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Original Article

Psychiatry/Mental Health Section

Prevalence of Major Depression and Assessment of Burden among Caregiver's of Intellectually Differently Abled Persons: A Cross-sectional Study

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ABSTRACT

Introduction: Intellectual Disability has major negative impact on the lives of the person and their families as they experience psychological distress and burden while providing care to them. Families while engaging in the caregiving process are said to experience psychiatric morbidities such as depression and anxiety more commonly. Identifying those helps in the holistic management of intellectually differently abled persons together with caregiver's.

Aim: To assess major depression and assessment of burden among caregiver's of intellectually differently abled persons and their association with each other.

Materials and Methods: This cross-sectional, observational study among 220 caregiver's were conducted at Psychiatry Department of Pandit Deendayal Upadhyay Government Medical Hospital, Rajkot district, Gujarat, India, from June 2018 to May 2019. Socio-demographic details of caregiver's and intellectually differently abled persons were obtained after taking into consideration inclusion and exclusion criteria. Zarit scale of caregiver burden was used for burden assessment and its severity. Depression was screened by Patient Health Questionnaire. Those screened positive were evaluated in detail for major depression and diagnosed based on Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5) criteria. Severity was assessed by Hamilton Depression Rating Scale (HAM-D). Data was analysed to find out statistical significance with the help of t-test, Chi-square test, Fisher's-exact test and non parametric tests (Wilcoxon-Mann-Whitney U test and Kruskal-Wallis test). Probability value less than 0.05 was considered statistically significant.

Results: Out of 220 caregiver's, prevalence of major depressive disorder in caregiver's as per DSM-5 was 56 (25.45%). A 51 (23.18%) caregiver's had severe burden, 100 (45.45%) moderate to severe burden, 61 (27.72%) mild to moderate burden, 8 (3.63%) caregiver's had little or no burden. Association between Intellectually differently abled persons with psychiatric and non psychiatric co-morbidities and caregiver's depression were statistically significant (p-value=0.030). Association between intellectual disability severity (p-value=0.031), affected sibling of intellectually differently abled person (p-value <0.001) and caregiver's burden was statistically significant.

Conclusion: The study emphasises that even though there is vast body of literature addressing psychological distress and suffering of caregiver's of intellectually differently abled persons, it still remains a prominent challenge to manage it effectively. Thereby, treatment providers should shift their focus on the mental health of caregiver's along with that of persons with intellectual disability as having healthy caregiver's cannot only maximise the chances of intellectual disability persons' successful re-establishment in society but can themselves lead a psychologically healthy life.

Keywords: Mental disorders, Non psychiatric co-morbidities, Psychological distress, Zarit scale of caregiver burden

INTRODUCTION

Intellectual disability is identified in 2.5% of the general population [1]. General population surveys in India showed that around 2% people live with Intellectual Disability (ID) [2]. ID is not a disease in and of itself, but the developmental consequence of a variety of pathogenic processes. Intellectual disability results from brain dysfunction, generally due to abnormal brain development or brain injury resulting from genetic and environmental causes [3]. As per Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5) criteria, severity levels are now classified by adaptive rather than intellectual function or Intelligence Quotient (IQ) scores which include conceptual, social and practical domains. Onset of intellectual and adaptive deficits during the developmental period is taken into consideration as per DSM-5 [3].

Primary caregiver is defined as the family member, friend or significant other who satisfied greatest number (≥3) of following five criteria [4]:

1. Spouse, parent or spouse equivalent.
2. Has the most frequent contact with the patients.
3. Helps to support patient financially.
4. Has been most frequent collateral participant in patient's treatment.
5. Is the person contacted by treatment staff in case of emergency.

The World Health Organisation (WHO) states caregiver burden as the "the emotional, physical, financial demands and responsibilities of an individual's illness that are placed on the family members, friends or other individuals involved with the individual outside the healthcare system" [5]. The caregiver's are usually the mother of the child, elderly family members, or the unemployed members of the family. Such people do not normally plan to be caregiver's but find the need unavoidable. In addition, the caregiver's are not prepared for this role and in process of engaging in the same, they find it increasingly demanding [6]. During this process of caregiving, the caregiver may be deprived of privileges, rights, and respect that go with the carers. Further, there is lack of career progression, and the individual may continue to work involuntarily [7].

