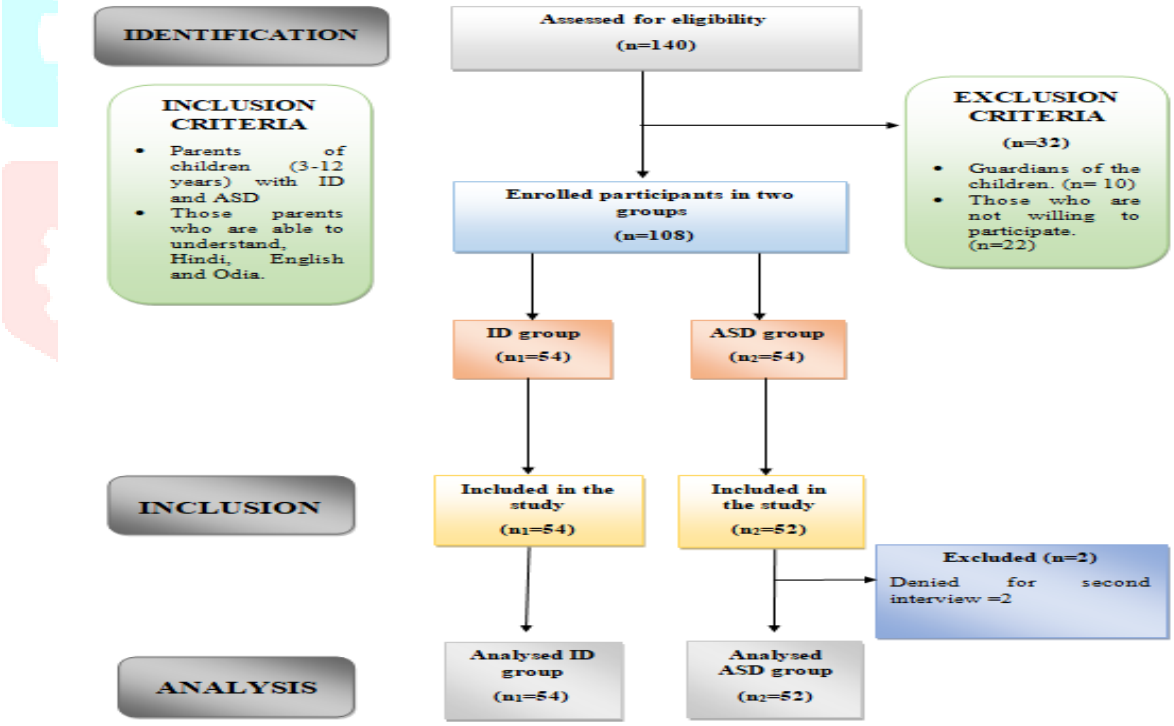
The study addresses the gap in the literature by investigating various dimensions; also seeks to shed light on the distinctive challenges faced by parents of children with ID and ASD, contributing to a nuanced understanding of their experiences. The objectives of the study were, to compare the parental stress, family burden and coping, and to identify the correlates of parental stress, family burden and coping among parents of children with ID and ASD.

II. MATERIALS AND METHODS

The study adopted a quantitative research approach, using an observational design with a descriptive co-relational framework to explore parental stress, family burden and coping among parents of children diagnosed with ID and ASD. It was conducted at the Child and Adolescent Psychiatry Outpatient Department (OPD) within the Department of Psychiatry at the tertiary care hospital. The target population included parents with children aged 3-12 years diagnosed with ID and ASD by psychiatrists using Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5) criteria, actively seeking treatment at the clinic. Inclusion criteria involved parents capable of understanding English, Hindi or Odia, while exclusion criteria included guardians and those unwilling to participate. The sample size of 108 was determined based on a prior study on caregivers' burden, evenly distributed between two groups. Subjects were conveniently divided into these groups after screening, ensuring a representative sample for each category (STROBE diagram Figure 1). The study used multiple standardized tools for data collection with high internal content validity index, with the Structured Demographic Proforma collecting socio-demographic

