

Anxiety, depression, and quality of life in mothers of children with intellectual disability

Abstract

Background: Intellectual disability (ID) in children can trigger a range of psychological responses in parents. The present study was an attempt to investigate psychological conditions of mothers of children with ID and to determine whether these problems were more prominent in mothers of children with ID than mothers with healthy children. **Aim and objectives:** Were to investigate psychological impact (i.e. anxiety, depression, and quality of life [QOL]) on mothers of children with ID. **Materials and methods:** Comprised of two groups of subjects, i.e. mothers of sixty children with ID and mothers of sixty healthy children. The study was conducted at the Outpatient Department of Lokopriya Gopinath Bordoloi Regional Institute of Mental Health (LGBRIMH), Tezpur, Assam. Both groups were assessed with Beck Depression Inventory (BDI-II); State Trait Anxiety Inventory (STAI), and World Health Organization QOL-BREF (WHOQOL-BREF). Data was analysed by descriptive statistics, correlation, and t test. **Result:** The results of the study conclusively found out that the mothers of children with ID were having higher anxiety and depression than mothers with healthy children. The anxiety and depression had negative correlation with QOL of mothers of children with ID. **Conclusion:** This study shows that anxiety and depression affected QOL in mothers of children with ID.

Keywords: Mental Retardation. Caregivers. Mental Health.

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Introduction

Intellectual disability (ID) is a condition, not a disease. ID is characterised by significant limitation in intellectual functioning and in adaptive behaviour and a reduced ability to understand new or complex information and to learn and apply every social and practical skills and stipulates that the onset of mental retardation should be before the age of 18 years.[1] A mother expects her child to be born healthy but diagnosis of a child as disabled during infancy or in later stages takes a heavy toll on her happiness and well-being. Such a diagnosis can precipitate a range of psychological responses in a mother thereby constituting a crisis for mothers and demanding extraordinary psychological adjustment. The psychological problems include feeling of guilt, feeling responsible for producing a mentally retarded child. The emotional response of denial, shock, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence, disillusionment, and fear are seen in parents and family members of an intellectually disabled child.[2] A research was conducted by Singhi *et al.*[3] in India on psychosocial problems faced by parent and family members, and they found that parents of disabled children face severe economic problems, distractions in family activity schedule, problems in social interaction, and marital disadjustment, and also higher neurotic condition. Hedove *et al.*[4] suggested that the presence of a family member with Down's syndrome might have a negative impact on maternal quality of life

(QOL). Noor[5] has noted that parents of children with ID face problems like absenteeism in workplace, inattentiveness in job activity, disturbances in mental and physical health, marital dissatisfaction, and poor overall well-being. Increased prevalence of depression and anxiety were reported in various caregiver groups.[6,7]

The present study attempts to examine the level of anxiety and depression, and their relationship with QOL in mothers with intellectually disabled children. This study also tries to establish whether psychological problems are more prominent in the mothers with intellectually disabled children than mothers with healthy children.

Materials and Methods

The research design employed was descriptive, cross-sectional, and comparative study.

Sample

Participants were sixty mothers with children of moderate to severe level of ID as per tenth revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) criteria[8] (Group A) and sixty mothers with healthy children (Group B). Mothers staying with the children since their birth were selected using purposive sampling technique from the outpatient department (OPD) of Lokopriya Lopinath Bordoloi Regional Institute of Mental

Health (LGBRIMH), Tezpur, Assam. For the control group B, mothers staying with their children since their birth were selected from Tezpur Municipal area. This group was matched for age, educational qualification, duration of stay with child, family type, nil past history of psychiatric illness, and nil physical disability. Mothers with previous psychiatric history, more than one child with any form of disability, and mothers of children aged more than 18 years were excluded.

Tools

All the respondents of both the groups was interviewed and assessed separately. Beck Depression Inventory (BDI-II)[9] was administered to determine the level of depression, State Trait Anxiety Inventory (STAI)[10] to assess the anxiety, and World Health Organization QOL-BREF (WHOQOL-BREF) for assessment of QOL.[11]

Statistical analysis

Data was coded and entered into a master chart. Data was analysed with the help of SPSS 18. Frequency table, percentages, means and standard deviation (SD), chi-square test, correlation, and *t* test were used.

