

Depression and Quality of Life in Parents of Intellectually Disabled Children: A Cross-Sectional StudySukanya S Kamble¹, AvinashV Gawande², BhagyashreeS Gawande³, Uday W Narlawar⁴¹Assistant Professor, Dept. of Community Medicine, Govt. Medical College, Nagpur.²Associate Professor, Dept. of Community Medicine, Govt. Medical College, Nagpur.³Assistant Professor, Dept. of Community Medicine, Govt. Medical College, Nagpur⁴Professor, Dept. of Community Medicine, Govt. Medical College, Nagpur

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Abstract

Background: Intellectual disability (ID) is characterized by significant impairment in cognitive and adaptive behavior. Delivery of a baby with intellectual retardation in one's own family is generally an unanticipated and unwelcome occasion. They have to make adjustments in their lifestyle, limit is imposed on their social existence, they've less time for themselves, and their recreational and leisure interest get compromised. So, this study was conducted to assess depression and quality of life in parents of intellectually disabled children. **Methods:** A cross-sectional study was conducted among 200 parents (100 mothers and 100 fathers) of intellectually disabled children at the district disability rehabilitation center (DDRC) and psychiatric OPD of a tertiary health care center in central India. Beck's Depression Inventory (BDI) is used to document depression. Quality of life among parents of ID children assessed by WHOQOL-BREF scale by interview method.

Results: The mean age of mothers was 37.06 ± 6.66 years and fathers were 41.79 ± 7.75. The present study showed that 82 (82%) fathers & 92 (92%) mothers had depression. Out of four domains of quality of life psychosocial, social, and environmental domains were found to be significant with depression in parents of ID children. (p < 0.05)

Conclusion: Since the proportion of depression in parents (mothers > fathers) of ID children is higher, it is recommended that the DDRC center and psychiatric department should have screened all those parents who came to register their ID children Through Psychological assessment.

Keywords: Intellectual Disability, Parents, Depression, Quality of life.

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Introduction

Intellectual disability, formerly known as mental retardation (American Association on Intellectual and developmental disabilities 2010)

“Intellectual disability (ID) is defined as a condition characterized by significant limitations both in intellectual (reasoning, learning, problem-solving) and in adaptive behavior (conceptual, social, and practical skills) which covers a range of everyday, social, and practical skills.”

Intellectual disability (ID) is characterized by significant impairment in cognitive and adaptive behavior. The term used to depict this condition has gone under consistent change throughout the years because of social and political impulses. The principal motivation to look for another term was to locate a less stigmatizing terminology. Thus, mental retardation, which was in use all over the world till

the late 20 century, has now been replaced with ID in most English-speaking countries. [1] Worldwide prevalence of intellectual disability is reported to be as high as 2.3%. [2] and in India, it is reported to be around 2% for mild intellectual disability and 0.5% for severe intellectual disability. [3]

Childbirth is a major event, that hugely affects the family dynamics. It is associated with bliss, dreams, desires, and hope. However, parenting is a demanding job which gets more so in case the child is suffering from a disability, such as intellectual disability (ID). There are different clinical and mental comorbidities in addition to the management of the intellectually disabled. [4]

The definition of individual quality of life has been debated more over the last three decades and has been defined differently depending on the

researcher.[5,6] Quality of life is a multidimensional construct encompassing several core domains, generally identified as material conditions, physical status and functional abilities, social interactions, and emotional well-being. [7] Regardless of the specific way, individual quality of life is defined as general feelings of well-being, feelings of positive social involvement, and opportunities to achieve personal potential. [8] They have also agreed that quality of life should include various domains of life and taken together as a whole should encompass the entirety of life. [8,9] During past decades studies on quality of life have primarily focused on normal people and then studies focused on quality of life of children with disabilities. Researchers have studied the quality of life of exceptional children and their families.[10]

Delivery of a baby with intellectual retardation in one's own family is generally an unanticipated and unwelcome occasion. The social stigma that attaches to the circle of relatives, frustration, and helplessness with incapability to cure the situation leaves the mother and father unhappy and depressed. They have to make adjustments in their lifestyle, limit is imposed on their social existence, they've less time for themselves, and their recreational and leisure interest get compromised. [11]

So, this study was conducted to assess depression and quality of life in parents of intellectually disabled children.

