ORIGINAL ARTICLE

Anxiety, depression and quality of life in mothers of intellectually disabled children

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Abstract

Introduction: *Studies have shown that there is an association between Anxiety, Depression in mothers of children having Intellectual disability with poor quality of life(QOL) in mothers of such children. This study was carried with the objectives to describe the clinico-socio-demographic profile of mothers of intellectually disabled children and to investigate the relationship among anxiety and depression with quality of life in mothers with intellectually disabled children.*

Material And Method: *Mothers(N=31), whose children's IQ score was below 70, were enrolled in to the study with their informed consent. Depression and Anxiety disorders were diagnosed as per ICD 10. Severity of depression was measured with BDI and Anxiety symptoms with STAI. WHOQOL-BREF was used to assess Quality of life. The relationship among anxiety, depression and QOL were analysed using diagonal matrix, ANOVA and Pearson correlation test.*

Results: *The mean age of participants was 50.23(S.D= 6.11), BDI score was 13.65(S.D= 11.301), STAI score was 53.90(SD= 15.821), WHOQOL- BREF in all four domains was 290.90(S.D=49.42). There was significant correlation between BDI and STAI(P=0.01, r:0.651) and the three domains of WHOQOL- BREF(P=0.01, r:0.821,0.843,0.635 respectively) scale except Environment domain. Among the participants, 48.4%(ICD 10) had depression of varying degree along with 54.8% depression as per BDI cut off score. Anxiety disorder was seen in 22.6% as per ICD 10 but as per STAI it was 53.90(SD=15.821) which was statistically significant(p:0.01, r: -0.507). Depression when compared with no diagnosis persons has poor quality of life in WHOQOL-BREF physical domain(p:0.002) but with compared to Anxiety or both it was not statistically significant.*

Conclusion: *The findings of this study revealed that mothers of children having Intellectual disability have high level of Anxiety and Depression which indeed had impact in quality of life.*

Keywords: Anxiety, Depression, WHOQOL BREF, Intellectual Disability

INTRODUCTION

Mental retardation (MR) is a generalized disorder appearing before adulthood, characterized by significantly impaired cognitive functioning and deficits in two or more adaptive behaviors. It has been defined as an Intelligence Quotient under 70[1]. Once focused almost entirely on cognition, the definition now includes both a component relating to mental functioning and one relating to individuals' functional skills in their environment. As a result, a person with a below-average intelligence quotient (BAIQ) may not be considered mentally retarded. Syndromic

mental retardation is intellectual deficits associated with other medical and behavioral signs and symptoms. Non-syndromic mental retardation refers to intellectual deficits that appear without other abnormalities.

The phrase intellectual disability is increasingly being used as a synonym for people with significantly below-average cognitive ability. These terms are sometimes used as a means of separating general intellectual limitations from specific, limited deficits as well as indicating that it is not an emotional or psychological disability. Intellectual disability may also used to describe the outcome of traumatic brain injury or lead poisoning or dementing conditions such as Alzheimer's disease. It is not specific to congenital disorders such as Down syndrome[2].

Mental retardation is a subtype of intellectual disability, although that term is now preferred by most advocates in most English-speaking countries as a euphemism for MR. However, intellectual disability is a broader concept, and includes intellectual deficits that are too mild to properly qualify as mental retardation, too specific (as in specific learning disability), or acquired later in life, through acquired brain injuries or neurodegenerative diseases like dementia[2]. Intellectual disabilities may appear at any age.

Developmental disability is any disability that is due to problems with growth and development. This term encompasses many congenital medical conditions that have no mental or intellectual components, although it, too, is sometimes used as a euphemism for MR. According to the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), three criteria must be met for a diagnosis of mental retardation: an IQ below 70, significant limitations in two or more areas of adaptive behavior (as measured by an adaptive behavior rating scale, i.e. communication, self-help skills, interpersonal skills, and more), and evidence that the limitations became apparent before the age of 18[3].

Having disability brings about different hardness for child and his/her parents. This Condition commonly starts with a shock. Sometimes there are feelings of guilt, sorrow and helplessness. When children are diagnosed with developmental delays, their parents may experience psychological turmoil similar to that experienced by suicidal individuals[4] .

