

Types of coping as a determinant of quality of life of mothers of children with intellectual disability and autism

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ABSTRACT

Background: It is well established that caregivers of children with developmental disabilities experience greater stress than caregivers of children without developmental disabilities. However, the experience of stress is dependent on the types of coping strategies that are used to manage stress. Such stress also affects the quality of life (QoL) of parents. Thus, parents of children with disabilities have specific mental health needs which play an important role in affecting their own and their child's QoL. **Aim:** To study coping as a determinant of QoL of mothers of children with intellectual disability (ID) and children with autism. **Methodology:** The sample consisted of 100 mothers of children (between 5-12 years of age) selected with purposive sampling, having an ID (n=50) or autism (n=50), diagnosed as per ICD-10 DCR criteria. In addition, the diagnostic assessment was also based on psychometric testing. Types of coping were assessed using Ways of Coping Questionnaires. QoL of caregivers was assessed by WHOQoL-BREF. **Result:** Multiple regression analysis revealed that seeking social support and planful problem solving were significant determinants of all four domains of QoL. Escape avoidance was a significant determinant of physical, psychological and social domains of QoL of mothers. Positive reappraisal significantly predicted the psychological and social domains of QoL in mothers. **Conclusion:** Types of coping are the determinant of QoL of mothers of children with ID and autism.

Keywords: Quality of life, coping, autism

INTRODUCTION

Throughout life's transitions, parents are considered the most important part of a person's life. Parents have a key role in children's psychological, social, and academic development.^[1] For children with chronic disabilities, studies have found that children's welfare and developmental outcomes can be substantially affected by their parents' mental health.^[2-3] An individual's mental health can have a great impact on his/her Quality of Life. Quality of Life is defined as individuals' perception of their position in life in the context of the culture and value systems in

which they live and in relation to their goals, expectations, standards, and concerns. It is a broad-ranging concept, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment. This definition highlights the view that quality of life is subjective, includes both positive and negative facets of life and is multi-dimensional.^[4] Thus, QoL includes the conditions of life resulting from the combination of the effect of a complete range of the factors such as those determining health,

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happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and expression.^[4]

Although, Western studies have reported poor QoL of caregivers of children with developmental disabilities, little, if any, data are available on the determinants of QoL in parents of children with developmental disorders as compared to other severe neurological or psychiatric disorders. Also, as discussed earlier, both contextual and health conditions, influence a person's functioning.^[5] Not only the International classification of functioning, disability and health (ICFDH) definition but also according to the medical model of QoL,^[6] it is proposed that a number of meditational factors including coping influence the perceived QoL. Thus, although there could be a wide range of factors that could determine the QoL of an individual, coping appears to be significantly important in understanding an individual's perceived QoL. However, although these theoretical propositions indicate an important role of coping in determining QoL, there is little research-based evidence for this, especially for family caregivers of children with developmental disabilities.

Intellectual disability and autism are considered developmental disabilities, which also often result in requirements for long term care far exceeding the usual needs of children as they develop, or the expectations of their families as parents. Thus, considering the high prevalence rates of ID and autism along with the long term functional, emotional and social dependency of these two groups of developmental disabilities on their caregivers; these two disability groups were specifically chosen for the present study. In view of the gaps in understanding of the psychological determinants of QoL of caregivers of these disability groups, a need for the present study was felt. Furthermore, since in India mothers share the maximum responsibility of caring for their children, so they were studied with the aim of to explore the type of coping processes used and QoL of mothers of children with intellectual disability and autism.

METHODS AND MATERIALS

Sample: The study population consisted of (a) children with intellectual disability, and (b) children with autism; and their mothers.

Children with intellectual disability and autism were those attending OPD at various neuro-psychiatric hospitals/clinics and special schools in Delhi. Purposive sampling was used. The total sample of 100 consisted of 50 mothers of children with ID and 50 mothers of children with autism.

Inclusion Criteria for Children: Children diagnosed as cases of mental retardation and childhood autism as per the International Classification of Diseases- Diagnostic Criteria for Research (ICD-10-DCR)^[7] Parents of both boys, as well as girls, were taken. The age range of children was between 5 to 12 years.

Exclusion Criteria for Children: Children with comorbid conditions like epilepsy, hearing impairment, visual impairment, motor impairment, speech impairment any other significant medical illness were excluded from the study.

Mothers in the age group of 30 years to 45 years were recruited for the study. Single mothers, mothers having any significant medical/psychiatric illness or those mothers having any other significant medical/psychiatric family history that might contribute to caregiver burden were excluded from the study.

