NON COMMUNICABLE DISEASES

Assessment of "Quality of Life" of Parents and Siblings of Intellectually Disabled Children residing at one of Metropolitan cities at Western India

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Keywords

Columbia Impairment Scale-Youth version • Intellectually disabled • National Institute of Mental health Disability Impact Scale • Quality of Life

Summary

Introduction. *Intellectual disability is a permanent disability and raising such a child may lead to varied physical, social, emotional response from caregivers. Data of Quality of life of family members of such children is underexplored.*
Objectives. *To measure quality of life of family members of intellectually disabled children.*
Methodology. *A cross-sectional study was conducted involving seven functional special schools in Ahmedabad. Out of 382 eligible children, 253 parents (Category A) and 195 siblings (Category B) were included. Data were collected using a pre-tested, semi-structured questionnaire. Quality of life for parents was assessed using the National Institute of Mental Health Disability Impact Scale, while siblings were evaluated using the Columbia Impairment Scale (Youth Version).*
Results. *Among Category A participants, the most negatively affected domains were social life (77.1%), physical care (65.2%) and embarrassment (60.5%). Positive effects included better family relationships and increased empathy. Among siblings, 80.5% exhibited functional impairment (score >16), with common problems related to emotional well-being, behaviour and peer interactions. Age, education, and employment status significantly influenced impairment scores.*
Conclusion. *Parents and siblings of children with ID experience considerable negative impacts on their quality of life. These findings highlight the need for targeted psychosocial and support interventions to address the challenges faced by these families.*

Introduction

Intellectual disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behaviour that originates before the age of 22 [1]. Even in present times birth of a child with intellectual disabilities is considered unwelcome event [2]. Parents suffer from guilt, grief, shock and bitterness [3]. Parents of such children are usually underprepared for role and responsibilities as parents. They have to make changes in their lifestyle, restrictions are imposed on their social life, they have less time for themselves, their leisure and recreational activity get compromised [4]. This causes stress which leads to psychological morbidity and disturbance in marital harmony [5]. The impact is not only on parents but also on other family members including siblings. As per census 2011, a total of 2.68 crore persons in India are living with disabilities, amongst which 15 lakh comprise of intellectual disability [6]. In Gujarat, 66393 people are living with intellectual disability [6]. A recent meta-analysis of ID studies among children and adolescents showed a summary prevalence of 2% (range 1-3%) in India [7]. No specific data is available for number of children every year detected with Intellectual disability.

The present study was undertaken to explicitly find the demands and challenges faced by the parents and siblings of children with intellectual disability. Studies conducted in India & other international countries which evaluate the quality of life of parents of intellectually disabled children are available however studies regarding quality of life of siblings of such children in India or any other countries are unexplored.

Objectives

To measure quality of life among family members of intellectually disabled children
To find determinants affecting quality of life of the study participants.

Methodology

A cross-sectional study was started after seeking permission from Institutional Ethics Committee. List of special schools for intellectually disabled children situated in Ahmedabad was prepared. Out of 11 schools list obtained, 7 schools were functional at the time of

the study. Remaining schools informed to have closed due to lack of student enrolment. Functional schools were contacted and data of total number of students enrolled in each school was obtained. From the obtained data, 382 students were enrolled. Parents and siblings were considered as family members for the current study. All 382 children were included in the sampling frame. Per child, parents included in the interview were either father or mother, who-so-ever was available of the selected child; both were not included in the study. Socio-demographic details of spouse were asked to the study participants. In case of divorce, last known socio-demographic details of spouse which was provided by the study participants were considered in the result. If a selected child had more than one sibling, than elder most sibling was interviewed. Not more than one sibling per selected child was interviewed. Permission from head of each school was obtained before start of study. In-person interview was carried out by study investigators on priorly fixed days at venue like school premises, home or work place whichever was convenient to family members using pre-tested semi-structured questionnaire. Before the initiation of the study, validation of questionnaire was done as questionnaire was also translated to the local language. Amongst 20 family members of Intellectually disabled children, pilot study was conducted. Validation was checked through applying Cronbach alpha which was found to be reliable ($\alpha = 0.76$). These 20 family members included in pilot study were later included in the final study and their second interview after validation of questionnaire was carried out. During the course of data collection if contact with parent or sibling was not established for interview, second attempt to interview was made as per convenience. Before interviewing siblings, parents' permission was obtained.

Out of 382 participants, contact with parents of 102 participants could not be established with multiple attempts and 27 refused to provide consent to participate in the study. Final sample size in the study which was analyzed was 253. Amongst 253 participants, 216 participants had siblings in which 195 were interviewed as remaining were not eligible to participate in the study. Questions regarding socio-demographic profile of family like type of family, total family members, age of parents, marital status of parents of affected child, total family income, education and occupation of parents of affected child, details of siblings of intellectually disabled child were asked.