data and child illness related details. The Parental Stress Scale (PSS) developed by Judy Berry and Warren Jones (1995), assessed positive and negative themes of parenthood; the Family Burden Interview Schedule (FBIS) by Pai and Kapur is a semi-structured interview schedule, to measured the comprehensive burden experienced by family caregivers; and the Coping Checklist (CCL) developed by Ritu Nehra, evaluated parents' coping skills. Additionally, the Multidimensional Scale of Perceived Social Support (MSPSS) is a public domain developed by Gregory D. Zimet, measured perceived social support. Permission was taken from the developers to translate their respective tools in regional languages, i.e. English, Hindi or Odia. These tools were validated by seven experts from relevant fields. Necessary modifications were made on demographic and clinical Proforma based on their feedback and a pilot study involving ten subjects was conducted to ensure feasibility. Ethical clearance was obtained from Institutional Ethics Committee (IEC) at the tertiary care hospital. As the study was conducted during COVID-19 pandemic, the procedure of data collection involved recruiting subjects from Child and Adolescent Psychiatry OPD registry due to restricting in-person visits in hospital. Subjects were contacted via telephone, provided with a detailed explanation of the study and verbal consent was obtained with permission for call recordings. Confidentiality was assured and data usage was restricted to research purposes. The entire process was recorded with the subjects' permission and the collected data were coded and entered into an Excel sheet. Data analysis involved entering data into Statistical Package for Social Science (SPSS) trial version 20. The data collection spanned from November 2020 to December 2020.

Figure 1: STROBE flow diagram of the study



III. RESULTS

3.1 Socio-demographic characteristics of parents and child illness related characteristics

The baseline demographic characteristics of parents of children with ID and ASD are depicted in Table 1. The median age of parents was 35.5 years and 36 years in ID and ASD group respectively. There were an equal proportion of mothers and fathers (50%) in ID group, whereas majorities were mothers (51.9%) in ASD group. More than half of the parents in both groups were married, staying together and employed. The majority of parents 83.3% in ID group had two or more children and 51.9% in ASD group had a single

child. Hence, it can be interpreted that the subjects in both groups were comparable as per their socio-demographic characteristics.

The baseline demographic and child illness-related characteristics of ID and ASD groups are also depicted in Table 1. The median age of the children was 9 years and 6.5 years in ID and ASD groups respectively. The majority of parents had their firstborn child suffering from ID/ASD, i.e. (63%) in ID group and (71.2%) in ASD group respectively. The median age of diagnosis was 2.5 years within ID group and 3 years in ASD group. Hence, it can be interpreted that the subjects in both groups were comparable as per their child's illness-related characteristics at the baseline.

Table 1: Comparison of Socio-demographic and Child illness related characteristics of the subjects, as per the diagnosed disorder

n=106

Variables	**ID (n_1=54) f (%)**	**ASD (n_2=52) f (%)**	**Test statistic P value**
Socio-demographic characteristics of the Parents:			
Age of the parents (years) Median (IQR)	35.50 (9)	36 (10)	z=-1.02 p=0.30
Relationship with the child			
Father	27 (50%)	25 (48.1%)	χ^2=0.03
Mother	27 (50%)	27 (51.9%)	p=0.84
Educational qualification			
No formal education	1 (1.9%)	-	Fisher's exact test **p<0.001****
Up to 5th std education	7 (13%)	-	
6th to 12th Standard	38 (70.4%)	12 (23.1%)	
Graduate and above	8(14.8%)	40 (76.9%)	
Parental marital status			
Parents together	52 (96.3%)	51 (98.1%)	Fisher's exact test p= 1.00
Single parent/divorced	-	-	
Widow	2 (3.7%)	1 (1.9%)	
Employment Status of Parents			
Employed	30 (55.6%)	35 (67.3%)	χ^2=1.54 p=0.21
Unemployed	24 (44.4%)	17 (32.7%)	
Place of living			
Rural	28 (51.9%)	12 (23.1%)	χ^2=9.36 **p<0.001****
Urban	15 (27.8%)	24 (46.2%)	
Semi urban	11 (20.4%)	16 (30.8%)	
Type of family			
Nuclear	16 (29.6%)	30 (57.7%)	χ^2=8.74 **p=0.01***
Joint	25 (46.3%)	13 (25%)	
Extended Nuclear	13 (24.1%)	9 (17.3%)	
No. of children			

