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To Assess the Quality of Life among Primary Caregivers of Intellectually Disabled Children Attending Outpatient Department in a Tertiary Health Center of City

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ABSTRACT

Introduction: Acceptance of child with intellectual disability (ID), once called mental retardation, becomes difficult to parents and the whole family, particularly when competence and achievement are very much valued in modern world. A parent shows a series of reaction including shock, denial, guilt, sorrow, rejection, and acceptance after knowing that their child is disabled. It is also important to note that caring for a child with disability does not equally affect all parents. There are families who cope well despite the adversity. There could be a number of factors that can affect the quality of life (QOL) of carers which could include severity of the disability of the child, presence of cognitive or behavioral problems, socioeconomic status of the families, lack of education, low social support, etc. The research investigated differences of overall QOL between QOL for caregivers of children with autism spectrum disorder and an ID was compared to QOL for those caring for a normally developing child. **Materials and Methods:** The study was conducted in Maharashtra Institute of Mental Health, Sassoon General Hospital, Pune. Target population was primary caregivers of intellectually disabled children. The samples were selected by convenience sampling technique, a total of 100 samples were selected. **Results:** Data analysis was done by descriptive and inferential statistics. Chi-square test was applied to find out the association between the study findings with selected demographic variables. The Chi-square value for the type of family was 24.6 with 0.05% level of significance, which is greater than tabulated value; hence, there was a significant association between the type of family and QOL of primary caregivers. This was also evident that the overall QOL of primary caregivers comes under satisfactory category. **Conclusion:** The study concludes that the QOL of primary caregivers is related to the type of disability, duration of disability, and the social support available for the caregivers. More the duration, more the social support, and lesser disability lead to better QOL of primary caregivers of intellectually disabled children.

Keywords: Intellectual disable child, Mental retardation, Quality of life

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Introduction

Intellectual disability (ID), once called mental retardation (MR), is characterized by below-average intelligence or mental ability and a lack of skills necessary for day-to-day living. People with IDs can and do learn new skills, but they learn them more slowly. There are varying degrees of ID, from mild to profound.[1] ID can be genetic or the result of a disorder that interferes with brain development. Most children with ID do not develop noticeable symptoms until they are in preschool. The diagnosis is based on the result of formal testing. Proper prenatal care lowers the risk of having a child with ID. Support from many specialists, therapy and special education help children to achieve the highest label of functioning possible.[2]

Quality of life (QOL) as defined by the World Health Organization (WHO) is an individual's perception of his/her position in life in the context of the culture and value systems, in which he/she lives, and in relation to his/her goals, expectations, standards, and concerns.[3] Verdugo *et al*. (2012) conceptualized QOL as consisting of the following domains, personal development, and self-determination; interpersonal relations, participation, rights, emotional well-being, physical well-being, and material well-being.[4]

It is also important to note that caring for a child with disability does not equally affect all parents. There are families who cope well despite the adversity. There could be a number of factors that can affect the QOL of carers which could include severity of the disability of the child, presence of cognitive or behavioral problems, socioeconomic status of the families, lack of education, low social support, etc.[5]

Sawyer (2010) found that when QOL for caregivers of children with autism spectrum disorder and an ID was compared to QOL for those caring for a normally developing child, the result showed a difference in overall QOL between groups. Their child behavior was found to have a significant relationship with caregiver's QOL.[6] Malhotra, Khan, and Bhatia study, in 2012, revealed that parents of children with MR and autism seem to display a higher burden and impaired QOL.[7]

The problems associated with rearing of such children can be multifold and problems such as disturbance of routing, family leisure, family health work absenteeism, and physical and emotional stress not only result in increased economic coast but also have a negative impact on the QOL of caregivers. Thus, it is important that the QOL is needed to be adequately researched and studied in the caregivers of children with mentally retarded. This will ensure the sensitivity while dealing comprehensively with not only children suffering from MR but also the suffering of caregivers.[8]

India has a prevalence of 10.5/1000 in ID. Urban population has slightly higher rate (11/1000) than rural (10.8/1000; $P = 0.044$). Age was found to be highly correlated with the prevalence of ID in rural children ($Q = 98$, $P = 0.019$) as well as in children ($Q = -0.954$, $P = 0.0000$) and adults ($Q = -0.957$, $P = 0.000$) in urban population. The possibility of confounding or the existence of covariates for children in urban setting was noted.[9]