For assessing quality of life of parents of affected child, National Institute of Mental Health Disability Impact Scale [8] was used. It is pre-validated questionnaire [9-11]. It has 11 areas of impact; within each area further questions are present. Each question needs to be responded in either of three ways: not affected- score 0, somewhat affected- score 1 and lot of affected- score 2. Higher the score in 10 areas, greater is the negative impact. Higher the score in area 11, greater is the positive impact. From maximum possible score in 10 areas, score with more than 50% were considered as negative impact while in 11th area, score with less than 50% of maximum possible score was considered as negative impact.

For assessing quality of life of siblings, Columbia Impairment Scale (CIS) Youth Version was used [12]. It is 13 question pre-validated [13, 14] scale which categorizes problem of siblings from No problem- Score 0, Some problem- Score1 to 3, Very Bad problem- Score 4 and Not Applicable / Don't know- Score 5. Functional impairment was considered if total score was above 16.

Data entry was done in MS Excel. Analysis was done using MS Excel and Statistical Package for Social Science (SPSS) Version 20. Heat map was created to explain spearman correlation analysis. In heat map RED suggest Weak/ Negative correlation, GREEN suggest strong Positive correlation and YELLOW suggest Moderate correlation. In current manuscript Parents are addressed as Category A participants and Siblings as Category B participants.

Inclusion & Exclusion criteria

Inclusion criteria

Parents and siblings having child with intellectual disability and they are their main caregiver and those giving consent. Age of Siblings should be 18 years or above at the date of interview.

Exclusion criteria

Parents and siblings not living and not main carer of intellectually disabled child, parents and siblings reporting of having mental illness at time of interview, those parent or sibling who couldn't be contacted and those not giving consent.

Results

A total of 253 parents of the selected participants were interviewed. Amongst the selected children, 224 (88.5%) were male and 29 (11.5%) were female. Age of disabled children was 16.33 + 2.655 with minimum age 11 and maximum age 21. By religion, 200 (79.1%) were Hindu, 36 (14.2%) were Muslim while 17 (6.7%) were Christian. Chronological order of the affected child amongst total children of Category A participants was first child in 101 (39.9%), second in 82 (32.4%), third in 35 (13.8%) & fourth in 35 (13.8%) participants.

Category A component

Socio-demographic detail of the Category A participants is given in Table I. Amongst interviewed, 220 (87.0%) were male and 33 (13.0%) were female.

Mothers who were currently homemaker by occupation, 29 (14.9%) were working in the past before the diagnosis of the child with intellectual disability. Amongst all participants, 37 (14.6%) had no children other than the affected child. Number of siblings elder to affected child were one in case of 82 (38.0%), two in 35 (16.2%) and three in 35 (16.2%) participants. One sibling younger to the affected child was in 64 (29.6%) participants. Age of siblings was 27.62 + 7.911. Current level of education

Tab. I. Socio-demographic details of the Category A participants (n=253).

Variable	Subcategory	Frequency (%)
Type of Family	Nuclear	185 (73.1%)
	3-generation	58 (22.9%)
	Joint	10 (4.0%)
Age of Father (in completed years)	<50	23 (9.1%)
	51-60	195 (77.1%)
	>60	35 (13.8%)
Age of Mother (in completed years)	<50	23 (9.1%)
	51-60	201 (79.4%)
	>60	29 (11.5%)
Education of Father	Secondary	72 (28.5%)
	Higher Secondary	35 (13.8%)
	Graduate	81 (32.0%)
	Post graduate	65 (25.7%)
Education of Mother	Primary	35 (13.8%)
	Secondary	72 (28.5%)
	Higher Secondary	53 (20.9%)
	Graduate	93 (36.8%)
Occupation of Father	Business	64 (25.3%)
	Private job	95 (37.5%)
	Government job	65 (25.7%)
	Retired	29 (11.5%)
Occupation of Mother	Business	29 (11.5%)
	Government job	29 (11.5%)
	Home maker	195 (77.1%)
Currently marital status	Married	224 (88.5%)
	Divorced	31 (11.5%)

of siblings was Primary in 6 (2.8%), Secondary in 58 (26.9%), Higher secondary in 23 (10.6%) & Graduate or above in 129 (59.7%) participants.