Methods

In the present cross-sectional study depression and quality of life were assessed in 200 parents (Mothers = 100, Fathers = 100) of intellectually disabled children at the district disability rehabilitation center (DDRC) and psychiatric OPD of a tertiary health care center in central India. Prior permission was taken from the institute's ethics committee. Beck's Depression Inventory (BDI) is used to document depression. Quality of life among parents of ID children assessed by WHOQOL-BREF scale.

Sample Size and Sampling Procedure

The sample size was calculated using the formula

$$n = Z^2_{1-\alpha} p^*(1-p)/d^2$$

The studies done in different countries on parents of intellectually disabled children suggested that 44% of mothers of children with disability have symptoms of depression. [Emerson E et al]¹² with absolute precision (d) of 7% and 95% confidence level, a total of 193 taken as round figure 200 parents of intellectually disabled children. Parents were

selected by using the Convenient Sampling Technique.

Data Collection

The selected psychiatric OPD and DDRC centers were visited on the pre-defined scheduled days in routine outpatient hours. During these visiting days, those patients who had confirmed intellectual disability, came to the psychiatric OPD & DDRC center with their parents to make a new certificate of disability or renew the certificate were enrolled in the study. Irrespective of their children's mental status i.e. mild, Moderate, severe, or profound mental retardation (ID) was contacted and explained the purpose of the study in detail and they were assured about the confidentiality of the data collected. Only those subjects who had given the written consent were enrolled in the study. [12]

In a dedicated cabin, those consented subjects were personally interviewed to know the basic socio-demographic characteristics such as age, gender, residence, income status, etc. Parents were interviewed for Beck's Depression Inventory (BDI) [13] to document depression. Quality of life among parents of ID children assessed by WHOQOL-BREF scale. [14]

Statistical Analysis

Data were analyzed using IBM SPSS Statistics Version 23. Descriptive statistics such as mean (standard deviation) and percentages were used to summarize the data. The association of depression with sociodemographic characteristics and clinical characteristics was measured by using the Chi-square test. The significance level was kept at <0.05.

Results

Table 1 shows the distribution of parents of ID Children according to epidemiological factors, The mean age of mothers was 37.06 ±6.66 years and fathers were 41.79 ±7.75. Most of the parents belonged to Hindu (66%) followed by Buddhist (20%) and Muslim religion (11%) respectively. The majority of parents (66.00 %) were residents of urban areas compared to rural (34.00%) areas. 98% of parents were literate. The maximum number of 42(42%) parents belonged to the upper middle class followed by 27(27%) parents from the upper class, 22(22%), and 9(9%) parents from the middle class and lower middle class respectively. More than half of the study participants belonged to the nuclear family (60%) followed by three-generation families (23 %). Only parents belonged to a joint family (17%).

Table 1: Distribution of parents of ID Children according to epidemiological factors

Epidemiological characteristics	Number (n)	Percentage (%)
1. Mean age in years		
Mother	37.06 ±6.66	
Father	41.79 ±7.75	
2. Religion		
Hindu	66	66
Muslim	11	11
Buddhist	20	20
Others	3	3
3. Residence		
Urban	66	66
Rural	34	34
4. Literacy status		
Literate	98	98
Illiterate	2	2
5. Socioeconomic Status		
Class I	27	27
Class II	42	42
Class III	22	22
Class IV	09	09
6. Type of Family		
Nuclear	60	60
Joint	23	23
Three generation	17	17

Table 2, depicts the characteristics of ID Children, most of the children were male 51% compared to female (49%). The majority of children were 1st order (47%) followed by 2nd order (42%) and 3rd order (11%) children.