Result and Discussion

No significant difference in socio-demographic variables of age, educational status, religion, family type, duration of stay with the child between both the groups. But there was differences found in occupation ($p < 0.05$), socioeconomic status ($p < 0.05$), and place of residence ($p < 0.05$) between mothers of children with ID and mothers with healthy children (Table 1).

Table 2 described the group differences in STAI and BDI-II, and QOL domains' scores between mothers of children with ID and mothers with healthy children. The findings of STAI on State Anxiety Inventory (SAI) domain suggest that Group A mean score (47.55 ± 5.30) was more than Group B (35.13 ± 5.84) mean score. The difference of SAI score was statistically significant ($t = 12.18$, $p < 0.001$). On Trait Anxiety Inventory (TAI) domain, mean score was high on Group A (48.23 ± 5.67) with comparison to Group B (34.40 ± 5.20). The difference of TAI score was $t = 13.85$, $p < 0.001$, indicating significant difference between both the groups. With respect to the BDI-II score, the result suggests more depression in Group A (21.88 ± 6.12) with comparison to Group B (6.7 ± 5.26). Further, result support that there was significant difference (t value = 14.56 , $p < 0.001$) between both the groups. The statistical findings of SAI, TAI, and BDI scores indicate that mothers of children with ID had higher anxiety and depression as compared to mothers with healthy children.

Results of this study are similar to the findings of Bumin *et al.*[12] They found that mean score for the study sample on BDI was 14.22 (SD=13.03), SAI was 41.95 (SD=6.55), and on TAI was 47.27 (SD = 7.94), indicating mild to moderate level of depression and higher anxiety in the mothers. Zigmond and Snaith[13] conducted a study which shows that parents caring for intellectually disabled children had much higher levels of depressive symptomatology than parents of typically

developed children, $F(1, 59) = 41.64$, $p < 0.001$, $\eta^2 = 0.414$. They also had much higher anxiety scores, $F(1, 59) = 43.12$, $p < 0.001$, $\eta^2 = 0.422$.

In respect to QOL on physical, psychological, social relationship, and environment domains, the findings of *t* test indicate significant difference between both groups. All the QOL domains in mothers of children with ID had lower QOL than mothers with healthy children (Table 2).

Many studies show that parents of children with Down's syndrome spent more time in child care, and they have less recreational time and social activities in comparison to parents without a disorder.[14-16] They conducted study on health-related QOL in parents of children with Down's syndrome using the WHOQOL-BREF and found that parents scored lower on environmental domain, which encompasses opportunities for recreation. Lin *et al.*[17] also examined the differences between caregivers of children and adolescents with ID than the general population, and their results show the mean scores in each domain of WHOQOL-BREF as followings: physical domain was 13.71 ± 2.35 , psychological domain was 12.21 ± 2.55 , social relationship domain was 12.99 ± 2.43 , and environment domain was 12.32 ± 2.38 . These mean scores were lower than the general population.

Our study found that mothers of children with ID had significantly decreased QOL as compared to the mothers with healthy children. Mothers of children with ID decreased the QOL in all the four domains of physical, psychological, social relationship, and environment. More specifically, mothers of children with ID displayed lower physical health and psychological well-being.

In mothers of children with ID, 50% had moderate level of depression followed by 31.7% having mild depression, 13.3% had severe depression, and only five per cent mothers had minimal level of depression. But in case of mothers of healthy children, 93.9% had minimal depression and only 6.7% had moderate level of depression. Similar kind of findings confirmed that mothers with disabled children have depression in general.[18] It was found that 73% of the mothers in the study had various degrees of depression; 36% of them suffering from mild depression and 21% from severe depression. Gallagher *et al.*[19] reported parents caring for intellectually disabled children reported higher level of depression symptoms than parents of typically developing children. The statistics show that $F(1, 59) = 41.64$, $p < 0.001$, $\eta^2 = 0.414$. Bitsika and Sharpley[20] found that nearly 50% of the parents were severely anxious and about two-thirds were clinically depressed.