Tools used:

Socio-demographic Performa: It consisted of a structured format to record variables regarding the caregiver and the child with intellectual disability/autism such as age and gender of the child; age, gender, education, occupation, marital status of caregivers.

Seguin Form Board Test: For the present study, norms given by Goel^[8] were used. This test was used to get an IQ of children for diagnostic confirmation.

Vineland Social Maturity Scale (VSMS)^[9]: It is a useful instrument in measuring the social maturity of children and young adults. It serves the purpose of estimating the differential capacities of an individual. It comprises of 89 items and was used to assess the social adaptive functioning of children in the present study. The VSMS measures the differential social capacities of an individual. It provides an estimate of social age (SA) and Social Quotient (SQ) and shows a high

correlation (0.80) with IQ. Considering its high correlation with IQ, SQ was considered wherever the patient was not able to perform on SFBT.

Childhood Autism Rating Scale (CARS)^[10]:

It is a 15 item behavioural rating scale developed to identify children with autism and to distinguish them from developmental disabilities other than autism. It further distinguishes children with autism in the mild to moderate range from children with autism in the moderate to severe range. The 15 CARS items include ability to relate with others; imitation; emotional response; body use; object use; adaptation to change; visual response; listening response, taste/ smell/ touch response and use; fear or nervousness; verbal communication; nonverbal communication; activity level; level and consistency of intellectual response and general impressions. The coefficient alpha for CARS has been reported to be 0.94. The inter-rater reliability of this scale ranges from 0.55 to 0.93; while test-retest reliability has been reported to be 0.88. The scale has a criterion-related validity of 0.80. In the present study, CARS was used to ascertain the presence and severity of autism.

Ways of Coping Questionnaire: It has been designed by Folkman & Lazarus^[11] to identify the thoughts and actions that an individual has used to cope with a specific stressful encounter. The questionnaire comprises of 66 statements which are rated by the subject using 4 points Likert scale. The scale comprises of eight coping scales namely confrontative coping, distancing, self-controlling, seeking social support, accepting responsibility, escape avoidance, planful problem solving and positive reappraisal. Psychometric properties of the scale reveal high alpha coefficients for eight scales along with face and construct validity. This scale was used in the present study to identify the coping processes used by mothers of children with developmental disabilities.

WHO Quality of Life BREF (WHOQoL-BREF)^[12]: In order to assess QoL, the Hindi version of the WHOQoL-BREF was used. The WHOQoL-BREF, an abbreviated version of the WHOQoL-100, is a self-administered questionnaire. It comprises of 24 items categorized into four broad domains: physical

health, psychological well-being, social relationships and environment. The items are rated on a 5-point scale. The reported values for Cronbach's α were 0.82 for physical health, 0.81 for the psychological domain, 0.68 for social domain and 0.80 for environment domain.^[13]

Procedure: All children who were referred with a provisional diagnosis of intellectual disability or autism were evaluated in the following way for the purpose of the study:

Those children and their mothers who fulfilled the inclusion and exclusion criteria were furnished with the necessary information about the study and a written informed consent was obtained from mothers. Those who gave their consent were enrolled and further evaluated on study tools. Data were collected in two sessions; both the sessions were conducted in the clinical setting. In the first session, the nature of the study was explained to the caregivers and their consent was taken. Further, in the first session, socio-demographic Performa was administered to elicit information about socio-demographic, clinical and caregiver details. Diagnostic confirmation of children was done by administering Seguin Form Board Test, Vineland Social maturity scale and CARS. After assessments with the children, in the second session, the Ways of Coping Questionnaire, and WHOQoL-BREF scale were administered on mothers.

Statistical Analyses: Data obtained has been analyzed using descriptive and inferential statistics. Correlation and multiple regression analyses have been used to study the influence of types of coping processes on domains of QoL. The Statistical Package for Social Sciences (SPSS, version 17.0) was used. Significance level $p < .05$ was regarded as statistically significant.

RESULTS

Socio-demographic profile of the sample is shown in table 1. Correlation and multiple regression analysis were done to analyse the relationship between types of coping process and domains of QoL. The results were analyzed using multiple regression analysis, a statistical technique through which one can analyze the relationship between criterion and predictor variables.