Table 2: Characteristics of ID Children

Characteristics of ID Children	Number (n)	Percentage (%)
1. Gender		
Male	51	51
Female	49	49
2. Birth Order		
First	47	47
Second	42	42
Third	11	11

Figure 1 describes the distribution of intellectually disabled children according to the severity of intellectual disability. The findings show that the majority of male children 33.3% and female children 40.8% had moderate, followed by 31.4% of male

children and 26.5% of female children had mild, 23.5% of male children and 14.3% of female children had severe & Only 11.8% of male children and 18.4% of female children had profound type intellectually disability.

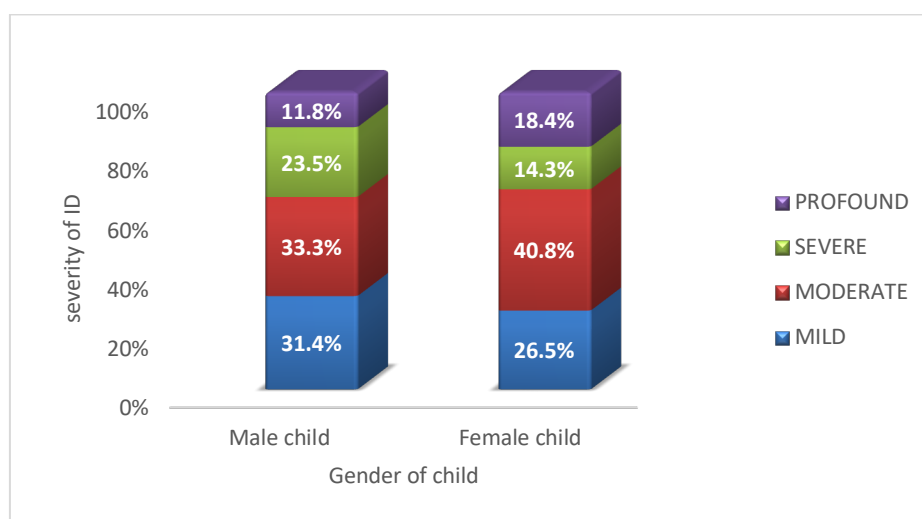


Figure 1: Distribution of intellectually disabled children according to severity of ID

Figure 2 (a) shows the distribution of fathers according to the severity of depression as per Beck’s depression scoring, 18% fathers were normal while 82% fathers were found to be depressed. Out of 82% of depressive fathers, 34% fathers had mild depression followed by 27% fathers had borderline clinical depression, 17% of fathers and 4% of fathers had moderate and severe depression respectively.

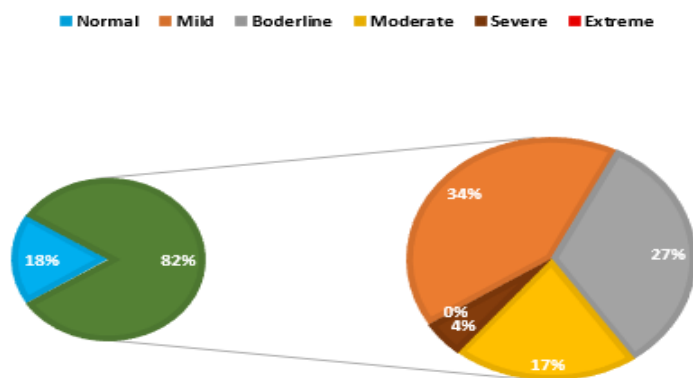


Figure 2 (a): Distribution of fathers according to the severity of depression

Figure 2 (b) shows the distribution of mothers according to the severity of depression as per Beck’s depression scoring. 8% of mothers were normal while 92% of mothers were found to be depressed. Out of 92% of depressive mothers, 29% of mothers had moderate depression followed by 22% had borderline clinical depression, while 20% and 19% of mothers had mild and severe groups of depression, and only 2% of mothers were extremely depressed.