Caregiver's of the intellectually differently abled persons bear the burden and stress of upbringing an underprivileged child. Mothers of those children, being the primary caregiver's for their children suffer more psychological distress than other members in their families [8]. Primary caregiver who is closest to person with intellectual disability bears the brunt of their disability. As the child grows up and disability becomes quite noticeable, both the parents and child face stigmatising situations. It leads to unavoidable stress and psychological trauma among the caregiver's. Caregiver burden impoverishes the physical, psychological, emotional and functional health of the caregiver's [9]. A study has revealed that 35.4% of fathers and 66.3% of mothers had significant depressive symptoms (above cut-off score of 7) [10]. Research has revealed that psychiatric morbidities such as depression and anxiety are common among mothers of intellectually disabled children. In the Indian society, it is mostly the mothers of the intellectually disabled children who bear the burden and stress of upbringing an underprivileged child [11]. Studies from different countries on parents of children with disabilities suggested that 35-53% of mothers of children with disabilities have symptoms of depression [12-14]. Demographic and illness related factors which varies across the globe are said to have impact on prevalence of depression and anxiety among caregiver's.

Though there's vast body of literature addressing psychological distress and suffering of caregiver's of intellectually differently abled persons, this study explores the association of infrequently addressed variables of intellectually differently abled persons such as age, gender, Intellectual Disability (ID) severity, affected siblings and co-morbidities with that of depression and caregiver's burden. Excessive burden negatively impacts the caregiving process. So, treatment providers should shift their focus to the mental health of caregiver's too along with that of individuals with ID. Having healthy caregiver's can maximise the chances of intellectually differently abled persons successful re-establishment in society. After assessing depression and burden in caregiver's one can improve their skills. Due to well-functioning collaboration between family members and professionals, intellectually differently abled persons gain advantages in special education and healthcare [15]. For holistic management of person living with intellectual disability, engaging caregiver's in the treatment plays a crucial role in improving patients' clinical outcome and compliance.

This study aimed at assessing major depression and assessment of burden among caregiver's of intellectually differently abled persons and their association with each other.

MATERIALS AND METHODS

This cross-sectional, observational study was conducted at Psychiatry Department of Pandit Deendayal Upadhyay Government Medical Hospital, Rajkot district, Gujarat, India, from June 2018 to May 2019. The study was conducted with prior approval from Institutional Ethics Committee (IEC Ref No.PDU/MCR/IEC/2192/2018).

Sample size calculation: Sample size was calculated using formula:

$$N=Z^2PQ/e^2$$

According to study conducted, the prevalence of depression in caregiver's of intellectually disabled children was 63% [16]. Considering standard normal deviate (Z) set at 1.96 with confidence interval of 95%, margin of error as 10%, the estimated sample size calculated was 220.

Inclusion criteria:

For intellectually differently abled persons:

- Persons diagnosed with ID (mild, moderate, severe, profound) according to DSM-5 criteria [17] and IQ testing using Seguin form board test (5-15 years) [18] and Wechsler Adult Intelligence Scale (16-90 years) [19] by clinical psychologist.

For caregiver's:

- Age between 18-60 years.
- Who gave written consent.
- Living with intellectually differently abled persons and taking care of them.
- Do not have serious medical condition.

Exclusion criteria:

For intellectually differently abled persons:

- Those with serious medical condition.

For caregiver's:

- Who did not gave consent and caregiver's who were not willing to participate in the study.
- Those who were not giving consistent and reliable history.
- Caregiver's who do not understand Gujarati, Hindi or English.
- Already suffering from or diagnosed with a psychiatric disorder.

A total of 220 patients were surveyed in an estimated time period of 12 months. A systematic sampling technique was used to collect data. The nature, purpose, procedure and other details of the study were explained to caregiver's as well as informed written consent was taken from those fulfilling inclusion criteria of caregiver's.

Procedure

Socio-demographic details of caregiver's (name, age, domicile, religion, education, occupation, marital status, type of family, number of family members and per capita income) was assessed based on a questionnaire [20] which was modified as per the requirements in the study and details of intellectually differently abled persons (age, gender, ID severity, affected sibling, co-morbidities like epilepsy, Attention Deficit Hyperactivity Disorder (ADHD), down syndrome, cerebral palsy, autism, psychosis, vision impairment) by the interviewer. Interview was taken to collect these details. Forward and backward translation was carried out for socio-demographic details questionnaire. Gender, religion, marital status, family status included as it is from the questionnaire. Age was modified considering marital starting age limit of 21 and grouped in format of 10 (i.e., 21-30, 31-40 and so on). In the questionnaire current location was mentioned which was modified to area of domicile as area is the word frequently used for knowing location of a person. Caregiver involvement was included to show who were involved in their care as single parent or both parents or whole family which would have different impact on distress and burden considering other articles. Level of education modified in context to Indian culture. Employment status title modified as occupation and modified as per Indian context. Modified BG Prasad scale was to measure socio-economic status. It is used in both urban and rural areas and is based on per capita monthly income [21].