Single child	9 (16.7%)	27 (51.9%)	χ^2=14.68
2 or more children	45 (83.3%)	25 (48.1%)	**P<0.001****
Monthly income (Rs.)			
<16,656	44 (81.5%)	14 (26.9%)	
16,657 to 22,208	1 (1.9%)	1 (1.9%)	Fisher's exact test
22,209 to 44,417	7 (13%)	11 (21.2%)	
44,418 and above	2 (3.7%)	26 (50%)	**p<0.001****
Employment Status of Spouse			
Employed	28 (51.9%)	31 (59.6%)	p=0.66
Unemployed	26 (48.1%)	21 (39.4%)	
Religion			
Hindu	54 (100%)	48 (92.3%)	
Muslim	-	2 (3.8%)	Fisher's exact test
Christian	-	2 (3.8%)	p=0.11
Distance of hospital from home (in kms)			z=-0.22
Median (IQR)	120 (199)	106 (305)	p=0.82
Travel time from home to hospital (in hours)			z=-0.27
Median (IQR)	3 (2)	3 (3)	p=0.78
Any family member is suffering from Physical/ Mental disability			
Yes	13 (24.1%)	9 (17.3%)	χ^2=0.73
No	41 (75.9%)	43 (82.7%)	p=0.39
Child illness related characteristics:			
Age of the child (in years)			z=-3.55
Median (IQR)	9 (4)	6.50 (4)	**p<0.001****
Gender of the child			
Male	31 (57.4%)	39 (75%)	χ^2=3.65
Female	23 (42.6%)	13 (25%)	p=0.05
Birth Order			
1st Child	34 (63%)	37 (71.2%)	
2nd child	18 (33.3%)	13 (25%)	Fisher's exact
3rd child	-	-	test
4th child or more	2 (3.7%)	2 (3.8%)	p=0.63
Education Status			
Play School	21 (38.9%)	22 (42.3%)	
LKG/UKG	24 (7.4%)	13 (25%)	χ^2=7.96
1st – 4th Standard	20 (37%)	11 (21.2%)	**p=0.04***
5th – 8th Standard	9 (16.7%)	6 (11.5%)	

Does your child go to school which addresses to his special needs?	9 (16.7%)	27 (51.9%)	χ^2=14.68
Yes	45 (83.3%)	25 (48.1%)	**p<0.001****
No			
Duration of Illness (in years)			
Median (IQR)	5 (3.5)	4 (4.8)	z=-2.71
			p<0.001**
Any other child suffering from mental/ physical illness			
Yes	5 (9.3%)	2 (3.8%)	Fisher's exact test
No	49 (90.7%)	50 (96.2%)	p=0.43
Age at which child diagnosed (in years)			z=-0.40
Median (IQR)	2.50 (3.5)	3 (1)	p=0.68

Z- Mann-Whitney U test, χ2- chi square test, level of significance p<0.05 p<0.001***

3.2 Comparison of the Perceived Social Support, Parental Stress, Family Burden and Coping among parents of children with ID and ASD

As depicted in Table 2, on comparing domain-wise perceived social support score, it was revealed that there was a significant difference in median scores of overall perceived social support, the domains of significant other support (domain A) and friend support (domain C) between the two groups. The median overall perceived social support score of ID group was 5 with Inter-quartile range (IQR) 2.25, whereas for ASD group, the median score was 5 with IQR 5 respectively, and the difference was found to be statistically significant (p=0.01). It can be interpreted that, ASD group had significantly higher social support scores as compared with ID group.

As depicted in Table 2, the mean parental stress score in ID group was 50.72 with a Standard Deviation (SD) (9.83) and 46.79 with a SD (10.29) in ASD group respectively, which were significantly different between both the groups (p=0.04). It can be interpreted that subjects in ID group had a significantly higher PSS score.