Cause of intellectual disability was identified by the parents amongst 116 (45.8%) participants. Amongst reasons identified delayed conception was in 55 (47.4%) participants, followed by birth injury in 13 (11.2%), lack of oxygen damaging brain due to breach delivery in 19 (16.4%) & head injury in 29 (25.0%) participants. Other disabilities in addition to intellectual disability were reported by 29 (11.5%) participants. Among disabilities, flat feet were reported by 23 (79.3%) & inability to speak by 6 (20.7%) participants. None of the intellectually disabled children had any family members with history of intellectual disability.

Quality life of Category A participants assessed using NIMH Disability Impact Scale is given in Table II. Maximum negative impact on caregivers was on Social aspect followed by Physical care, Embarrassment & Sibling effect. In positive impact area, maximum score was obtained in Better relationship with family members & More Empathy.

Heat map of Spearman's rank Correlations amongst various domains of NIMH disability impairment scale is given in Table III.

As per Table III, Strong positive correlation was obtained between physical care & health component, social & specific thoughts component, physical care & social component and financial & positive impact component. Weak or no correlation was obtained between sibling effect & relationship component. Negative correlation was obtained between financial & sibling effect component, embarrassment & sibling effect component and sibling effect & positive impact component.

Tab. II. Assessment of Quality of Life of Category A participants using NIMH Disability Impact Scale (n = 253).

Areas	Maximum possible score	Mean score	Number of participants having negative impact (%)
1. Physical Care	16	7.64 + 5.11	165 (65.2%)
2. Health	10	4.33 + 1.633	130 (51.4%)
3. Career	8	2.10 + 1.853	35 (13.8%)
4. Support	12	3.77 + 2.188	60 (23.7%)
5. Financial	10	4.40 + 2.252	107 (42.3%)
6. Social	6	3.82 + 1.449	195 (77.1%)
7. Embarrassment / Ridicule	8	3.75 + 1.832	153 (60.5%)
8. Relationship	12	4.72 + 3.178	37 (14.6%)
9. Sibling effect (n = 216)	14	6.06 + 5.445	128 (59.3%)
10. Specific Thoughts	8	1.88 + 1.491	58 (22.9%)
11. Positive impact	12	8.04 + 1.777	94 (37.2%)

Regression analysis was applied between sociodemographic variables of Category A participants (independent variable) and score of NIMH Disability Impairment Scale. All independent variables demonstrated a statistically significant association with the dependent variable ($p < 0.001$ for all).

Category B Component

A total of 195 siblings of selected intellectually disabled were interviewed. Mean age of study participants was 22.76 + 3.464. Demographic details of the participants along with its association to total score obtained in Columbia Impairment Scale Youth version (CIS-Y) are given in Table IV.

Quality life of category B participants assessed using Columbia Impairment Scale Youth version (CIS-Y) is given in Table V. Functional impairment (total score- > 16) was observed amongst 157 (80.5%) category B participants while absence of impairment (total score- < 16) was observed amongst only 18 (19.5%) category B participants. Linear regression was applied between various socio-demographic variables of Category B participants (independent) and score obtained in CIS-Y scale (dependent). Statistically significant regression was obtained between current age of Category-B participants (B = -0.827; $p \leq 0.001$), current status of education (B = -4.827; $p \leq 0.001$), current status of income (B = -1.448; $p = 0.05$) & relation to affected sibling (B = -3.308; $p = 0.002$) and score obtained in CIS-Y scale.

Tab. III. Correlation* between domains of NIMH Disability Impairment Scale (n=253).

NIMH Disability Impairment Scale	1	2	3	4	5	6	7	8	9	10	11
1. Physical Care	1	0.902	0.393	0.526	0.128	0.819	0.09	0.403	0.771	0.819	0.134
2. Health	0.902	1	0.298	0.31	0.123	0.798	-0.029	0.365	0.588	0.754	0.138
3. Career	0.393	0.298	1	0.688	0.279	0.614	0.713	0.511	0.271	0.709	0.376
4. Support	0.526	0.31	0.688	1	0.206	0.629	0.673	0.749	0.2	0.603	0.337
5. Financial	0.128	0.123	0.279	0.206	1	0.373	0.482	0.673	-0.016	0.098	0.844
6. Social	0.819	0.798	0.614	0.629	0.373	1	0.263	0.709	0.623	0.855	0.293
7. Embarrassment	0.09	-0.029	0.713	0.673	0.482	0.263	1	0.536	-0.162	0.39	0.777
8. Relationship	0.403	0.365	0.511	0.749	0.673	0.709	0.536	1	0.017	0.385	0.578
9. Sibling effect	0.771	0.588	0.271	0.2	-0.016	0.623	-0.162	0.017	1	0.702	-0.139
10. Specific Thoughts	0.819	0.754	0.709	0.603	0.098	0.855	0.39	0.385	0.702	1	0.247
11. Positive impact	0.134	0.138	0.376	0.337	0.844	0.293	0.777	0.578	-0.139	0.247	1

* Pearson Correlation value.