Patient health questionnaire

Patient Health Questionnaire (PHQ) was used to screen depression in caregiver's. The PHQ is a self-administered instrument designed to screen for several common mental disorders. It was derived from the original PRIME-MD instrument. The PHQ-9 was used (9-item depression scale). PHQ takes about 5-10 minutes for the patient to complete. If answer to 1 or 2 and 5 or more of 1-9 are atleast more than half the days than it is considered positive [22].

Those screened positive was assessed as per DSM-5 [17] criteria for major depression under supervision of consultant psychiatrist in a clinical interview setting.

Hamilton Depression Rating Scale

Hamilton Depression Rating Scale (HAM-D) was used to measure the severity of depressive symptoms in those diagnosed with major depression as per DSM-5 criteria. Time taken to apply scale is about 15-20 minutes. HAM-D items are ranked on a scale 0-4 or 0-2. On this scale total score of [22]:

- >23 suggest very severe depression,

- 19-22 suggest severe,
- 14-18 suggest moderate,
- 8-13 suggest mild depression and
- ≤7 score suggestive of normal status.

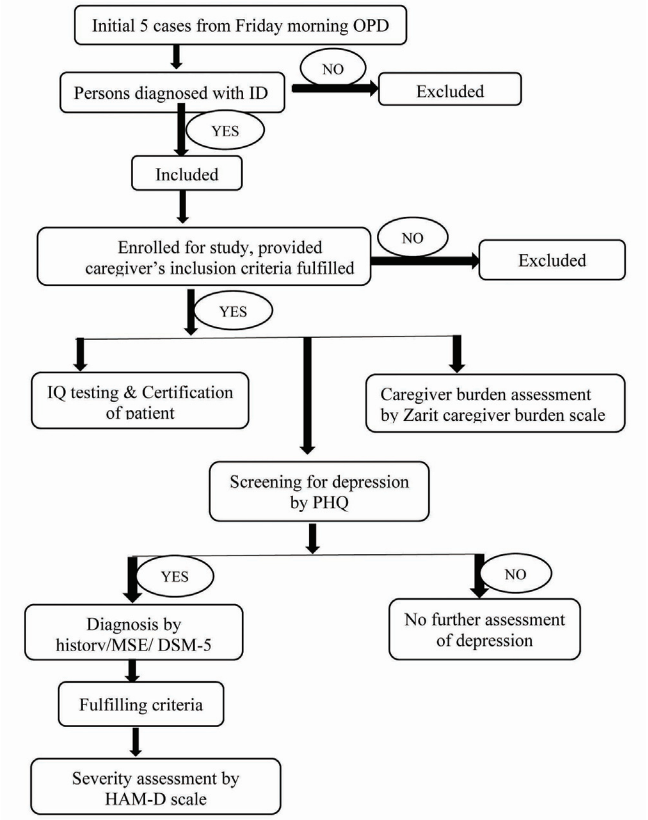
Zarit Burden Interview

Burden assessment was done for all caregiver's using Zarit Burden Interview (caregiver burden scale). The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0-4 (never, rarely, sometimes, quite frequently, or nearly always). Norms for the Burden Interview have not been computed but estimates of the degree of burden can be made from preliminary findings. These are [23]:

- 0-20: Little or no burden,
- 21-40: Mild to moderate burden,
- 41-60: Moderate to severe burden,
- 61-88: Severe burden.

The scales used were free to use. The assessment was carried out on friday morning Outpatient Department as the set-up runs child guidance clinic along with IQ testing and certification on the same day.

The [Table/Fig-1] depicts the process of caregiver's enrollment.



[Table/Fig-1]: Process of caregiver's enrolment.

STATISTICAL ANALYSIS

Data collected was subjected to appropriate descriptive statistics using frequencies, percentages, mean and standard deviation of different variables. Data was analysed to find out statistical significance with the help of t-test (Comparision of variable depression in terms of caregiver burden score), Chi-square test (association between gender and depression as well as caregiver burden, association between ID severity and depression as well as caregiver burden, association between depression and co-morbidities), Fisher's-exact test (association between affected sibling and depression as well as caregiver burden) where more than 20% of the total number of cells had an expected count of less than 5 and non parametric tests like Wilcoxon-Mann-Whitney U test and Kruskal-Wallis test. A p-value less than 0.05 was considered statistically significant. The IBM Statistical Package for the Social Sciences (SPSS) version 16.0 was applied to analyse the data.