Table 1: Socio-demographic profile

Variable	Autism	ID
Age (Mean ±S.D)	38.6 ±3.44	40.42 ± 5.25
Level of Education (%)		
12th	40	42
Graduation	44	42
P.G	16	16
Family Type		
Nuclear	58	54
Extended Nuclear	24	26
Joint	18	20

From Table 2, it is observed that seeking social support, planful problem solving and positive reappraisal was positively correlated with all four domains of QoL of mothers. Confrontative coping, distancing, self-control and escape avoidance are negatively correlated with the physical domain of QoL of mothers. The psychological and social domain of QoL is negatively correlated with confrontative coping and escape avoidance. Confrontative coping, escape avoidance and self-control are negatively correlated with the environment domain of QoL of mothers.

Table 2: Correlation between types of coping process used with domains of QoL

Domain of QoL	Physical	Psychological	Social	Environment
Type of Coping Process				
Confrontative	-0.36**	-0.55**	-0.44**	-0.27**
Distancing	-0.26**	-0.16*	-0.17*	-0.18*
Self Control	-0.00	0.03	-0.08	-0.08
Seeking Social Support	0.53**	0.24**	0.84**	0.56**
Accepting Responsibility	0.00	-0.13	0.14	0.14
Escape Avoidance	-0.47**	-0.77**	-0.14	-0.22**
Planful Problem Solving	0.36**	0.76**	0.23**	0.28**
Positive Reappraisal	0.39**	0.75**	0.30**	0.22**

Regression of types of coping processes (eight independent variables confrontative coping, distancing, self-control, seeking social support, accepting responsibility, escape avoidance, planful problem solving, positive reappraisal) for the dependent variable of physical domain of QoL is shown in Table 3. It is observed that the calculated adjusted $R^2 = 0.42$ $F(8,91) = 9.78$, $p < 0.01$ for physical domains of QoL,

Table 3: Multiple Regression Analysis for the Physical Domain of QoL of Mothers

Measures	Beta value	t-value	p-value
Confrontative Coping	-0.13	0.74	0.462
Distancing	-0.13	1.56	0.122
Seeking Social Support	0.49	5.04	0.000
Escape Avoidance	-0.30	1.97	0.049
Planful Problem Solving	0.41	2.97	0
Positive Reappraisal	0.19	1.18	0.241

$F = 9.78$ **, $R = 0.68$, Adjusted $R^2 = 0.41$, $SEE = 10.46$, $df = 99$

implying that the interaction of these eight coping processes contributes to 42% variance in the physical domain of QoL in mothers. Calculated ANOVA showed significance ($p < 0.01$) between residual and regression factors for the physical domain of QoL in mothers indicating that the predictor variables could significantly regress the dependent variable. Beta value for seeking social support and escape avoidance is found to be 0.49 ($p = 0.01$) and -0.30 ($p = 0.049$) indicating that 49% and 30% variance in the physical domain of QoL of mothers is due to seeking social support and escape avoidance. Seeking social support, planful problem solving and positive reappraisal are positively correlated with the psychological domain of QoL of mothers (Table 2). Confrontative coping, distancing and escape avoidance are negatively correlated with the psychological domain of QoL of mothers.

Table 4: Multiple Regression Analysis of Psychological Domain of QoL of Mothers

Measures	Beta value	t value	p value
Confrontative Coping	0.02	0.15	0.880
Distancing	-0.01	0.18	0.858
Seeking Social Support	0.26	1.96	0.03
Escape Avoidance	-0.30	2.97	0.004
Planful Problem Solving	0.34	3.35	0.001
Positive Reappraisal	0.37	3.38	0.001

$F = 36.18$ **, $R = 0.87$, Adjusted $R^2 = 0.74$, $SEE = 5.41$, $df = 99$

Table 4 shows the multiple regression of types of coping processes (eight independent variables- confrontative coping, distancing,

self-control, seeking social support, accepting responsibility, escape avoidance, planful problem solving, positive reappraisal) for the dependent variable of the psychological domain of QoL. It is observed that the calculated adjusted $R^2 = 0.74$ $F(8,91) = 36.18$, $p < 0.01$ for the psychological domain of QoL, implying that the interaction of these eight coping processes contributes to 74% variance in the psychological domain of QoL in mothers. Calculated ANOVA showed significance ($p < 0.01$) between residual and regression factors indicating that the predictor variables could significantly regress the dependent variable. Beta value for escape avoidance, seeking social support, planful problem solving and positive reappraisal are found to be -0.30 ($p = 0.049$), 0.26 ($p < 0.05$) 0.34 ($p < 0.01$) and 0.37 ($p < 0.01$) respectively indicating that 30%, 26%, 34% and 37% variance in psychological domain of QoL of mothers is caused due to coping processes of escape avoidance, seeking social support, planful problem solving and positive reappraisal respectively.