Caregiving and its related burden are considered to be an important aspect in determining the QOL of caregivers. QOL as a concept has been increasingly accepted as an important outcome measure in patient and caregivers of chronic illnesses. QOL includes the conditions of life resulting from the combination of the effect of complete range of factors such as those determining health, happiness and a satisfying occupation, educational, social and intellectual attainments, freedom of actions, and freedom of expression.[10]

The family QOL is increasingly becoming the topic of great interest to researchers in many fields. These problems, in turn, can have a detrimental effect on their QOL, thus knowing the determinants of family QOL might help the community in creating better support program for these families.[11]

Materials and Methods

The study was conducted in Maharashtra Institute of Mental Health (MIMH), Sassoon General Hospital, Pune. Target population was primary caregivers of intellectually disabled children. The samples were selected by convenience sampling technique, a total of 100 samples were selected. Tool used was WHOQOL-BREF. The pilot study was conducted between April 4, 2019, and April 5, 2019, whereas the main data were collected during April 8, 2019–May 8, 2019. The semi-structured interview technique was used for data collection. Data analysis included descriptive and inferential statistics.

Research approach

This was a cross-sectional research study.

Research design

This was a descriptive study design.

Setting

The present study was conducted in MIMH, Sassoon General Hospital, Pune, at the Psychiatric Outpatient Department (OPD).

Sample

In the present context of the study sample consisted of primary caregivers of intellectually disabled children attending OPD at tertiary center in city.

Sample selection criteria for the study

The following criteria were set for the selection of sample:

Inclusion criteria

Primary caregivers attending psychiatric OPD who are:

1. Willing to participate in the study
2. Caregivers with the age group between 20 and 45 years
3. Able to understand Marathi and English language
4. Available at the time of interview.

Exclusion criteria

Primary caregivers attending psychiatric OPD who are:

1. Not willing to participate in the study
2. Not available at the time of interview.

Sample size

In the present study, the sample size was calculated as follows:

Confidence level 95%

$n = 50$, Mean = 98.3, SD= 14.1 (parents)

Power = 80%

Absolute precision = E = 4%

$n = (Z\alpha + Z\beta)^2 sd^2/E^2$

$= (1.96+0.84)^2(14.1)^2/(4)^2$

$= 97.42 \approx 98$

Considering attrition rate, 100 samples were selected.

Sampling technique

"Convenience Sampling" technique was used for this study as this method helped the investigators to select samples based on convenient accessibility and proximity of the subjects.

Data collection tool

In the present context of the study, the tool used was WHOQOL-BREF for assessing QOL of primary caregivers of intellectually disabled children and demographic data are collected with the help of questionnaire.

- Part 1 – demographic data
  - Demographic data of primary caregiver
  - Demographic data of the intellectually disabled child.
- Part 2 – WHOQOL-BREF a questionnaire which consists of 26 questions based on four domains (physical health domain, psychological domain, social relations domain, environment domain).

Results

Section I

Distribution of demographic data of primary caregivers in frequency and percentage

Table 1 shows the distribution of demographic data of primary caregivers participated in the study. The total number of participants is 100. Table 1 shows the following findings:

Age

Out of 100 participants, the highest percentage of participants comes under the age group of 41–46 years with the percentage of 28%, 3% belongs to the age group of 20–25 years, 21% belongs to 26–30 years, 25% belongs to 31–35 years, and 23% belongs to 41–45 years of age.

Table 1: Distribution of frequency and percentage of demographic variables of primary caregivers, n=100

Demographic variables	Frequency	Percentage
Age (years)		
20–25	3	3
26–30	21	21
31–35	25	25
36–40	28	28
41–45	23	23
Gender		
Female	70	70
Male	30	30
Education		
Primary	26	26
Secondary	32	32
Higher secondary	20	20
Graduate	15	15
Other	17	17
Occupation		
Government	6	6
Private	23	23
Semi-government	5	5
Other	32	32
Not working	34	34
Monthly income		
Up to 10,000 Rs.	31	31
10,001–20,000 Rs.	29	29
20,001–30,000 Rs.	23	23
30,001–40,000 Rs.	6	6
40,001–50,000 Rs.	6	6
Above 50,000 Rs.	5	5
Type of family		
Joint family	45	45
Nuclear family	51	51
Separated parents	2	2
Divorce parents	2	2
Residential area		
Urban	76	76
Rural	24	24
Term of gestation		
Full term	88	88
Pre-term	12	12
Type of delivery		
Normal delivery	68	68
Cesarean section	31	31
Other	1	1
Infection during pregnancy		
Present	7	7
Absent	93	93

Gender

Out of 100 participants, 70% are female and 30% are male participants.