RESULTS

As depicted in [Table/Fig-2], the majority 68 (30.90%) of caregiver's were in the age group of 31-40 years. Female caregiver's 159 (72.27%) were more as compared to male caregiver's 61 (27.72%). Majority of caregiver's were Hindu 178 (80.90%), married 193 (87.72%), homemaker 116 (52.72%) and had completed secondary education 81 (36.81%).

Socio-demographic variables of caregiver's		n (%)
Age (years)	21-30	32 (14.54%)
	31-40	68 (30.90%)
	41-50	62 (28.18%)
	51-60	58 (26.36%)
Gender	Male	61 (27.72%)
	Female	159 (72.27%)
Area of domicile	Urban	145 (65.90%)
	Semi-urban	45 (20.45%)
	Rural	30 (13.63%)
Religion	Hindu	178 (80.90%)
	Muslim	42 (19.09%)
Marital status	Married	193 (87.72%)
	Unmarried	2 (0.90%)
	Separated	3 (1.36%)
	Divorced	3 (1.36%)
	Widow	19 (8.63%)
Family status	Nuclear	141 (64.09%)
	Joint	79 (35.90%)
Caregiver involvement	Single parent	134 (60.90%)
	Two parents	58 (26.36%)
	All families	28 (12.72%)
Level of education	Illiterate	61 (27.72%)
	Primary	63 (28.63%)
	Secondary/Higher secondary	81 (36.81%)
	Graduate	15 (6.81%)
Occupation	Unemployed	8 (3.63%)
	Labourer	49 (22.27%)
	Job	15 (6.81%)
	Business	17 (7.72%)
	Retired	5 (2.27%)
	Farmer	10 (4.54%)
	Homemaker	116 (52.72%)
Economic status (Modified BG prasad scale)	I (≥6254)	19 (8.63%)
	II (3127-6253)	36 (16.36%)
	III (1876-3126)	70 (31.81%)
	IV (938-1875)	71 (32.27%)
	V (<938)	24 (10.90%)

[Table/Fig-2]: Socio-demographic variables of caregiver's.

The variables of intellectually differently abled persons are depicted in [Table/Fig-3], which shows that majority belonged to the age group of 5-15 years 110 (50%) with males dominating the number of intellectually differently abled persons 148 (67.27%).

Out of 220 caregiver's of ID persons, 56 (25.45%) had major depression and 164 (74.54%) caregiver's had no depression as assessed by DSM-5 criteria for major depressive disorder and HAM-D scoring. Out of 56 caregiver's who had major depression, 20 (9.09%)

Variables of Intellectually differently abled persons		n (%)
Age (years)	5-15	110 (50%)
	16-25	63 (28.63%)
	26-35	29 (13.18%)
	36-45	13 (5.90%)
	46-55	5 (2.27%)
Gender	Male	148 (67.27%)
	Female	72 (32.72%)
ID severity	Mild	63 (28.63%)
	Moderate	95 (43.18%)
	Severe	48 (21.81%)
	Profound	14 (6.36%)
Affected sibling	Yes	19 (8.63%)
	No	201 (91.36%)
Co-morbidities	No co-morbidities	67 (30.45%)
	Epilepsy	39 (17.72%)
	Behavioural problems	41 (18.63%)
	Epilepsy+behavioral	31 (14.09%)
	Cerebral palsy	8 (3.63%)
	Down syndrome	9 (4.09%)
	Attention deficit hyperactivity disorder	3 (1.36%)
	Autism	1 (0.45%)
	Psychosis	3 (1.36%)
	Vision impairment	2 (0.90%)
	Multiple from above	16 (7.27%)

[Table/Fig-3]: Variables of Intellectually differently abled persons.

caregiver's had mild depression, 27 (12.27%) caregiver's had moderate depression, 9 (4.09%) caregiver's had severe depression and none had very severe depression [Table/Fig-4].

Severity	n (%)
No depression	164 (74.54%)
Mild depression	20 (9.09%)
Moderate depression	27 (12.27%)
Severe depression	9 (4.09%)
Very severe depression	0

[Table/Fig-4]: Severity of major depressive disorder in caregiver's of ID persons (N=220).