Further, from table 2 it is observed that seeking social support, planful problem solving and positive reappraisal are positively correlated with the social domain of QoL of mothers. Confrontative coping, distancing and self-control are negatively correlated with the social domain of QoL of mothers.

Table 5: Summary of Multiple Regression Analysis for the dependent variable of Social Domain of QoL of Mothers (N=100)

Measures	Beta value	t value	p value
Confrontative Coping	-0.23	1.98	0.051
Distancing	-0.03	0.06	0.954
Seeking Social Support	0.86	13.49	0.000
Escape Avoidance	0.14	3.17	0.002
Planful Problem Solving	0.23	2.87	0.005
Positive Reappraisal	0.30	3.30	0.001

$F = 37.77^{**}$, $R = 0.88$, Adjusted $R^2 = 0.75$, $SEE = 8.48$, $df = 99$

Summary of multiple regression analysis of types of coping processes (eight independent variables confrontative coping, distancing, self-control, seeking social support, accepting responsibility, escape avoidance, planful problem solving, positive reappraisal) for the dependent variable of social domain of QoL is shown in Tables 5. It is observed that the

calculated adjusted $R^2 = 0.75$ $F(8,91) = 37.77$, $p < 0.01$ for the social domain of QoL, implying that the eight coping processes together contribute to 75% variance in the social domain of QoL in mothers. Calculated ANOVA showed significance ($p < 0.01$) between residual and regression factors indicating that the predictor variables could significantly regress the dependent variable. Beta values for seeking social support, escape avoidance, planful problem solving and positive reappraisal are found to be 0.86 ($p < 0.01$), 0.14 ($p < 0.01$), 0.23 ($p < 0.01$) and 0.30 ($p < 0.01$) respectively indicating that 86%, 14%, 23% and 30% variance in social domain of QoL of mothers is caused due to these four coping processes respectively.

Table 6: Summary of Multiple Regression Analysis for the dependent variable of Environment Domain of QoL of Mothers (N=100)

Measures	Beta value	t value	p value
Confrontative Coping	-0.31	1.66	0.100
Seeking Social Support	0.59	5.82	0.000
Escape Avoidance	-0.2	1.29	0.202
Planful Problem Solving	0.43	2.71	0.008
Positive Reappraisal	0.24	1.39	0.168

$F = 7.82^{**}$, $R = 0.64$, Adjusted $R^2 = 0.36$, $SEE = 14.30$, $df = 99$

It is observed from table 2 that seeking social support, planful problem solving and positive reappraisal are positively correlated with the environment domain of QoL of mothers. Confrontative coping, escape avoidance and self-control are negatively correlated with the environment domain of QoL of mothers.

Multiple regression analysis of types of coping processes (eight independent variables confrontative coping, distancing, self-control, seeking social support, accepting responsibility, escape avoidance, planful problem solving, positive reappraisal) for the dependent variable of environment domain of QoL was carried out and the summary of results is shown in Tables 6. It is observed that the calculated adjusted $R^2 = 0.36$ $F(8,91) = 7.82$, $p < 0.01$ for environment domain of QoL, implying that the interaction of eight coping processes together contributes to 36% variance in the social domain of QoL in mothers. Calculated ANOVA showed significance ($p < 0.01$) between residual and regression

factors for the environment domain of QoL in mothers indicating that the predictor variables could significantly regress the dependent variable. Beta values for seeking social support and planful problem solving are found to be 0.59 ($p < 0.01$) and 0.43 ($p < 0.01$) respectively indicating that 59% and 43% variance in environment domain of QoL of mothers is caused due to the coping processes of seeking social support and planful problem solving respectively.

DISCUSSION

It is by now well established that parents of children with developmental disabilities have poorer QoL as compared to parents of typically developing children.^[14-15] Some of the variables that have been reported to be associated with lower parental QoL include child behavioural difficulties, unemployment, being a mother and lack of social support.^[16]

In the present study, it was also hypothesized that the domains of QoL of mothers of children with intellectual disability and autism would be significantly determined by types of coping used. There was a positive correlation between seeking social support, planful problem solving and positive reappraisal while all other types of coping had a negative correlation with all the domains of QoL. The findings indicate that the more the mothers used confrontative coping, distancing, self-control accepting responsibility, escape avoidance as a coping process, the lower was their QoL. On the contrary, the higher the use of seeking social support, planful problem solving and positive reappraisal the better is the QoL of mothers.