On the other hand, obligation in dependent daily living activities demolishes dynamics in family. Consequently, family member's roles have to change. These different responsibilities cause stress, anxiety and depression. Depression among parents of children having disabilities is an important symptom for therapists and other professionals to consider when providing treatment for a child or family[5] . Children whose mothers are depressed show a variety of problems in cognitive, linguistic and social functioning when compared to children whose mothers are not

Depressed[6] .The most affected person in the family is usually mother in such a situation. Mothers of children with disabilities often experience greater stress and emotional demands than do other mothers [5] . Mothers have to undertake too much stress because they are alone with their children in daily life. Not all mothers of children with disabilities have difficulties of adaptation even when they have to face highly stressful life situations. However, it has been explained that children and mothers are at risk of stress-related problems when mothers are overburdened by the demands of care giving, earning a living, and other responsibilities [7]. Many a times we over look at the fact that mothers of the mentally retarded child also have psychiatric morbidities. Hence why not to explore the very common psychiatric illness?

Children with different disabilities cause different levels of stress in their mothers. Mothers of children with epilepsy show increased levels of expressed emotion towards their children. Maternal over- involvement being significantly positively correlated with maternal stress suggests that concern and worry about children with epilepsy is an extra burden for mothers[24] . Also mental retardation in the epileptic child had the significant impact on the other depressive symptom[25] .The mothers of children with impairments of speech met criteria for depression better as compared to mothers of healthy children[26]. Parents of autistic children have described stressful conditions in their families [27,28,29] . Anxiety and depression were significantly higher among the mothers of

psychotic children[30] It was demonstrated that the mothers of children with cerebral palsy experienced higher levels of stress than mothers of healthy children[31,32] On the other hand, maternal mental situations affect the quality of life in mothers. Quality of life is an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, quality of life can be viewed as including all aspects of community life that have a direct and quantifiable on the physical and mental health[33] ·Despite to these studies depression and anxiety effect on quality of life in mothers of children with intellectual disability has not been investigated enough in our context. The aim of our study was to determine the relationship among anxiety and depression with quality of life on mothers with intellectually disabled children.

MATERIAL AND METHOD

This study was conducted in B. P. Koirala Institute of Health and Sciences. It is a tertiary level, referral health institute in eastern part of Nepal. The psychiatric unit of the Institute is in the setting of a general hospital and has an active outpatient and a 30 bedded in patients service. The department of psychiatry runs out patient service on all days of the week except Saturdays. We also receive patients from emergency and various other departments including community services. Also the children who are suspected to have intellectual disability are referred to this department from the Bhutanese refugee camp which is situated in the eastern part of Nepal.

The mothers of all consecutive cases of intellectually disabled children during the study period referred for I.Q assessment and whose I.Q is below 70 were included in the study.

The procedures and purpose of the study was described in detail to the mothers and informed consent was obtained. The proforma prepared for the study was used to fill up socio-demographic variables. Beck Depression Inventory (BDI) was used to assess depression. State-Trait Anxiety Inventory (STAI) was used to assess anxiety and World Health Organisation Quality of life BREF version was used to assess the quality of life of the mothers. Participation was voluntary and data was handled confidentially.

Parametric & non-parametric technique was applied wherever appropriate. The relationship between Anxiety, depression and quality of life were analysed using diagonal matrix, ANOVA and Pearson correlation test with the help of statistician.

RESULT

In this study mean age of the participants was 50.23 with a 6.11 standard deviation. Majority of them belonged to the age group between 41 to 60 years of age. Only 5% of them were young mothers and 4% were elderly taking care of their children.(Table 1)

Table 1: Age Wise Distribution of Subjects

Age Interval in yrs	Frequency	Percent
<40	2	6.5
41-50	14	45.2
51-60	13	41.9
61-70	2	6.5
Total	31	100.0

Among the participants 45% were Hindu, 19% Kirant, 20% Buddhist, 13% Christian and 3% Muslim by religion. Regarding the marital status 81% were married and 13 % were widow, 3% were divorced and in equal number mother's were married but separated.

Though majority of the studied sample belonged to the urban setting but 35.5% of the participants were from Bhutanese refugee camp. The CARITAS Nepal working in association with UNHCR and AMDA Nepal refers many cases of Intellectually disabled children for IQ assessment. This was done during the process of resettlement to the third country probably for the disability certificate. 25% of the participants had primary level of education whereas 22.6% of the participants went high school. When added together 35.5% of them didn't go school at all.

Only 19% of them were employed which mostly includes self employment. Majority of the children, 87% had significant Intellectual disability in which 45% had severe mental retardation, 42% had moderate mental retardation and 13% of them had mild. Among

the referred cases 19% had self injurious behaviour that needed treatment.