Out of 220 caregiver's, 8 (3.63%) caregiver's had little or no burden, 61 (27.72%) caregiver's had mild to moderate burden, 100 (45.45%) caregiver's had moderate to severe burden and 51 (23.18%) caregiver's had severe burden as assessed by Zarit caregiver burden scale [Table/Fig-5].

Caregiver's burden	n (%)
Little or no burden	8 (3.63%)
Mild to moderate burden	61 (27.72%)
Moderate to severe burden	100 (45.45%)
Severe burden	51 (23.18%)

[Table/Fig-5]: Prevalence of caregiver's burden and severity (N=220).

A significant difference was present between the two groups in terms of caregiver burden score (t=6.486, p-value <0.001), with the mean caregiver burden score being highest in the depression present group [Table/Fig-6].

There was a significant difference between the three groups in terms of caregiver burden score (χ^2=7.442, p-value=0.024), with the median caregiver burden score being highest in the depression severity i.e., severe group [Table/Fig-7].

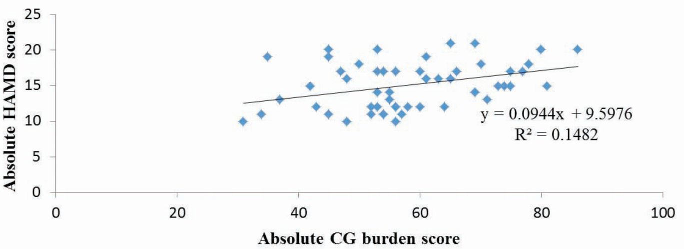
Caregiver burden score	Depression		t-test	
	Present (n=56)	Absent (n=164)	t-value	p-value
Mean (SD)	58.73 (13.18)	44.97 (15.15)	6.486	<0.001
Median (IQR)	56 (51.5-69)	45.5 (35-54)		
Range	31-86	6-81		

[Table/Fig-6]: Comparison of the two subgroups of the variable depression in terms of caregiver burden score using t-test (N=200).
p-value <0.05 considered significant

Caregiver burden score	Depression severity			Kruskal-Wallis test	
	Mild (n=20)	Moderate (n=27)	Severe (n=9)	χ^2	p-value
Mean (SD)	51.80 (9.82)	62.19 (12.18)	63.78 (17.15)	7.442	0.024
Median (IQR)	54 (47.25-56.25)	63 (53-73.5)	65 (53-80)		
Range	31-71	42-81	35-86		

[Table/Fig-7]: Comparison of the three subgroups of the variable depression severity in terms of caregiver burden score using Kruskal-Wallis test.
p-value <0.05 considered significant

In scatter diagram [Table/Fig-8], looking at the direction of the relationship between the two variables (absolute caregiver burden score and absolute HAM-D score), there is positive association between two variables as there is an upward trend line indicating that as caregiver burden score increases, there is an increase in absolute HAM-D score. While measuring linear correlation which measures the strength of linear relationship between two variables, R^2 value turns out to be 0.1482 which shows that absolute caregiver burden score and absolute HAM-D relationship accounts for 14.82% of the variation.



[Table/Fig-8]: Correlation between absolute HAM-D score and absolute caregiver burden score.

Association between intellectually differently abled person's variables with depression and caregiver's burden:

Age: Wilcoxon-Mann-Whitney U-test and Kruskal-Wallis test was used to make group comparisons for depression and caregiver's burden respectively. There was no significant difference between the groups in terms of age (years) with depression (Wilcoxon-Mann-Whitney U test W=4733.500, p-value=0.731) [Table/Fig-9] and caregiver burden (χ^2=2.420, p-value=0.490) [Table/Fig-10].

Age (years)	Depression		Wilcoxon-Mann-Whitney U test	
	Present (n=56)	Absent (n=164)	W	p-value
Mean (SD)	18.14 (10.12)	18.04 (11.29)	4733.500	0.731
Median (IQR)	16 (10-24.5)	15.5 (9-22)		
Range	5-45	5-63		

[Table/Fig-9]: Comparison of the 2 subgroups of the variable depression in terms of age (years) using Wilcoxon-Mann-Whitney U test.

Gender: Chi-square test was used to explore the association between gender and depression as well as caregiver burden. There was no significant difference between the various groups in terms of distribution of gender with depression (χ^2=0.049, p-value=0.824) [Table/Fig-11] and caregiver burden (χ^2=5.117, p-value=0.163) [Table/Fig-12].