The present study also revealed that the SAI and TAI have significant positive correlation with BDI-II score in mothers of children with ID ($r = 0.557$, $p < 0.001$ and $r = 0.613$, $p < 0.001$, respectively). Bumin *et al.*[12] also examined the association between anxiety and depression with QOL, and they found a significant correlation between depression scores and trait anxiety scores. Tabassum and Mohsin[21] also hypothesised that there is positive relationship between the depression and anxiety among parents of children with disabilities. Azeem *et al.*[22] also reported that depression is most common diagnosis among mother of children with moderate ID and

Table 1: The distribution of socio-demographic profile of both groups

Variables	Mothers of children with ID (N=60) (%)	Mothers of healthy children (N=60) (%)	df	χ^2
Age (years)				
20-34	17 (28.3)	10 (16.7)	2	5.92
35-49	40 (66.7)	50 (83.3)		
50-64	3 (5)	0		
Qualification				
Illiterate	10 (16.7)	10 (16.7)	5	8.10
Up to primary level	16 (26.7)	15 (25)		
Up to class X	28 (46.7)	21 (35)		
Up to class XII	6 (10)	7 (11.7)		
Up to graduation	0	6 (10)		
Up to post-graduation	0	1 (1.7)		
Occupation				
Unemployed	19 (31.7)	6 (10)	3	10.28*
Self-employed	14 (23.3)	20 (33.3)		
Govt. service	13 (21.7)	22 (36.7)		
Agriculture	14 (23.3)	12 (20)		
Socioeconomic status				
Poor	25 (41.7)	15 (25)	2	6.41*
Middle	34 (56.7)	39 (65)		
Upper	1 (1.7)	6 (10)		
Religion				
Hindu	36 (60)	44 (73.3)	2	2.80
Muslim	20 (33.3)	12 (20)		
Christian	4 (6.7)	4 (6.7)		
Family type				
Nuclear	49 (81.7)	50 (83.3)	1	0.058
Joint	11 (18.3)	10 (16.7)		
Place of residence				
Rural	40 (66.7)	26 (43.3)	2	6.73*
Urban	15 (25)	27 (45)		
Semi-urban	5 (8.3)	7 (11.7)		
Duration of stay with the child (years)				
1-5	6 (10)	2 (3.3)	2	4.91
6-10	23 (38.3)	16 (26.7)		
>10	31 (51.7)	42 (70)		

ID=Intellectual disability, df=Degree of freedom, *Statistically significant

anxiety was highest among mother of children with profound ID. The results of this study shows a highly significant positive correlation between depression and anxiety ($r=0.833$, $p<0.01$).

The relationship of SAI and TAI with quality of life domains (Table 3) shows that SAI has negative correlation with psychological ($r=-0.519$, $p<0.001$), social relationship ($r=-0.337$, $p<0.01$), and environmental ($r=-0.371$, $p<0.01$) domains, but SAI has no significant relationship with physical domain ($r=-0.237$, $p>0.05$), as well as TAI has negative correlation with QOL domains (physical, $r=-0.400$,

$p<0.01$, psychological, $r=-0.526$, $p<0.001$, social relationship, $r=-0.265$, $p<0.05$, and environmental, $r=-0.336$, $p<0.01$).

Bumin *et al.*[12] also found that mothers with disabled children have higher anxiety, depression and lower QOL. Increased depression and anxiety affected badly in mother's QOL. Shanbhag and Krishanmurthy[23] observed that there was a significant ($p<0.05$) correlation between the General Health Questionnaire (GHQ) scores and QOL. They assessed the association between the mental health status and QOL of the caregiver with child of cerebral palsy and ID. They assessed

Table 2: Group differences in SAI, TAI, BDI-II scores, and QOL domains between mothers of children with ID and mothers with healthy children