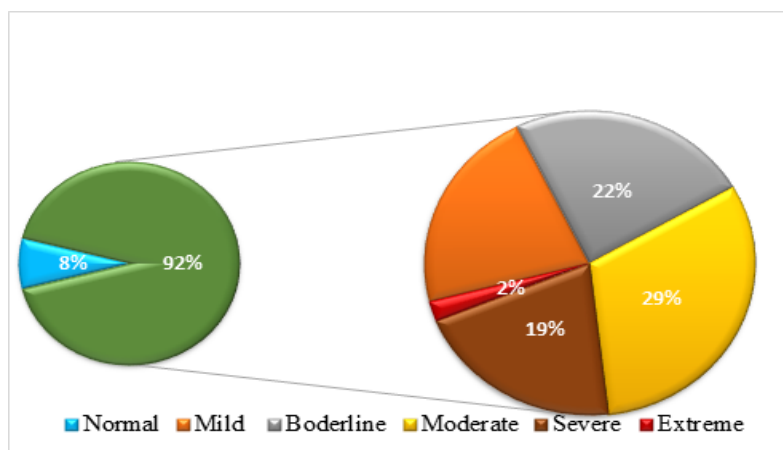


Figure 2(b): Distribution of mothers according to severity of Depression

Table 3 reveals the assessment of the quality of lifein parents of intellectually disabled children's Mean score for the physical domain of quality of life was 13 ±1.92, for the psychological domain was 13.5 ±1.92, for social relationship domain was 15 ±2.84,

the environmental domain was 14.2 ±1.99. out of all domains social relationship domain had a higher mean score compared to other domains of the WHOQOL-BREF scale.

Table 3. Assessment of quality of life as per mean domain score of WHOQOL-BREF scale

Domains of WHOQOL-BREF scale	Mean Score
Physical Domain	13 ±1.92
Psychological Domain	13.5 ±1.92
Social Domain	15 ±2.84
Environmental Domain	14.2 ±1.99

When we studied the association of depression with various epidemiological factors, we found mothers (92%) were significantly more depressive than fathers (82%) of ID children. (p<0.05). In the type of family nuclear family (90%) faced significantly more depression than other types of families. (p<0.05). (Table 4)

Table 4. Association of depression with epidemiological factors

Epidemiological factors	Depression in parents		Test value	P value
	Present (%) (n=174)	Absent (%) (n=26)		
1. Parents				
Father	82(82)	18(18)	4.42	0.03
Mother	92(92)	8(8)		
2. Age				
<35 years	97(56)	14 (54)	1.011	0.31
≥35 years	77(44)	12 (46)		
3. Residence				
Urban	114(86)	18(14)	0.02	0.88
Rural	60(88)	8(12)		
4.Socioeconomic status				
Class I	49(91)	5(9)	1.78	0.18
Class II	74(88)	10(12)		
Class III	38(86)	6(14)		
Class IV	13(72)	5(28)		
Class V	00	00		
6. Type of family				
Nuclear	108(90)	12(10)	6.594	0.03
Joint	25(73)	9(27)		
Three generation	41(89)	5(11)		
7. Gender of child				
Male	89(87)	13(13)	0.012	0.91
Female	85(87)	13(13)		
8. Birth order of child				
1 st	81(86)	13(14)	0.88	0.76
2 nd	73(87)	11(13)		
3 rd	16(91)	2(9)		
9.Severity of ID				
Mild	47(81)	11(19)	3.58	0.06
Moderate	64(86)	10(14)		
Severe	35(92)	3(8)		
Profound	28(93)	2(7)		

Table 5 shows the association of quality of life with depression, in the physical domain, maximum depression present in parents 136(88%) with a medium quality of life followed by 38 (84%) with a high quality of life. For the psychosocial domain, maximum depression was present in parents 2(100%) with a low quality of life followed by 113(95%) parents with a medium quality of life and 59(75%) had a high quality of life. For social relationship domain in parents. Maximum depression

was present in parents 2(100%) with low quality of life f/b 74(99%) parents with medium quality of life and 98(80%) with high quality of life. For environmental domain in parents. Maximum depression was present in parents 106(92%) with medium quality of life f/b 68(80%) parents with high quality of life. There was a statistically significant difference in social relationships, psychosocial, and environmental domains with depression ($p < 0.05$).