From the regression analysis, the obtained F-values were found to be statistically significant for all the four domains of QoL in mothers. This implied that the overall model of prediction fits in well for all the domains of QoL of mothers with types of coping accounting for 41%, 74%, 75% and 36% variance respectively in physical, psychological, social and environment domains of QoL of mothers.

Escape avoidance, seeking social support and planful problem solving was found to be a significant determinant of the physical domain of QoL of mothers. The psychological and social domain of QoL of mothers is

significantly determined by escape avoidance, seeking social support, planful problem solving and positive reappraisal. The environment domain of QoL for mothers is significantly determined by seeking social support and planful problem-solving. Thus, overall different domains of QoL are influenced by different types of coping. Seeking social support and planful problem solving is a significant predictor of all the four domains of QoL in mothers.

Also, the beta value showed that seeking social support, planful problem solving and positive reappraisal contributed positively in the prediction of the domains of QoL in mothers while all other types of coping contributed negatively.

Thus, since different coping strategies are related to different emotional states, therefore, one type of coping could be more predictive of QoL than another type of coping. In this respect, a classical study has been done by Folkman and Lazarus^[11] who examined the extent to which eight different types of coping processes mediate the emotional responses in a younger (ages 35-45) and older sample (mean age of 68) of white men/women who had recently experienced a stressful encounter. Coping was reported to be associated with all four types of emotions: disgust and anger; pleasure and happiness; confidence; and to a lesser extent fear and worry and since emotions play a crucial role in determining ones' perceived QoL, the findings of this study become especially relevant to the findings of the present study.^[11] Planful problem solving was associated with an improved emotional state, suggesting that people often feel better when they directly focus on finding solutions to the problem. Confrontive coping and distancing had a negative effect on emotions because it failed to diminish the distress. Positive reappraisal had improved emotional states in the younger group but seemed to contribute to a worsened emotional state in the older group. One possible explanation for this could be that the when faced with difficult situations, the older group had difficulty sustaining the positive beliefs. In the present research, such effects of different emotional states on types of coping^[11] could have possibly led to the differential predictive influence of different types of coping on different domains of QoL.

Similar findings have also been reported by Smith et al.^[17] who found that mothers of toddlers having ASD, lower levels of emotion-focused coping and higher levels of problem-focused coping were generally associated with better maternal wellbeing, regardless of the level of child symptomatology. According to these researchers, the presence of significant buffering effects reflects adaptation in the face of stress, particularly for mothers of adolescents. Associations between coping strategies and parental stress and mental health have also been reported by Hastings et al.^[18] Their findings indicate that coping strategies like problem-solving and social support operate as factors that facilitate QoL. It may be that solving skills and support from others facilitates individual goal attainment against the negative emotions associated with having a child with a disability. Similar findings are obtained in the present research.

Escape avoidance has also been found to be a negative determinant type of coping for various domains of QoL in mothers. Escape avoidance is generally considered to be a maladaptive coping characterized by the effort to escape from having to deal with a stressor. Those who cope using avoidance make an effort to avoid thoughts or feelings associated with the stressful event and a loss of interest in once positive activities.

This further indicates that caregiver's problem behaviours are positively associated with escape avoidance coping and depressive symptoms.^[19] In the present research also, it is found that escape avoidance is a negative determinant of physical, psychological and social domains of QoL for both mothers and fathers, implying that the more one uses escape avoidance, lower is their perceived QoL.

This study would have clinical implications in developing primary care health services for caregivers which would help in developing programmes aimed at helping caregivers enhance the use of specific coping processes that are associated with better QoL. The findings of the study could be used to develop effective and sustainable psycho-social programmes to help caregivers. Interventions aimed at addressing caregiver stress could be instrumental in improving mental health outcomes for caregivers. The study also has

implications for resource allocation and at the policy level by providing more empirically based data to help the authorities develop appropriate infrastructure and guidelines to enhance the QoL of these caregivers.

Limitations: No research is complete in itself, likewise the present research work also had its limitations - care giving is a multidimensional concept, the nature and determinants of which evolve over time. The transitions in care giving experience and the caregiver characteristics such as age, changing responsibilities, quality of family support may also affect the caregivers which were not evaluated in the present study.

CONCLUSIONS

The study concluded that the types of coping used by the mothers of children with disability are a significant determinant of domains of QoL of their mothers.

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