ID severity: Chi-square test was used to explore the association between ID severity and depression as well as caregiver burden. There was no significant difference between the various groups

Age (years)	Caregiver burden				Kruskal-Wallis test	
	Little or no burden (n=8)	Mild to moderate burden (n=61)	Moderate to severe burden (n=100)	Severe burden (n=51)	χ^2	p-value
Mean (SD)	15 (12.82)	17.97 (12.72)	17.71 (9.06)	19.37 (12.04)	2.420	0.490
Median (IQR)	10.5 (9.5-13)	14 (8-22)	16 (10.75-22)	15 (9-29.5)		
Range	7-46	5-63	5-45	5-52		

[Table/Fig-10]: Comparison of the four subgroups of the variable caregiver burden in terms of age (years) using Kruskal-Wallis test.

Gender	Depression			Chi-square test	
	Present (n=56)	Absent (n=164)	Total (n=220)	χ^2	p-value
Male (n=148)	37 (66.1%)	111 (67.7%)	148 (67.3%)	0.049	0.824
Female (n=72)	19 (33.9%)	53 (32.3%)	72 (32.7%)		
Total	56 (100%)	164 (100%)	220 (100%)		

[Table/Fig-11]: Association between depression and gender (N=220) using Chi-square test.

Gender	Caregiver burden					Chi-square test	
	Little or no burden (n=8)	Mild to moderate burden (n=61)	Moderate to severe burden (n=100)	Severe burden (n=51)	Total	χ^2	p-value
Male (n=148)	7 (87.5%)	46 (75.4%)	61 (61.0%)	34 (66.7%)	148 (67.3%)	5.117	0.163
Female (n=72)	1 (12.5%)	15 (24.6%)	39 (39%)	17 (33.3%)	72 (32.7%)		
Total	8 (100%)	61 (100%)	100 (100%)	51 (100%)	220 (100%)		

[Table/Fig-12]: Association between caregiver burden and gender (N=220) using Chi-square test.

in terms of distribution of ID severity and depression (χ^2=0.684, p-value=0.877) [Table/Fig-13] but there was a significant difference between the various groups in terms of distribution of ID severity and caregiver burden (χ^2=18.418, p-value=0.031) [Table/Fig-14].

ID severity	Depression			Chi-square test	
	Present (n=56) n (%)	Absent (n=164) n (%)	Total	χ^2	p-value
Mild (n=63)	16 (28.6%)	47 (28.7%)	63 (28.6%)	0.684	0.877
Moderate (n=95)	22 (39.3%)	73 (44.5%)	95 (43.2%)		
Severe (n=48)	14 (25%)	34 (20.7%)	48 (21.8%)		
Profound (n=14)	4 (7.1%)	10 (6.1%)	14 (6.4%)		
Total	56 (100%)	164 (100%)	220 (100%)		

[Table/Fig-13]: Association between depression and ID severity using Chi-square test.

Affected sibling: Fisher's-exact test was used to explore the association between affected sibling and depression as well as caregiver burden. There was no significant difference between the various groups in terms of distribution of affected sibling and depression (χ^2=3.039, p-value=0.099) [Table/Fig-15] but there was a significant difference between the various groups in terms of distribution of affected sibling and caregiver burden (χ^2=19.758, p-value <0.001) [Table/Fig-16].

Co-morbidities: Chi-square test was used to explore the association between co-morbidities and depression. Kruskal-Wallis test was used to explore the association between co-morbidities and caregiver burden. There was a significant difference between the various groups in terms of distribution of co-morbidities and depression (χ^2=19.941, p-value=0.030) [Table/Fig-17] but there was no significant difference between the various groups in terms of distribution of co-morbidities and caregiver burden (χ^2=11.558, p-value=0.316) [Table/Fig-18].

ID severity	Caregiver burden					Chi-square test	
	Little or no burden (n=8) n (%)	Mild to moderate burden (n=61) n (%)	Moderate to severe burden (n=100) n (%)	Severe burden (n=51) n (%)	Total n (%)	χ^2	p-value
Mild (n=63)	6 (75.0%)	16 (26.2%)	31 (31.0%)	10 (19.6%)	63 (28.6%)	18.418	0.031
Moderate (n=95)	1 (12.5%)	27 (44.3%)	46 (46.0%)	21 (41.2%)	95 (43.2%)		
Severe (n=48)	0	13 (21.3%)	21 (21.0%)	14 (27.5%)	48 (21.8%)		
Profound (n=14)	1 (12.5%)	5 (8.2%)	2 (2.0%)	6 (11.8%)	14 (6.4%)		
Total	8 (100%)	61 (100%)	100 (100%)	51 (100%)	220 (100%)		

[Table/Fig-14]: Association between caregiver burden and ID severity using Chi-square test.
p-value <0.05 considered significant

Affected sibling	Depression			Fisher's-exact test	
	Present (n=56)	Absent (n=164)	Total	χ^2	p-value
Present (n=19)	8 (14.3%)	11 (6.7%)	19 (8.6%)	3.039	0.099
Absent (n=201)	48 (85.7%)	153 (93.3%)	201 (91.4%)		
Total	56 (100%)	164 (100%)	220 (100%)		

[Table/Fig-15]: Association between depression and affected sibling using Fisher-exact Test.