Table 5. Association of quality of life with depression

WHO BREF scale domains	Depression in parents		Test value	P value
	Present (%) (n=174)	Absent (%) (n=26)		
1. Physical Domain				
Low (4-9.9)	0	0	0.33	0.56
Medium (10-14.9)	136(88)	19(12)		
High (15-20)	38(84)	7(16)		
2. Psychosocial Domain				
Low (4-9.9)	2(100)	0	17.09	<0.001
Medium (10-14.9)	113(95)	6(5)		
High (15-20)	59(75)	20(25)		
3. Social Relationship Domain				
Low (4-9.9)	2(100)	0	14.59	<0.001
Medium (10-14.9)	74(99)	1(1)		
High (15-20)	98(80)	25(20)		
4. Environmental Domain				
Low (4-9.9)	0	0	0.67	0.01
Medium (10-14.9)	106(92)	9(8)		
High (15-20)	68(80)	17(20)		

Discussion

In this study, the mean age (SD) of the fathers was 41.79 ± 7.75 with a range of 28 – 57 years. The mean age (SD) of the mothers was 37.06 ± 6.66 with a range from 25 – 50 years. This finding was similar to the study done by Muhammad Waqar Azeem et al [15] where the mean age of fathers was 42.9 ± 8.8 years and mothers were 37.42 ± 8.8 years. The majority, of parents (66%) were Hindu by religion followed by 20% who were Buddhist, 11% Muslim, and 3% were others consisting of Christian and Sikh. Also, in studies conducted by Gourav et al, [16] the majority were Hindus 55% followed by Muslims i.e. 41%. A maximum number of 42(42%) parents belonged to the upper middle class followed by 27(27%) parents from the upper class. middle and lower middle included 22(22%) and 9(9%) parents respectively. A study done by Rene de Souza et al [17] reported that according to Modified Kuppaswamy's socio-economic class, 36% belonged to the lower class, 30% of parents belonged to a lower middle class, and 28% to the upper middle class, 3 parents belonged to the upper class. More than half of the parents 60% belonged to the nuclear family followed by 23% of parents from three-generation families and 17% of parents belonged to a joint family. Similarly in a study done by Suyog et al, [18] among 100 participants sixty-nine of the children were being raised in a nuclear family and the rest belonged to joint families.

In the present study, among 100 intellectually disabled children, 51% of children were male and 49% were females. Similarly in the study done by Gourav et al [16] the majority of children were male (62%) as compared to female (38%). 47% of children were of 1st birth order followed by 42% of 2nd order and 11% were 3rd order children. The mean order of birth of the intellectually disabled child in the study was 1.64 ± 0.67 which is different from the

study done by Gourav et al [16] who had the mean order of birth of the mentally retarded patients in their study as 1.79 ($SD \pm 0.81$).

We studied the quality of life in parents of intellectually disabled children as per the WHOQOL-BREF scale, the mean scores for the physical domain of quality of life was 13 ± 1.92 , the psychological domain was 13.5 ± 1.92 , the social relationship domain was 15 ± 2.84 , the environmental domain was 14.2 ± 1.99 . While Cecilia Yuen Shan Leung et al [19] stated the mean score of the physical domain of parents having a child with a disability by using the WHO QOL-BREF scale as 13.99 ± 2.25 . for the social relationship domain was 15 ± 2.84 , environmental domain 12.04 ± 2.34 .

The majority of studies that compared the mental health of father and mother caretakers indicated that there is a difference between the mental health of father and mother, with fathers exposed to a lower risk of depression, anxiety, stress, and poor general mental health. [20,21]

In the present study while calculating depression in parents of ID children, mothers (92%) had more depression as compared to fathers (82%) and the difference was statistically significant. ($p = 0.03$). The mean score of depression in fathers was 18.30 ± 5.37 and in mothers was 22.92 ± 7.69 . Similarly, Sheikh M H et al [22] stated mean AKUADS score for fathers was 19.64 ± 11.12 , while for mothers it was 28.02 ± 13.58 and the difference was statistically significant ($p = 0.031$).