Tab. IV. Demographic details of Category B participants and their association to score obtained in CIS-Y (n = 195).

Variable	Sub-category	Frequency (%)	Chi-square test (*p*-value)
Age (in completed years)	<21	76 (39.0%)	**30.143 (< 0.001)**
	>21	119 (61.0%)	
Gender	Male	165 (84.6%)	0.180 (0.672)
	Female	30 (15.4%)	
Education (last completed)	Secondary (9-10 std)	28 (14.4%)	**111.484 (< 0.001)**
	Higher Secondary (11-12 std)	58 (29.7%)	
	Graduate or above	109 (55.9%)	
Current status of income	Student	96 (49.2%)	**109.747 (< 0.001)**
	Unemployed	41 (21.0%)	
	Employed	58 (29.8%)	
Your relation to Affected sibling	Participant younger in age	76 (39.0%)	**30.143 (< 0.001)**
	Participant elder in age	119 (61.0%)	

Tab. V. Quality of life of Category B participants based on CIS-Y scale (n = 195).

Variable	Mean score	Number of participants identified with problem (%)
Problem of getting into trouble	1.95 + 1.114	87 (44.6%)
Problem in getting along mother/mother figure	1.44 + 0.806	19 (9.7%)
Problem in getting along with your father/father figure	2.07 + 0.806	70 (35.9%)
Problem of feeling unhappy or sad	2.39 + 0.660	109 (55.9%)
Problem with your behavior at school or at your job	2.27 + 0.990	88 (45.1%)
Problem with having fun	1.35 + 0.652	137 (69.3%)
Problem getting along with adults other than your mother and/or your father	2.26 + 1.218	47 (24.1%)
Problem with feeling nervous or afraid	1.47 + 1.076	96 (49.2%)
Problem in getting along with your sister(s) and/or brother(s)	2.30 + 0.776	96 (49.2%)
Problem in getting along with other kids your age	1.23 + 0.996	19 (9.7%)
Problem getting involved in activities like sports or hobbies	1.35 + 1.011	39 (20.0%)
Problem with your school work OR doing your job	1.75 + 0.819	28 (14.4%)
Problem with your behavior at home	1.30 + 0.776	19 (9.7%)
Overall score	23.12 + 6.267	157 (80.5%)

Discussion

Current study included parents & siblings of intellectually disabled children. In the present study male children were higher than female which is similar to a study done at Delhi [4] where male: female children ratio was 3:1. Amongst the parents interviewed in the present study, 87% were males while a recent study at Anand district in Gujarat state [15], India showed almost equal number of male and female participants which could be attributed to better sex ratio in Anand district as compared to the location of present study.

Majority of the children belonged to Hindu family in this study (79.1%) which is nearer to the studies done in Odisha state (86.7%) [16] and a study done in North India (74.2%) [17]. This may be due to majority religion being Hindu in India. Majority of mothers in the present study (79.4%) belonged to 51-60 years age group while a South Indian study[18] which included only mothers showed that 70% mothers were 30-41 years old. This difference is probably due to variations in the age distribution and age at first birth in female populations of the two locations. Around two thirds of the children belonged to nuclear family (73.1%) in the current study which is close to a study done in Hyderabad City in Telangana state (68%) [19]. The reason for this maybe schools giving admission to especially abled children are located in urban areas where the study is conducted are having nuclear families more. Most of the parents (88.5%) were married which is nearer to the result from a study done in the country of Saudi Arabia [20] where 83% parents were married.

The chronological order of the affected child among his/her siblings was most commonly first (39.9%) and second (32.4%) in the present study. This result is similar to a study done at Vizianagaram in Andhra Pradesh state [21] where first order child (42.8%) were affected more. This may be due to current scenario of late marriage leading to delay in undergoing first pregnancy preference amongst educated population in India. A study done in the country of Saudi Arabia[20] showed that third and higher order children were more affected (54.7%) as compared to first and second order. This difference may be due to difference in geographical and reproductive preference amongst populations of India and Saudi Arabia.

The present study revealed that 65.2% of the parents were facing difficulty with respect to physical care requirements of mentally retarded children which is somewhat near to the result from Vizianagaram [21] where 52.2% parents faced difficulty in physical care domain. When it comes to social restrictions, 77.1% parents responded with a negative impact while 60.5% parents had negative impact in Embarrassment domain. Similar studies conducted at Vizianagaram [21] and Raipur [22] showed much lower impact in social restrictions (31.7% & 23.2% resp.) and Embarrassment domains (26.7% & 21.6% resp.). This difference may be due to socio cultural differences across different states of India and difference in the sample size and time duration during which studies are conducted. Less negative effect was seen on areas like Career, Relationship, Support, Specific thoughts & Finance. Negative correlation was obtained between Embarrassment & Health, Sibling effect & Financial, Sibling effect & Embarrassment, Sibling effect & Positive impact.