Affected sibling	Caregiver burden					Fisher's-exact test	
	Little or no burden (n=8)	Mild to moderate burden (n=61)	Moderate to severe burden (n=100)	Severe burden (n=51)	Total	χ^2	p-value
Present (n=19)	0	1 (1.6%)	6 (6%)	12 (23.5%)	19 (8.6%)	19.758	<0.001
Absent (n=201)	8 (100%)	60 (98.4%)	94 (94%)	39 (76.5%)	201 (91.4%)		
Total	8 (100%)	61 (100%)	100 (100%)	51 (100%)	220 (100%)		

[Table/Fig-16]: Association between caregiver burden and affected sibling using Fisher's-exact test.
p-value <0.05 considered significant

Co-morbidities	Depression			Chi-square test	
	Present (n=56)	Absent (n=164)	Total	χ^2	p-value
No co-morbidities	13 (23.2%)	54 (32.9%)	67 (30.5%)	19.941	0.030
Behavioural problems	16 (28.6%)	25 (15.2%)	41 (18.6%)		
Epilepsy	6 (10.7%)	33 (20.1%)	39 (17.7%)		
Epilepsy+behavioral	9 (16.1%)	22 (13.4%)	31 (14.1%)		
Multiple from above	4 (7.1%)	12 (7.3%)	16 (7.3%)		
Down syndrome	1 (1.8%)	8 (4.9%)	9 (4.1%)		
Cerebral palsy	3 (5.4%)	5 (3%)	8 (3.6%)		
ADHD	0	3 (1.8%)	3 (1.4%)		
Psychosis	3 (5.4%)	0	3 (1.4%)		
Vision impairment	1 (1.8%)	1 (0.6%)	2 (0.9%)		
Autism	0	1 (0.6%)	1 (0.5%)		
Total	56 (100%)	164 (100%)	220 (100%)		

[Table/Fig-17]: Association between depression and co-morbidities using chi-square test.
*ADHD: Attention deficit hyperactivity disorder; p-value <0.05 considered significant

Co-morbidities	Caregiver burden					Kruskal-Wallis test	
	Little or no burden (n=8)	Mild to moderate burden (n=61)	Moderate to severe burden (n=100)	Severe burden (n=51)	Total	χ^2	p-value
No co-morbidities	4 (50%)	13 (21.3%)	34 (34%)	16 (31.4%)	67 (30.5%)	11.558	0.316
Beha-vioural problems	0	8 (13.1%)	18 (18%)	15 (29.4%)	41 (18.6%)		
Epilepsy	0	17 (27.9%)	16 (16%)	6 (11.8%)	39 (17.7%)		
Epilepsy+behavioral	2 (25%)	8 (13.1%)	14 (14%)	7 (13.7%)	31 (14.1%)		
Multiple from above	1 (12.5%)	7 (11.5%)	4 (4%)	4 (7.8%)	16 (7.3%)		
Down syndrome	1 (12.5%)	3 (4.9%)	5 (5%)	0	9 (4.1%)		
Cerebral palsy	0	3 (4.9%)	3 (3%)	2 (3.9%)	8 (3.6%)		
ADHD	0	1 (1.6%)	2 (2%)	0	3 (1.4%)		
Psychosis	0	0	3 (3%)	0	3 (1.4%)		
Vision impairment	0	1 (1.6%)	0	1 (2%)	2 (0.9%)		
Autism	0	0	1 (1.0%)	0	1 (0.5%)		
Total	8 (100%)	61 (100%)	100 (100%)	51 (100%)	220 (100%)		

[Table/Fig-18]: Association between caregiver burden and co-morbidities using Kruskal-Wallis test.