In this study, maximum depression is present in <35-year-old parents 97(56%), This difference (<35 years/ ≥ 35 years) was statistically not significant ($P > 0.05$). Similar findings given by Suyog et al (32) found Psychopathology had a significant negative correlation with the age of parents

($P=0.015$). maximum depression present in parents from rural areas was 88% as compared to parents from 86% of urban areas, but this difference was not statistically significant ($p = 0.88$). Similarly, the study done by Gourav et al¹⁶ stated 46 and 33 mothers belonging to urban and rural regions had depression respectively. the proportion of depression in parents of the nuclear family was 108(90%) whereas the proportion of depression among the three-generation family and joint was 41(89%) and 25(73%) and this difference between the type of family and depression was statistically significant ($p = 0.03$). Similarly, Chourasiya SK et al²³ observed that (67.3%) of nuclear families showed mild stress while only 22 (52.3%) joint families had mild stress. This may be due to other members of the joint family who also simultaneously took care of the ID child so the burden of care in the joint family was somewhat less in comparison to the nuclear family.

There was no difference in depression in parents of male 89(87%) and female 85(87%) children also no statistical significance was detected ($p = 0.91$). Similarly, Nagarkar et al¹² stated no statistically significant difference ($p= 0.443$) but the prevalence of depression in mothers was seen to be more in female patients (90%) as compared to the male mentally retarded patients (82.5%). maximum depression was seen in 28(93%) parents of profound child followed by in 35(92%) parents of severe child. While depression in parents of moderate and mild severity of ID was 64(86%) and 47(81%) respectively, it was found to be not significant ($p=0.06$). Similarly, the study done by Gourav et al [16] stated that 100% (16) of patients with severe mental retardation had depression in their mothers while the prevalence of depression was comparatively lower in mothers 78.12% (38) of patients with moderate retardation and least 73.07% (25) in those with mild retardation.

These were new findings for this study as the quality of life worsened from high to low, and there was a worsening of depression found in those parents. In the present study, depression and quality of life for the physical domain in parents stated that maximum depression is present in parents 136(88%) with medium quality of life followed by 38(84%) parents with high quality of life, which is statically not significant ($p=0.56$). For the psychosocial domain in parents, maximum depression is present in parents 2(100%) with low quality of life followed by 113(95%) parents with medium quality of life and 59(75%) with high quality of life. This was found to be highly significant statistically with p p-value <0.001 . For the social relationship domain in parents, maximum depression is present in parents 2(100%) with low quality of life followed by 74(99%) parents with medium quality of life and 98(80%) with high quality of life which is found to

be highly significant statistically with p -value <0.001 . For the environmental domain in parents, maximum depression is present in parents 106(92%) with medium quality of life followed by 68(80%) parents with high quality of life. This is found to be significant statistically with p p-value of 0.01.

Another new finding was regarding depression in parents according to birth order of ID children as we saw more depressed parents with higher birth order children with ID. Depression in parents of 3rd-order children was 16(91%), while depression in parents of 2nd and 1st-order was 73(87%) and 81(86%), respectively but statistically, it was not found to be significant ($p=0.76$).

Limitations

Since the study was done in a single DDRC center for feasibility, the findings may not be generalizable to the entire Parents of ID children in Central India. Different levels of personality traits have not been taken into consideration, which also influences the perception of depression. This is a hospital-based study so bias may have occurred in the selection of the sample population and so results obtained may not be applied to the universe.

Conclusion

Since the proportion of depression in parents (mothers > fathers) of ID children is higher, it is recommended that the DDRC center and psychiatric department should have screened all those parents who came to register their ID children Through Psychological assessment. All these services should preferably start from the birth of the mentally disabled child to help the parents cope and should be extensively provided for mothers who are at more risk of developing psychiatric morbidity and awareness. The study suggests that further research to confirm the findings is recommended.

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