As depicted in Table 2, on comparing domain-wise family burden score, it was revealed that all domains of burden were comparable between ID and ASD group subjects, except for domain B (Disruption of routine family activities). The median score of domain B was 8 with an IQR of 3 in ID group and 5 with an IQR of 3 in ASD group respectively, which was statistically significant (p<0.001). Hence, it can be interpreted that even though the overall burden score among both groups is comparable but the burden scores of the domain B were significantly higher in ID group.

As depicted in Table 2, on comparing coping scores, it was revealed that the overall coping score as well as the domain scores of problem-focused coping, avoidance coping and collusion and coercion coping score were comparable across both groups. The median domain score of seeking social support scores of ID group was 7 with an IQR of 2, whereas the median score of ASD group was 9 with an IQR of 2 respectively, which were statistically different (p<0.001). Hence, it can be interpreted that even though the overall coping score among both groups is comparable, the coping scores of the domain of seeking social support were significantly higher in ASD group. Hence, the entire null hypothesis is rejected and the alternate hypothesis is accepted.

Table 2: Comparison of the Perceived Social Support, Parental stress, Family burden and Coping among parents of children with ID and ASD

n=106

Variables	ID (n_1=54)	ASD (n_2=52)	Test statistic value / P value
Perceived Social Support:			
Overall perceived social support Median (IQR)	5 (2.25)	5.45 (2.19)	z=-2.43 **p=0.01***
Domain A Significant other support Median (IQR)	6 (2)	7 (1)	z=-2.95 **p<0.001****
Domain B Family support Median (IQR)	6.25 (2)	6.6 (2)	z=-0.83 p=0.40
Domain C Friend support Median (IQR)	3 (4.5)	5 (5)	z=-2.47 **p=0.01***
Parental stress:			
Parental stress score Mean±S.D	50.72±9.83	46.79±10.29	t=2.01 p=0.04*
Family burden: FBIS (Family burden interview schedule):			
Domain A (financial burden) Median (IQR)	4 (3)	3 (4)	z=-1.42 p=0.15
Domain B (Disruption of routine family activities) Median (IQR)	8 (3)	5(3)	z=-2.80 **p<0.001****
Domain C (Disruption of family leisure) Median (IQR)	5 (3)	4 (4)	z=-0.41 p=0.96
Domain D (Disruption of family interaction) Median (IQR)	3 (3)	3 (4)	z=-0.50 p=0.61
Domain E (Effect on physical health of others) Median (IQR)	1 (2)	1 (2)	z=-0.05 p=0.95
Domain F (Effect on mental health of others) Median (IQR)	2 (3)	2 (2)	z=-0.94 p=0.34
Domain G (Any other burden) Median (IQR)	1 (2)	1 (2)	z=-0.94 p=0.34
Overall burden Mean±S.D	25.26±8.56	23.06±10.74	t=1.16 p=0.24

Coping: CCL (Coping checklist):

Domain 1 (Problem focused)			z=-0.27
Median (IQR)	7 (2)	7 (3)	p=0.78
Domain 2 (Seeking social support)			z =-2.84
Median (IQR)	7 (2)	9 (2)	**p<0.001****
Domain 3 (Avoidance)			z =-0.24
Median (IQR)	9 (2)	9 (2)	p=0.80
Domain 4 (Collusion & Coercion)			z =-0.87
Median (IQR)	4 (0)	4 (0)	p=0.38
Overall Coping			z =-1.45
Median (IQR)	26 (5)	28 (5)	p=0.14

*z- Mann-Whitney U test, t- independent sample t test, level of significance p<0.05*p<0.001***

3.3 Identify the correlates of Parental Stress, Family Burden and Coping among parents of children with ID and ASD

After performing bivariate analysis, the socio-demographic variables which were found to have a significant association with parental stress, family burden, coping and perceived social support were plotted to a multiple linear regression model and the variables significantly predicted and are listed in Table 3.

