

Quality of Life of Mothers of Children with Intellectual Disability in Relation to Mother Empowerment Program



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ABSTRACT:

Background: The present study investigated the quality of life of 100 mothers of children with intellectual disability in selected special schools of Kottayam district, Kerala.

Materials & methods: A descriptive survey was conducted among 100 mothers of children attending special schools of Kottayam district from February 2020 to September 2020. The Quality of Life was measured by using WHO QOL Malayalam questionnaire, after obtaining Institutional Ethics Committee Approval and after seeking informed consent from the participants. The purpose of the study was explained, socio demographic data collected by interview and the data recorded. The mothers filled up the instrument and returned back to the investigator. Data were analyzed with descriptive statistics such as mean and standard deviations and appropriate parametric test such as independent t test for parametric data.

Results: Out of the 100 mothers studied, educational status of the mothers showed that 10 had primary education, 37 had high school education, 32 had higher secondary education and 21 graduates.; occupation of the mothers showed that, 18(18%) had Government job, 20 (20%) had private job, 15(15%) were self employed and 47 (47%) were not employed. It was found that 95(95%) of children obtained financial assistance and other benefits from local self governing bodies.

The Overall quality of life scores of mothers and financial assistance obtained from the local self governing bodies was studied. The overall QOL scores of mothers is influenced by the financial assistance obtained from local self governing bodies. ($P=0.01$, $t= 2.51$). The Overall QOL Score ranged from 2 to 130 with a mean of 69.93 and Standard Deviation of 20.13. Results shows that the highest mean value was obtained for Psychological Domain with a standard Deviation of 19.85, the lowest mean value was obtained for social relationships domain with a mean value of 39.55 and a standard deviation of 26.30.

BACKGROUND

The American Association on Intellectual and Developmental Disabilities AAIDD, formerly AAMR, has refined and modified the criteria for the diagnosis of intellectual disability. The three primary criteria are limitations in intellectual functioning, limitations in adaptive behavior and this disability originates before the age of 18. The National Sample Survey Organization (NSSO) estimates that currently 1.8% of the total Indian population is disabled, yet the data may not be completely accurate. The prevalence of intellectual disability has been estimated at 1-4% i.e. about 20 people per 1000 in the population. (Dr. Sanjay Parva, 2017). As mothers are the primary caregivers of these children, mothers experience a variety of mental conflicts which indeed reduce their quality of life. Dezaki et.al. (2018) suggested that mother is an important member of the Social rehabilitation team involved in the rehabilitation of the child with intellectual disability. Research findings conclusively prove that the quality of life of mothers are much more affected than any other family members in this overwhelming situation.

Quality of Life is defined as an individual's perceptions of their position in life in the context of the culture and value systems in which they live in relation to their goals, expectations, standards and concerns. (WHO, 1996)

The present study investigated the quality of life of 100 mothers of children with intellectual disability in selected special schools of Kottayam district, Kerala. A descriptive survey was conducted among 100 mothers of children attending special schools of Kottayam district from February 2020 to September 2020. The Quality of Life was measured by using WHO QOL Malayalam questionnaire, after obtaining Institutional Ethics Committee Approval and after seeking informed consent from the participants.

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Objectives of the study

- ❖ To find out the QOL of mothers of children with intellectual disability.
- ❖ To determine the differences in QOL score of mothers with regard to socio demographic variables.

Hypotheses

- There will be no significant difference in mean QOL scores of mothers with respect to selected demographic variables.

Sampling – through simple random sampling selected 12 special schools in Kottayam.

Instruments

1. Demographic data sheet
2. WHO QOL Malayalam version

INCLUSION CRITERIA

1. Mothers who can read and write Malayalam and those who are willing to participate.
2. Biological mothers of children with intellectual disability, staying with the child.

EXCLUSION CRITERIA

1. Mothers above the age of 60 and below the age of 25.
2. Mothers having previous history of mental illness
3. Mothers who are not staying with the child.

MATERIALS AND METHODS

After obtaining the permission from the special school authorities and informed consent from mothers, the investigator administered WHO QOL BREF Questionnaire and socio demographic data sheet to 100 mothers of children attending 12 special schools of Kottayam district. The purpose of the study was explained, socio demographic data collected by interview and the data recorded. The mothers filled up the instrument and returned back to the investigator .Each mother took about 30 to 40 minutes to complete the instrument. Data were analyzed with descriptive statistics such as mean and standard deviations and appropriate parametric tests & independent t test for parametric data.