Education

Out of 100 participants, the highest percentage of participants is educated up to secondary education and the percentage is 32%. About 26% are taken primary education, 20% educated up to higher secondary, 15% are graduates, and 17% come under other education.

Occupation

Out of 100 participants, maximum participants are not working and the percentage is 34%. About 32% are working in other sectors, 23% are working in private sector, 6% are working in government sector, and 5% are working in semi-government sector.

Monthly income

Out of 100 participants, maximum participants come under the monthly income up to 10,000 Rs. and the percentage is 31%. About 29% comes under 10,001–20,000 Rs., 6% come under 20,001–30,000, 6% come under 30,001–40,000, and 5% come above 50,000 income group.

Type of family

Out of 100 participants, maximum participants are from nuclear family and the percentage is 51%. About 45% are from joint family, 2% are separated parents, and 2% are divorce parents.

Residential area

Out of 100 participants, 76% are residents of urban area, whereas 24% are residents of rural area.

Term of gestation

Out of 100 participants, 88% have full-term gestation, whereas 12% have pre-term gestation.

Type of delivery

Out of 100 participants, 68% have normal delivery, 31% have cesarean section, whereas 1% have other types of delivery, i.e., forceps delivery.

Infection during pregnancy

Out of 100 participants, 93% of participants had not suffered from any kind of infection during pregnancy and 7% of participants had infection during pregnancy.

Section II

Table 2 shows the demographic data of intellectually disabled children.

Gender

Out of 100 participants, 60% are male while 40% are female.

Table 2: Distribution of frequency and percentage of demographic variables of intellectually disabled children, *n*=100

Demographic variables	Frequency	Percentage
Gender		
Male	60	60
Female	40	40
Type of disability		
Mental retardation	83	83
Autism	7	7
Cerebral palsy	4	4
Down's syndrome	6	6
Duration of disability		
0–3	33	33
3–6	21	21
6–9	16	16
9–12	15	15
12–15	15	15
Comorbid illness		
Present	24	24
Absent	76	76

Table 3: Overall QOL among primary caregivers, *n*=100

QOL	Poor	Average	Satisfactory	Good	Excellent
Score	0–26	26–52	52–78	78–104	104–130
Frequency in percentage	0	7	45S	43	5

QOL: Quality of life

Table 4: Physical health domain wise QOL of primary caregivers

QOL	Poor	Average	Satisfactory	Good	Excellent
Sample	0–7	8–14	15–21	22–28	29–35
Frequency in percentage	0	4	52	43	1

QOL: Quality of life

Table 5: Psychological domain wise QOL of primary caregivers

QOL	Poor	Average	Satisfactory	Good	Excellent
Sample	0–6	7–12	13–18	19–24	25–30
Frequency in percentage	1	8	34	48	9

QOL: Quality of life

Type of disability

Out of 100 children, maximum numbers of children have MR and the percentage is 83%, 7% are having autism, 4% have cerebral palsy, and 6% have Down's syndrome.

Duration of disability

Out of 100 children, 33% are having duration between 0 and 3 years which is maximum, 21% have duration of 3–6 years, 15% have duration of 9–12 years, and 15% have duration of 12–15 years.

Comorbid illness

Out of 100 children, maximum children do not have any comorbid illness and the percentage is 76%, whereas 24% of children are having comorbid illness.

Section III

It deals with the analysis of data related to the QOL among primary caregivers.
Table 3 shows overall distribution of QOL among primary caregivers of intellectually disabled children, maximum participants belong to satisfactory category, the percentage is 45%, whereas 0% of participants belong to poor category.