Variables	Mean±SD		df	t value
	Mothers of children with ID (N=60)	Mothers of healthy children (N=60)		
STAI				
SAI	47.55±5.30	35.13±5.84	118	12.18*
TAI	48.23±5.67	34.40±5.20	118	13.85*
BDI-II score	21.88±6.12	6.7±5.26	118	14.56*
WHO-QOL-BREF				
Physical	11.60±1.45	15.30±1.49	118	13.73*
Psychological	11.01±1.65	14.33±1.73	118	10.72*
Social relationship	12.45±2.15	14.93±1.32	118	7.61*
Environment	11.78±1.61	14.53±1.39	118	9.97*

SAI=State Anxiety Inventory, TAI=Trait Anxiety Inventory, BDI=Beck Depression Inventory, QOL=Quality of life, SD=Standard deviation, STAI=State Trait Anxiety Inventory, *Statistically significant

Table 3: Relationship between anxiety and depression with QOL in mothers of children with ID

Variables	r value		
	SAI	TAI	BDI-II
Physical	-0.237	-0.400**	-0.448***
Psychological	-0.519***	-0.526***	-0.328*
Social Relationship	-0.337**	-0.265*	-0.428**
Environmental	-0.371**	-0.336**	-0.295*

QOL=Quality of life, ID=Intellectual disability, SAI=State Anxiety Inventory, TAI=Trait Anxiety Inventory, BDI=Beck Depression Inventory, *p<0.05, **p<0.01, ***p<0.001

QOL through WHOQOL-BREF and mental health status was assessed through GHQ-28 which included the subscales of somatic illness, anxiety, social dysfunction, and depression. They show a significant association between the GHQ scores and QOL. All the domains were negatively correlated with GHQ and the values were found to be statistically significant.

The relationship between BDI-II score and QOL domains (Table 3) shows that depression has a significant negative correlation with the QOL domains, i.e., physical domain ($r=-0.448$, $p<0.001$), psychological domain ($r=-0.328$, $p<0.05$), social relationship domain ($r=-0.428$, $p<0.01$), and environmental domain ($r=-0.295$, $p<0.05$).

Bumin *et al.*[12] revealed that mothers with disabled children were more anxious, hopeless, and worthless which also negatively influenced their physical health and overall quality of life. Zanon and Batista[24] studied 82 caregivers; they found high levels of anxiety and depression among the caregivers (49% and 31% respectively), as well as their low QOL demonstrate the need for a greater attention to the health of these people. Kazmi *et al.*[25] reported that mother of disabled children were having more depression and low QOL in comparison of father of disabled children. In this study, significant correlation was found between depression scores and all subscales of QOL. There is a significant correlation between depression and social relationship in mothers ($r=-0.428$ and $p<0.01$). Depending on responsibilities in daily life, mothers do not have enough time for social activities. Another study shows that both parents of a child with Down's

syndrome devoted more time for child care and spends less time in social activities.[6] Our findings suggest that the depressive symptoms and the QOL domains has relationship between them. It reflects that the depressive symptoms negatively affect the mother's QOL. As mentioned by Bumin *et al.*,[12] anxiety and depression is related to negative QOL of mothers.

Conclusion

The condition of psychological morbidity in mothers with ID children is a matter of particular concern. Disability is not just affecting the children; it has a greater impact on mothers and other significant persons. ID leads to significant distress in caregiver. Further, mother's development of psychological morbidity (anxiety, depression) and distress negatively affect mother's QOL. Compared to the parents of typically developing children, parents caring for intellectually disabled children have higher anxiety and depression, and different dimensions of caregiver burden; thus, precipitating anxiety and depression, and affecting QOL.

This present study reflects some clinical characteristics of depression and anxiety in the mothers with children having ID. Results show that maximum numbers of mothers with disabled children have moderate level of depression than mothers with healthy children. The present study also shows that the anxiety and depression are positively correlated to each other, and both anxiety and depression are negatively associated with QOL in mothers of children with ID. Understanding the mother's emotional condition is of utmost importance for the management of a child with disability as well as improving mothers' psychological well-being.

The study findings need to be interpreted within the limitation of having significant differences in three socio-demographic variables, namely occupation, socioeconomic status, and place of residence between the two groups. At the same time, our study had five matching criteria, i.e. age, educational qualification, duration of stay with the child, family type, nil past history of psychiatry illness, and nil physical disability between both the groups.

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