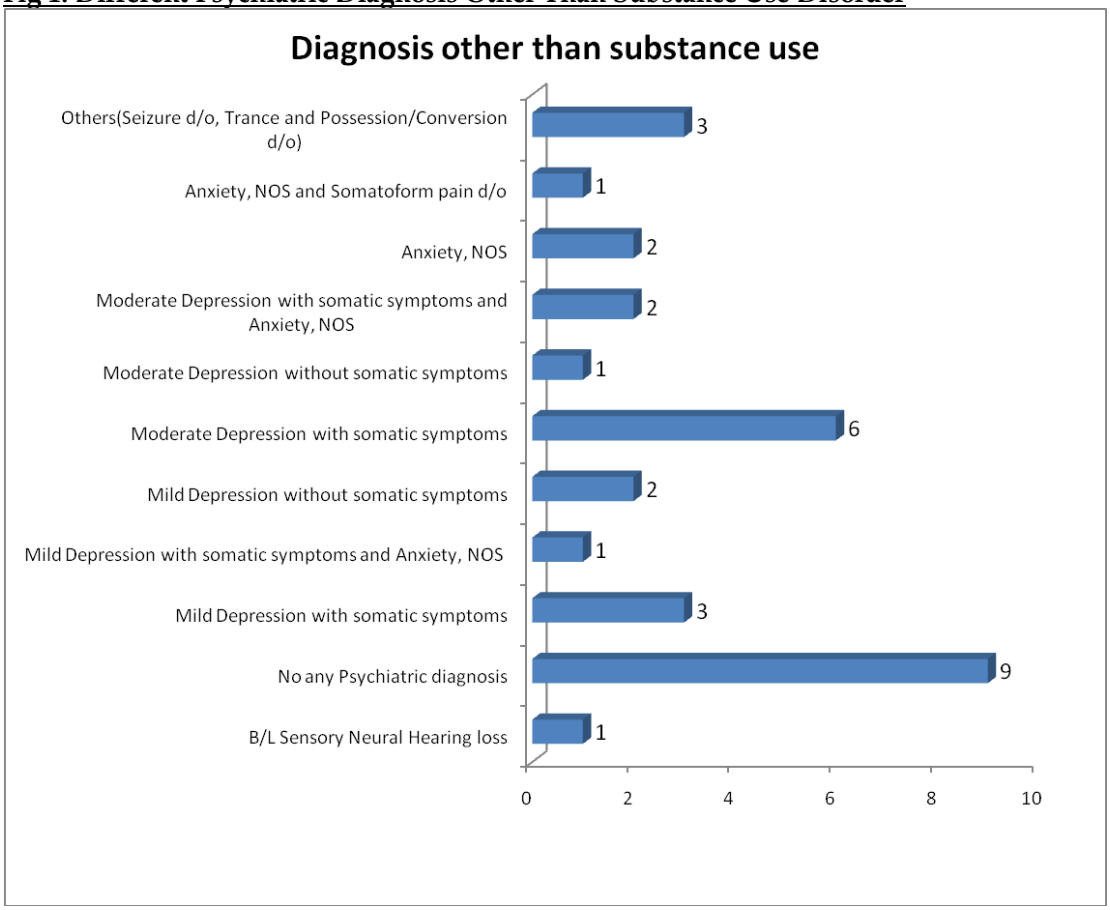
The care taker of Intellectually disabled(Mental retardation) child faces lot of burden and mother's who are mostly the primary care taker are likely to experience different Psychiatric illness. In this study 61% of the participants had Psychiatric illness in which depression was commonest.

Fig 1 shows different Psychiatric diagnosis other than Substance use disorder, which highlights moderate depression with somatic symptoms as the commonest form of depression.

Syndrome and all these participants were from Bhutanese refugee camp. In the refugee camp the Psychoactive substance use problem is quite common.

BDI score was 13.65(S.D= 11.301), STAI score was 53.90(SD= 15.821), WHOQOL- BREF in all four domains was 290.90(S.D=49.42). There was significant correlation between BDI and STAI(P=0.01, r:0.651) and the three domains of WHOQOL- BREF(P=0.01, r:0.821,0.843,0.635 respectively) scale except Environment domain. Among the participants, 48.4%(ICD 10) had depression of varying degree along with 54.8% depression as per BDI cut off score. Anxiety

Fig 1: Different Psychiatric Diagnosis Other Than Substance Use Disorder



About 74% of the patients scored more than 40 in State Trait Anxiety Inventory cut off(STAI: p=0.01, r= 0.507**)** but only 23% of them had syndromal level of Anxiety disorder as per ICD 10 criteria. So far as Psychoactive substance use is concerned 35% of the participants were taking alcohol.