DISCUSSION

The prevalence of major depression among caregiver's of intellectually differently abled persons was found to be 25.45% which is similar to studies conducted by Shanthi C et al., (25%) and Hu J et al., (22.1%) even though the sample size was three folds compared to other studies and different psychometric tools used [24,25]. One study performed by Nagarkar A et al., [11], although using HAM-D found higher prevalence of major depression (85%) [11]. This stark difference could be due to that depression was assessed only in mothers of the patients in a small sample size (n=60). Thus, the study reaffirms the findings of several others that providing care for an intellectually disabled child have long lasting detrimental psychological impact on primary caregiver's, often leading to diagnosable mental illnesses requiring treatment.

The severity of the major depression as per HAM-D scoring depicts 9.09% caregiver's with mild depression, 12.27% with moderate depression, 4.09% with severe depression and none with very severe depression. Whereas, Nagarkar A et al., [11] found 22% with mild, 25% with moderate, 15% with severe and 23% with very severe depression and Gogoi R et al., [26] found various degrees of severity ranging from 5% to 50% assessed with Beck Depression Inventory (BDI-II). The distinction as compared to Nagarkar A et al., though using HAM-D scoring could be due to already exhausted coping resources being only mothers as caregiver's and other psychosocial factors such as resilience, family support as well as differences in severity of intellectually differently abled persons [11].

Overall, 96.35% of caregiver's were burdened in the present study, out of which more burden was seen in moderate to severe burden category (45.45%) followed by mild to moderate burden category (27.72%) and severe burden category (23.18%). Whereas, Shanthi C et al., found that all primary caregiver's expressed burden (100%) assessed by similar instrument; in which 51.46% experienced mild burden, 29.88% moderate burden and 18.26% severe burden [24]. Study by Heller T et al., showed that mothers reported significantly more caregiving burden than the fathers [27]. Nam S and Park E, showed that overall caregiving burden tended to be higher in female caregiver's, the unemployed, and people with health problems [28]. Singh K et al., showed significant higher level of family burden in study group (n=50, mean 31.80±6.46) than healthy control group (n=50, mean 2.18±1.24) [29]. This could be due to a complex interplay between factors such as socio-economical background, psychological strength, marital and familial harmony along with anticipation and uncertainty surrounding the lifelong challenges in living with a disabled person at the sacrifice of their own interests and ambitions in life.

As the score of caregiver burden increases there is an increase in the score of depression on HAMD and vice versa. Shanthi C et al., found no association between caregiver burden and psychiatric morbidity [24]. This difference can be explained by the assessment of several psychiatric disorders (depression, alcohol abuse, generalised anxiety disorder) as per Mini International Neuropsychiatric Interview (MINI) and not only depression. Perhaps more studies exploring similar association can consolidate this finding.

Statistical significant association was found between intellectually differently abled persons with psychiatric and non psychiatric co-morbidities and caregiver's depression (p-value=0.030) suggesting that majority of caregiver's of intellectually differently abled persons with co-morbidities had depression which was in concordance with study conducted by Al-Kuwari M [30]. Statistical significant association was not found between other variables of intellectually differently abled persons like age, gender, identity severity, affected sibling and depression. The finding in context of age was similar to Bumin G though the rest of the variables require further research [31].

Statistically significant association was found between intellectually differently abled persons ID severity and caregiver's burden (p-value=0.031). This means that caregiver burden increases with increase in ID severity. The similar finding is posited by studies conducted by Shanthi C et al., [24], Sethi S et al., [32], Haveman M et al., [33] and Maes B et al., [34]. Statistical significant association between intellectually differently abled person's affected sibling and caregiver's burden (p-value <0.001) reinstates that having an intellectually disabled sibling increases family burden. Statistical significant association was not found between other variables of intellectual disability patients like age, gender, co-morbidities and caregiver burden which requires further research.

Services provided to intellectually differently abled persons should move on from an individual level to family level as engaging caregiver's in the treatment not only plays a crucial role in improving patients' clinical outcome and compliance but their own psychological issues if identified, addressed and managed effectively by making it a routine clinical practice will help in reducing their burden and feeling of burnout.

Limitation(s)

This was a cross-sectional study and therefore follow-up clinical assessment of each caregiver was not possible. There is no direct control group with respect to illness and depression has not been evaluated in other group of caregiver's representing general population. So, prevalence and pattern of depression can not be generalised as it was done only on caregiver's attending Psychiatry Department.

CONCLUSION(S)

The study emphasises that the psychological distress and suffering of caregiver's are forgotten and their sacrifices in living with an intellectually differently abled person are often taken for granted, especially in our country. Provision of routine psychiatric screening and specific services like self-help groups, parental training, support groups, individual and family therapy can bring about a significant change towards the outlook and management of a lifelong disability.

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