In ID group, multiple linear regression analysis revealed that 37% of the family burden score variance was explained by this regression model (adjusted R^2=0.37). The significant predictors of family burden in ID group were travel time from home to the hospital (p<0.001), type of family (p=0.02), number of children (p<0.001), monthly income (p=0.02), gender of the child (p<0.001) and birth order (p<0.001). There were no significant predictors of parental stress and coping found in ID group.

In ASD group, multiple linear regression analysis revealed that 29% of the parental stress score variance was explained by this regression model (adjusted R^2=0.29). The significant predictors of parental stress in ASD group were travel time from home to the hospital (p=0.02), duration of illness (p=0.04), and any family member suffering from physical/mental disability (p<0.001). Multiple linear regression analysis revealed that 33% of the variance in the family burden score was explained by this regression model (adjusted R^2=0.33). The significant predictors of family burden in ASD group were duration of illness (p=0.02), place of living (p<0.001), number of children (p=0.01), and any family member suffering from physical/mental disability (p<0.001). Multiple linear regression analysis revealed that 19% of the coping score variance was explained by this regression model (adjusted R^2=0.19). The significant predictor of coping in ASD group was parental marital status (p<0.001).

Table 3: Socio-demographic and child illness related characteristics predicting parental stress, family burden and coping among parents of children with ID and ASD (n=106)

Outcome variables	Variables	test statistic/ P value	Adjusted regression coefficient (β) 95% CI	Adjusted regression R^2
Socio-demographic and child illness related characteristics predictors in ID group:				
Parental stress	Family history	t=1.77 p=0.08	β=-0.23 p=0.08 (-17.10-1.06)	R^2=0.03
Family burden	Age of the parents (in years)	ρ=-0.12 p=0.36	β=-0.24 p=0.05 (-0.60-.00)	R^2=0.37
	Travel time from home to the hospital (in hours)	ρ=-0.09 p=0.47	β=-0.58 **p<0.001****	
	Type of family	F=3.27 p=0.04*	β=0.26 **p=0.02*** (0.34-5.91)	
	No. of children	t=0.66 p=0.51	β=-0.48 **p<0.001****	
	Monthly income	F=0.93 p=0.43	β=-0.29 **p=0.02***	
	Gender of the child	t=2.87 p<0.001**	β=-0.43 **p<0.001****	
	Birth Order	F=1.03 p=0.36	β=0.55 **p<0.001****	
	Special school	t=0.32 p=0.74	β=0.23 p=0.05 (-0.14-11.00)	
Coping	Age of the child (in years)	ρ=0.18 p=0.18	β=-0.25 p=0.05 (-0.01-0.76)	R^2=0.10
	Parental marital status	χ^2=2.08 p=0.14	β=0.40 **p<0.001****	
	No. of children	Z=-1.49 p=0.13	β=-0.25 p=0.05 (-4.63-0.08)	
Socio-demographic and child illness related characteristics predictors in ASD group:				
Parental stress	Distance of hospital from home (in kms)	ρ=-0.27 p=0.05	β=0.48 p=0.05 (-0.00-0.61)	R^2=0.29
	Travel time from home to hospital (in hours)	ρ=-0.28 p=0.04*	β=-0.57 **p=0.02*** (-3.46-0.22)	
	Duration of illness (in	ρ=-0.16	β=0.25	

	years)	p=0.45	**p=0.04*** (0.24-1.81)	
	Family history	t=3.69 p<0.001**	β=-0.49 **p<0.001****	
Family burden	Travel time from home to hospital (in hours)	ρ=-0.24 p=0.07	β=-0.23 p=0.08 (-1.66-0.10)	R^2=0.33
	Duration of illness (in years)	ρ=0.26 p=0.05	β=0.33 **p=0.02*** (0.14-2.43)	
	Place of living	f=0.32 p=0.72	β=-0.44 **p<0.001****	
	No. of children	t=-1.98 p=0.05	β=0.42 **p=0.01*** (2.03-16.00)	
	Family history	t=2.81 p<0.001**	β=-0.34 **p<0.001****	
Coping	Parental marital status	χ^2=2.08 p=0.14	β=0.40 **p<0.001****	
	Monthly income	χ^2=2.23 p=0.32	β=0.24 p=0.05 (-0.26-1.36)	R^2=0.19
	Birth Order	χ^2=1.78 p=0.41	β=0.23 p=0.07 (-0.10-2.47)	