Among the substance users; 54% of them were classified as suffering from Alcohol Dependence

disorder was seen in 22.6% as per ICD 10 but as per STAI it was 53.90(SD=15.821) which was statistically significant(p:0.01, r: -0.507). Depression when compared with no diagnosis persons has poor quality of life in WHOQOL-BREF physical domain(p:0.002) but with compared to Anxiety or both it was not statistically significant(Fig 2).

Fig 2: Showing Quality of Life comparisions

Diagonal Matrix: World Health Organization Quality of Life, Bref scale(WHOQOL-BREF)
WHO1- physical health domain, 2- Psychological, 3-Social relationship, 4- Environment domain.
STAI- State Trait Anxiety Inventory, BDI- Beck Depression Inventory.
***P<0.05, **P<0.01**

Variable	WHO1	WHO2	WHO3	WHO4	WHO-T	STAI SCORE	BDI SCORE
WHO1	1						
WHO2	0.678**	1					
WHO3	0547**	0.324	1				
WHO4	-0.078	0.086	0.036	1			
WHO-T	0.821**	0.843**	0.635**	0.34	1		
STAI SCORE	-0.542**	-0.615**	-0.366*	0.262	-0.507**	1	
BDI SCORE	0.626**	0.640**	-0.513**	0.292	-0.582**	0.651	1

DISCUSSION:

A family who has a child of Intellectual disability(mental retardation) experiences tremendous challenges such as emotional crises, disturbances in daily schedule and routines. It not only incurs additional financial burden but the parents would take their child to different treatment centers including faith healers which would further increase financial burden and distress to the family. The family who has disabled child often requires to repriotise family goals and responsibilities. They suffer a lot in terms of social involvement as well. A significant numbers of parents often meet diagnostic criteria for major Psychiatric illness like depression and anxiety. This study indicates that mothers of Intellectually disabled children have higher level of depression, anxiety and lower quality of life. Anxiety and Depression affect negatively in the quality of life which can be seen here in the WHO quality of life's scale. The level of Anxiety as per state trait Anxiety cut off score is higher than clinical diagnosis and as per ICD 10. The mother's of intellectually disabled child has to pass through different phases in life. When she realizes her baby has mental retardation and not able to play and function adequately like other age appropriate babies she becomes anxious. Giving birth to and bringing up such child may give rise to shock and denial, guilt, sorrow and helplessness which may give rise to depression and anxiety. The mother is the one who spends her most of the time with her children and this could one of the reasons of having depressive disorder in 48% of the sample. This finding is consistent with the findings observed in the study conducted by Bumin et al[44] in mothers of disabled children and Ryde-Brandt B et al in mothers of children with Psychotic disorders and mental retardation[30]. In this study a significant correlation(P=0.01, r=0.651) was found between Beck Depression Inventory score 13.65(S.D= 11.301) and STAI scores 53.90(S.D=15.821). This observation is similar in the studies conducted by Baker et al[45] in mothers of children with severe behavioural problem and Manne et al[46] who also conducted studies in mothers of children undergoing bone marrow

transplant. The children of different category who are having disability has been used for comparison to highlight the stress and burden in the mothers of such children. The psychological and social component as the etiology for developing depression and anxiety disorder is the well established fact. In this study, a significant correlation was found between depression and anxiety scores with three domains sub scales of WHOQOL-BREF except environment domain. This is in contrast with the findings observed by Bumin et al[44] , they have reported there was significant correlation in all four domains of quality of life scale. As already mentioned here most of the participants were from Bhutanese refugee camp. They are living in the same environment for last 20 years or more and for last seven years they are getting opportunity for third country resettlement in which they have the liberty of choosing the future country among the listed developed country. So the environment may have constant role. In the refugee camp they are provided food, medicine and shelter which appears to be at least better than the worst from the situation they were in and in comparison to the under developed nation like Bhutan and Nepal. Depression when compared with no diagnosis persons has poor quality of life in WHOQOL-BREF physical domain(p:0.002) but with compared to Anxiety or both it was not statistically significant. This finding is consistent with observation made by Bumin et al[44].

CONCLUSION:

The findings of this study revealed that mothers of children having Intellectual disability have high level of Anxiety and Depression which indeed had impact in quality of life. Mental health providers need to be aware with this fact so that appropriate mental health screening can be applied timely to the care givers before they burn out and identifiable Psychiatric disorders can be treated. The service providers for the children should also incorporate mother or primary care takers in the support system.

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