Table 6: Social relations domain wise QOL of primary caregivers

QOL	Poor	Average	Satisfactory	Good	Excellent
Sample	0–3	4–6	7–9	10–12	13–15
Frequency in percentage	6	5	23	52	14%

QOL: Quality of life

Table 7: Environment domain wise QOL of primary caregivers

QOL	Poor	Average	Satisfactory	Good	Excellent
Sample	0–8	9–16	17–24	25–32	33–40
Frequency in percentage	3	15	37	41	4

QOL: Quality of life

Table 8: Comparison of mean frequencies of all the domains

Domain	Domain 1	Domain 2	Domain 3	Domain 4
Mean frequency	20.66	19	10.1	22.85

Section IV

It deals with analysis of data related to domains of QOL and its comparison among primary caregivers of intellectually disabled children [Tables 4-8].

Section V

It deals with analysis of data to find out the association between selected demographic variables with the study findings.
Table 9 shows the association between demographic variables of caregivers with the study findings. There is a significant association between the type of family and study findings. The Chi-square value is 24.6 which is >0.05 for df 9.
Table 10 shows the association between selected demographic variables with the study findings. There is no significant association between the demographic variables and study findings.

Discussion

A QOL as a research construct has been examined in diverse samples and conceptualized in various ways. The QOL of primary caregivers is affected irrespective of age, gender, education, occupation, monthly income, etc. The objective experience of primary caregivers of intellectually disabled children shows stress due to the care required by the child, leading to more emotional reaction to child disturbances.
In the present study, the more samples were male children and the percentage was 60%, whereas female children were 40% which are similar to the study conducted in Japan, in 2015.[12] The present study shows that maximum

Table 9: Association between demographic variables of caregivers with the study findings

Parameters of primary caregivers	Assessment of quality of life of primary caregivers			
	Chi-square value (calculated)	Chi-square value (tabulated)	df	Significance
Age	9.3	21.03	12	Not significant
Education	5.58	21.03	12	Not significant
Occupation	9.38	21.03	12	Not significant
Monthly income	18.88	21.03	12	Not significant
Type of family	24.6	16.92	9	Significant
Residential area	2.41	7.82	3	Not significant
Term of gestation	3.9	7.82	3	Not significant
Type of delivery	3.4	12.59	6	Not significant
Infection during pregnancy	2.65	7.82	3	Not significant

Table 10: Association between selected demographic variables of children with the study findings

Parameters of intellectually disabled children	Assessment quality of life of primary caregivers			
	Chi-square value (calculated)	Chi-square value (tabulated)	df	Significance
Type of disability	11.41	16.92	9	Not significant
Duration of disability	7.53	21.03	12	Not significant
Comorbid illness	0.55	7.82	3	Not Significant

primary caregivers belong to satisfactory category and the percentage was 45%. The present study also shows that the various domains of QOL and its comparison among primary caregivers of intellectually disabled children showed satisfactory category. The study shows that there is no significant association between age, education, occupation, monthly income, residential area, term of gestation, type of delivery, and infection during pregnancy. The intellectually disabled children (type of disability, duration of disability, and comorbid illness) show no significant association between the selected demographic variables and study findings.

The type of family shows statistically significant with the study findings, thus though intellectually disabled child affects QOL of primary caregiver the family support helps to improve it. Thus, there is, the overall QOL of primary caregivers comes under satisfactory category and the most affected domains are physical and social relations as they fall in satisfactory category. The other domains, i.e., psychological and environment are less affected as they come under good category. Still, the primary caregivers are managing the children, to improve their QOL along with interventions by the psychiatrist and nurses, help from other agencies, for example, social workers and psychologists are also must.

Conclusion

The purpose of the study was to assess a QOL among primary caregivers of intellectually disabled children attending psychiatric OPD in MIMH, Pune. In the present study, there were a total of 14 demographic variables of both primary caregivers and intellectually disabled children. These include age, gender, education, and occupation. The overall QOL of primary caregivers comes under satisfactory range and the percentage is 45%, whereas the most affected domain observed are physical health and social relations come under satisfactory category and the percentage is 52% both. The Chi-square test was done to assess the association between selected demographic variables with the study findings. The study shows a significant association between the types of family with QOL among primary caregivers.

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