f- One-way ANOVA test, t-independent sample t test, Z- Mann Whitney U test, ρ- spearman's correlation multiple linear regression model analysis (enter method and backward method) level of significance p<0.05 p<0.001***

IV. DISCUSSION

4.1 Socio demographic characteristics

In this study, the median age of subjects in ID group was 35.5 years, and both mothers and fathers equally participated, which is similar to other studies conducted in India[11] and Turkey.[5] In this study, the median age of subjects in ASD group was 36 years, and the majority of the subjects were mothers, which is corresponding to other studies conducted in Nepal[8] and Poland.[12] Contrary to these findings, one of the recent research conducted in Malaysia stated that the majority (52.1%) of the subjects were fathers.[13] In the present study, the median age of children was 9 years, and majority were males, which is comparable to another studies conducted in Turkey and Spain.[5,14] Consistent with these findings, a recent study conducted in ID group in Ireland stated that, majority children were males and the average age was 13 years.[15]

4.2 Parental Stress, Family Burden and Coping among parents of children with ID and ASD

The present study revealed that on comparing ID group with ASD group, the mean parental stress score was higher in ID group (p=0.04). This indicates that, ID group experienced far greater stress than ASD group. Similar results were found in various studies conducted in India,[7,16] and Ireland.[15] The present study findings contradict the findings from several other studies, which revealed that parents of children with ASD experienced a higher level of stress than parents having a child with other disabilities. The same studies have reported that parents of younger and male children reported higher parental stress.[4,17,18]

Mothers reported a higher level of stress than fathers because of the gender role, socialization of emotions, being housewives, or unemployed parents, which is congruent with other recent studies.[19,10]

The present study revealed that there was no significant difference in the mean score of overall burden (p=0.24). Therefore, it may be interpreted that both groups were experiencing the same level of family burden in the aspect of their child's diagnosis. The present findings contradict the results from various studies, which revealed that parents of children with ID had experienced more burdens.[5,11] However, on comparing the family burden domain wise, there was a significant difference in the median scores of domain B between ID and ASD groups (p<0.001), which implies that, ID group had more disruption of routine family activities, which increased the family burden. It may be due to the challenges experienced by the parents, such as repeated physical and emotional crises, interactive family issues, ruined schedules, and additional expenses, which can create financial burden and emotional distress for a family. Moreover, other studies' findings revealed that parents with ASD children experienced moderate to severe burden, higher than the burden on parents of children with other NDDs.[8,20]

The present study revealed that there was no significant difference in the median score of overall coping (p=0.14). Hence, it was interpreted that both groups were using various coping skills/strategies to overcome stress and burden. However, on comparing the coping score domain-wise in between the two groups, there was a significant difference in the median scores of domain B (p<0.001). Parents of children in ASD group were seeking more social support to overcome their stress and burden related to their child's diagnosis. The present study findings are in line with the previous studies.[13,20] The recent researches also stated that, in the ASD group, the parents who used more coping strategies centered on positive reinterpretation and growth experienced significantly less anxiety.[21]

The present study revealed that there was a significant difference in the median scores of overall perceived social support between ID and ASD groups (p=0.01). On comparing the domain-wise perceived social support score, it was revealed that there was a significant difference in the median scores of domain A and domain C between two groups, which interprets that there was high perceived social support in ASD group, which trims down their stress and burden. The recent researches also stated that, in the ASD group, the majority of parents are receiving enough support and are satisfied with it. Support of social networks thus motivates and enables parents to reinterpret their situation in a positive way.[21] The present findings are in concordance with previous studies, which revealed that parents of children with ID lacked social support.[22] However, this study findings were contradicted by other studies, which revealed that parents of ASD children perceived support deprivation from family and friends but had perceived support from their spouse.[20]

4.3 Correlates of Parental Stress, Family Burden and Coping among parents of children with ID and ASD

The correlates of parental stress, family burden, and coping among parents of children with ID and ASD were not identified in any other studies from previous literature (to the best of our knowledge).