As per Table III, Strong positive correlation between Physical care & health component suggest caregivers who report physical caregiving burden & also experience more health-related issues. Correlation between social & specific thoughts component suggest care-givers who report higher social burden are more likely to have distressing specific thoughts. Correlation between physical care & social component indicates physical caregiving stress strongly affecting social functioning. And correlation between financial & positive impact component surprisingly suggests resilience or coping mechanism established by parents to combat financial challenges. Weak or no correlation was obtained between sibling effect & relationship component suggesting the sibling's burden doesn't directly influence caregiver's relationship perception. Negative correlation was obtained between embarrassment/positive impact & sibling effect component, suggesting that embarrassment and perceived positive impact are inversely related to sibling effects.

In the domain effect on sibling due to getting less time, 59.3% parents reported of having negative impact in the current study which is nearer to an observation of 54% in a study done at Anand [23].

Sibling Component analysis showed that males (84.6%) were more than females which is different as compared to a study done in United States of America [24] which showed 52.2% female siblings. This may be due to difference in sex ratio and gender demographics between India and America. More than half of the siblings had completed graduate (55.9%) level of education. The possible reason for this can be parent's investment in educating their apparently healthy child so that they may be able to support their dependant disabled sibling in all possible ways in future. Out of total siblings, 61% were elder in relation to the intellectually disabled child which is near to the observation of 56.4% in the study done at USA [24].

Columbia Impairment Scale youth version showed a mean score of 23.12 + 6.267 among siblings of affected child. Functional impairment (total score- >16) was observed amongst 157 (80.5%) siblings. Age, education, current status of income and relation to affected sibling had statistical association with score obtained in CIS-Y.

The overall regression model was statistically significant, and several predictors were found to be significantly associated with the total score of CIS-Y. Participant's age (B =-0.827, p <.001) and education level (B = -4.827, p < .001) were both significantly and negatively associated with the total score, indicating that higher age and education were associated with lower scores. Current income status also showed a marginally significant negative relationship (B =-1.448, p =.050). In addition, the variable indicating whether the affected

sibling was elder or younger than the respondent was significantly associated with the total score (B = -3.308, p = .002), suggesting that sibling age relation has a meaningful impact.

Limitations

Present study had a cross-sectional study design due to which follow up of parents and siblings of intellectually disabled children was not possible. The pattern of change in their quality of life during various stages of raising intellectually disabled child could not be observed. The study was limited to the parents and siblings of intellectually disabled children in Ahmedabad, India hence the results could not be generalized. Various determinants of parents and siblings like addiction, complications during pregnancy and childbirth, malnutrition, neglect or abuse were not asked.

Recommendations

A multicentric study involving parents and siblings of intellectually disabled children from diverse cultural and socioeconomic background, geographical locations across India needs to be conducted for a more generalizable result. A Longitudinal study design with a qualitative component as well as adding more determinants can further aid in shedding more light in this area of research.

Conclusion

This study highlights the considerable impact that intellectual disability in children has on the quality of life of their family members, particularly parents and siblings. Using standardized and validated tools, it was found that a significant proportion of parents experienced negative effects, especially in social life, physical care responsibilities and emotional burden such as embarrassment and sibling-related stress. Siblings, too, were notably affected, with over 80% demonstrating functional impairments in emotional well-being, social relationships, and daily functioning. Sociodemographic determinants such as age, educational attainment and employment status were found to be significantly associated with the extent of impairment, particularly among siblings. These findings fulfil both objectives of the study—measuring quality of life among family members and identifying key determinants influencing it.

The results underline the urgent need for structured psychosocial support, counselling services and inclusive policies aimed at enhancing coping mechanisms and resilience among families of children with intellectual disabilities. Focused interventions can play a crucial role in improving the well-being of not just the affected individuals, but their entire household ecosystem.

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Conflict of Interest statement

Authors fully disclose there is NO any existing or potential conflicts of interest of a financial, personal or any other nature that could affect or bias their research.

Authors' contributions

SRS: data collection, writing-original draft & writing-review. RPS: conceptualization, review of literature, methodology, study design, data collection, data entry & analysis, writing-original draft, writing-review & editing. VRD: methodology, study design, writing-original draft, writing-review, editing.

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