RESULTS

Out of the 100 mothers studied, educational status of the mothers showed that 10 had primary education, 37 had high school education, 32 had higher secondary education and 21 graduates.; occupation of the mothers showed that , 18(18%) had Government job, 20 (20%) had private job ,15(15%) were self employed and 47 (47%) were not employed. It was found that 95(95%) of children obtained financial assistance and other benefits from local self governing bodies.

The Overall quality of life scores of mothers and financial assistance obtained from the local self governing bodies was studied .The overall QOL scores of mothers is influenced by the financial assistance obtained from local self governing bodies.($P=0.01$, $t=2.51$). The Overall QOL Score ranged from 26 to 130 with a mean of 69.93 and Standard Deviation of 20.13 . The Overall QOL Score ranged from 26 to 130 with a mean of 69.93 and Standard Deviation of 20.13 . Results shows that the highest mean value was obtained for Psychological Domain with a standard Deviation of 19.85, the lowest mean value was obtained for social relationships domain with a mean value of 39.55 and a standard deviation of 26.30.

Table 1. Descriptive statistics of the Overall Quality of Life scores of mothers of children with Intellectual disability (N=100)

S. No	Measures	Overall QOL
1	Mean	69.93
2	Median	73.00
3	Mode	76
4	Standard Deviation	20.13
5	Coefficient of Skewness	-.186
6	Coefficient of Kurtosis	-.913
7	Range	78
8	minimum	31
9	maximum	109

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Table 1 shows the base line characteristics of the Overall QOL scores of mothers of children with Intellectual disability. The Overall QOL Score ranged from 26 to 130 with a mean of 69.93 and Standard Deviation of 20.13 .

Table 2. Mean values and standard deviations of domain wise QOL Scores of mothers of children with Intellectual Disability (N=100)

S. no	QOL DOMAINS (Possible Range of Scores)	Mean	Standard Deviation
1	Physical Domain (0-100)	42.43	19.99
2	Psychological Domain(0-100)	45.16	19.85
3	Social Relationships Domain(0-100)	39.55	26.30
4	Environment Domain (0-100)	43.35	20.83

Table 2 shows that the highest mean value was obtained for Psychological Domain with a standard Deviation of 19.85, the lowest mean value was obtained for social relationships domain with a mean value of 39.55 and a standard deviation of 26.30.

Table 3. Distribution of mothers of children with Intellectual Disability based on the overall QOL Scores. (N=100)

SL NO	Overall QOL	frequency	percentage
1	high QOL (91-130)	15	15.0
2	Medium QOL (50-90)	64	64.0
3	Low QOL(26-90)	21	21.0

Table 3 shows that the maximum possible Overall QOL Score is 130 and the minimum possible Overall QOL Score is 26.100 participants were categorized into three based on the QOL Scores. The QOL scores were classified into three categories such as high QOL, medium QOL and low QOL. This was done on the basis of mean values and standard deviations .The scores obtained by adding and subtracting one standard deviation from mean gives the lower and upper limit of the average category. Majority of the mothers 64 (64%) obtained medium Overall QOL, 21 (21%) of the mothers obtained low Overall QOL scores.

Table 4. The Overall QOL Scores of mothers of children with intellectual disability in relation to the financial assistance obtained from local self governing bodies.

Variable	Financial assistance obtained from local self governing bodies	N	Mean	Standard Deviation	t value
Overall QOL	Financial help obtained	95	71.06	19.71	2.51*
	Financial help not obtained	5	48.40	17.06	
	TOTAL	100			

From Table 4 it is found that the Overall QOL of mothers in relation to the financial help obtained from local self governing bodies showed that the mean was higher for the group which obtained the financial help. The independent t test was found to be significant at 0.01 level. (t=2.51).

DISCUSSION

The present study adds to the findings of the previous research .Vadakkedom et.al.(2017) conducted research on quality of life of mothers of children with Down Syndrome in the OP department of Institute of Child Health , Kottayam. The study found that medium quality of life was reported by most mothers of children with Down Syndrome which is consistent with the present study.

Anjali, et.al., (2017) conducted systematic review on pooled evidence on QOL of parents having children with intellectual disability from Data bases such as CINAHL, Pubmed, Medline and Proquest, the authors reviewed case control and descriptive studies with mother's QOL as the primary outcome. The study found that mothers of children with Intellectual disability have impaired QOL in all the four domains of QOL. Hence supportive interventions for mothers, financial aid,

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accessibility to health services are crucial. This finding is consistent with the present study that Overall QOL scores are influenced by the Financial help and assistance obtained from local self governing bodies.(P=0.01, t=2.51).

CONCLUSION

The findings of the study must be taken into consideration while formulating Government Policies in order to provide better supportive interventions for mothers of children with intellectual disability.

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