There were no significant correlates found in parental stress and coping among parents of the children with ID group. Present study findings revealed a significant association between family burdens in ID group with the time required to travel from home to the hospital, type of family, monthly income, number of children, gender of the child, and birth order. Subjects who were coming to the hospital from remote areas were taking more time to travel from home to the hospital had more family burden due to transportation issues, more time consumption, etc. The type of family was one of the predictors of family burden in ID group, as family burden may be due to more family conflicts, demands by other family members, disruption in family routines, etc. The monthly income of the family helps the parents to take good and better treatment for their child to cure his/her disorder, whereas low income exaggerates the financial

burden. More number of children may increase the parental care demands, which may increase the family burden. Having a male child is hard and challenging due to demands and the time required for caring for the male child by the family members and caregivers; hence the gender of the child may increase the family burden. Birth order was also a significant predictor of family burden in ID group because taking care of the first child is new and hard for the parents. Deficits in knowledge regarding the disorder, behavioural issues, and acceptance are the various factors that may lead to family burden.

Present study findings revealed a significant association between parental stress in ASD group with travel time from home to the hospital, duration of illness, and any family member suffering from physical/mental disability. Subjects who were coming to the hospital from remote areas and were taking more time to travel from home to the hospital had more parental stress due to transportation issues, more time consumption, etc. Subjects whose children had a longer duration of illness had a high level of parental stress. Subjects who had children with ASD for a long period might have adjusted and learned how their child responds to certain situations.Present study findings revealed a significant association between family burden in ASD group with the duration of illness, place of living, number of children, and any family member suffering from physical/mental disability. Subjects whose children had a longer duration of illness had a high level of family burden. Subjects who had children with ASD for a long duration might have more financial burden, continuation in disruption of family activities, lack of leisure activity and mental health effects.

Present study findings revealed a significant association between copings in ASD group with parental marital status. Subjects who lived together were using good and positive coping strategies and were able to take care of their child in a healthy manner.

Nurses role in Parental Counselling in ID and ASD

Nursing education should focus on training future nurses in providing counselling, health education, and relaxation therapies for parents, while nursing administration can facilitate training programs and nurse-led clinics to ensure high-quality care delivery. The quality of life for people with ID can be enhanced by provisions of support within the family and the available community resources.[23] It is identified that nurses have inadequate knowledge about ASD screening practices and this might be a major barrier to do early identification and interventions.[24] Education of nurses on how to best care for patients with ASD provides an avenue for ongoing advocacy to the entire healthcare team.[25] By addressing the unique needs of parents of children with ID and ASD, nursing professionals can contribute significantly to improving the overall well-being of families affected by neurodevelopmental disorders.

Strength and Limitations of the study

The present study included both mother and father to minimize the selection bias and also data was collected during the time of COVID-19 pandemic, which facilitates the availability of both the parents and their preferable timings. The present study was conducted in a single setting hence selection bias and self report bias cannot be eliminated completely. No opportunity for face to face interview due to COVID-19 pandemic.

Future recommendations

The present study findings underscore the need for targeted interventions and support for parents of children with ID and ASD, particularly in managing stress levels. Nursing practice can play a pivotal role in this regard by implementing screening protocols for early detection of parental mental health issues and providing interventions such as parent-child interaction therapy and stress management strategies.

V. CONCLUSION

This study identified a significant difference in the overall mean scores of parental stress between the ID and ASD groups. Parents of children with ID experiencing higher stress levels. However, no significant difference was observed in family burden and coping between parents of children with ID and ASD.

VI. DECLARATIONS

6.1 Financial support and sponsorship

Nil.

6.2 Conflicts of interest

There are no conflicts of interest.

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