IJNH Innovational Journal of Nursing and Healthcare (IJNH)

www.ijnursing.com

Research article

# Impact of quality of life in parents of mentally retarded children: Research findings in a regional center

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## Abstract

Families who have a child with mental retardation experience many challenges and such conditions also affect quality of life. The study under taken to evaluate the quality of life (QOL) of parents of children with mental retardation. To find out the association between the quality of life (QOL) and there selected socio demographic variables. To determine the relationship between the grades of mental retardation and the quality of life (QOL) of parents. In the study cross sectional survey approach was used to evaluate the quality of life. 100 parents of mentally retarded children were enrolled (Vikas Mandir, Mental Retardation School, Nashik.) for the study from 08-Jan-2014 to 07-Feb-2014. Non probability, convenient sampling technique was used. A semi structured interview schedule was prepared to collect data from subjects based on the study objectives. Findings revealed that the parents of children with mental retardation having poor quality of life in financial aspect (5.97+ 1.87) (29.95%), average quality of life in physical (45.27+ 7.86) (59.56%), psychological (24.69+ 4.84) (61.72%), social (16.47+ 3.31) (58.82%) and environmental as39pect (40.87+ 5.63) (53.7%). Chi square test shows significant association between socio demographic variables of mental retardation children with quality of life of parent such as sex of mental retardation child and duration of illness since diagnosed. Co-efficient of co-relation test value revealed that among the selected study variables mild and severe mental retardation were negatively correlated (r= -0.18, r= -0.06), and moderate mental retardation was positively correlated (r= 0.06) with quality of life of parents

**Keywords:** Quality of life, mental retardation, parents, nursing.

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## 1. Introduction

A family who has a child with mental retardation experiences many challenges such as physical problems, emotional stress, psychological disturbances, family problems, additional financial burden for family. Parents may suffer from mental worries because of having a child with mental retardation, family needs should be focused on early building and strengthening the social support systems, families should focused early intervention programs.

### Mental retardation

The DSM-IV TR classifies intellectual disability as mental retardation. Mental retardation requires an individual to have an IQ of 70 or under as measured on the IQ test with an appropriate measurement error of 5 points. [1] The DSM-IV definition specifies the degrees/ grades of mental retardation severity based on level of IQ, mild (50-55 to 70), moderate (34-40 to 50-55), severe (20-25 to 35-40) and profound (less than 20-25). The American Association of Mental Retardation (2008) defines mental retardation as a disability characterized by significant limitations, both in intellectual functioning and in adaptive behavior, as expressed in conceptual, social, and practical adaptive skills, the disability originating before the age of 18 (table 1). [2]

Table 1: Levels of support and its aspects

| Levels of support | Aspects |
|---|---|
| Intermittent | Support on 'as needed' basis, person needs sporadic supports or short term supports during life span transition crisis support may be high or low. |
| Limited | High/ low intensity support are needed consistently for only limited time (limited employment training) |
| Extensive | Supports characterized by regular involvement (daily) in at least some environment (work/ home) and are not time limited (long term home living support). |
| Pervasive | Supports characterized by constancy and high intensity across environment. Potentially life sustaining in nature typically involve more staff members and intrusiveness. |

(Source: The American Association of Mental Retardation (2008))

Mental retardation impacts on quality of life which is defined as individuals' perceptions and their position in life in the context of culture and value systems in relation to their goals, expectations, standards and concerns. [3] Barnett *et al* mentioned for most parents, the birth of their child is a joyous time. However, nearly 4% of parents receive distressing news about their child's health. In fact, about every 3.5 minutes a parent is told that their child has a serious chronic medical illness, health defect, disability, sensory impairment, or mental retardation**.** For these parents, the time of their child's birth may become mixed with stress and despair. [4] Parenting is a highly stressful job, and becoming a parent of a child with disability is one of the most stressful life events that can occur. Families with a child who has special health care needs experience life differently than other families. Thompson *et al* and Peters *et al* stated that mothers are usually the primary caregivers of these children, because most of them remain in the family environment during their treatment and they appear to carry the larger burden of care and they may feel a need to be with their child at all times so they experience stress related to coping with the heavy load of care giving. [5,6]

**Need for study**

Mohammadreza B. reported that the parents of mentally retarded children experience more psychological problems in aspects of aggression, depression, obsession, anxiety, physical complaint and psychosis than parents of normal children. [7] The parents of mentally retarded children are more vulnerable to stress than parents of normal children. Majumdar *et al* found that the high level of stress experienced by parents of mentally retarded children could be related to subjective factors such as a feeling of being restricted, social isolation and dissatisfaction, and might have paved the way for the manifestation of anxiety symptoms. [8] Based on the previous investigations, the study was designed to evaluate quality of life of parents of children with mental retardation in a localized region in Maharashtra, India.

**Statement of Problem**

A study to evaluate the quality of life (QOL) of parents of children with mental retardation enrolled in Vikas Mandir Mental Retardation School, Nashik.

**Objectives:**

1. To evaluate the quality of life (QOL) of parents of children with mental retardation

2**.** To find out the association between the quality of life (QOL) and there selected socio demographic variables

3**.** To determine the relationship between the grades of mental retardation and the quality of life (QOL) of parents.

**Assumptions:**

1. Parents of children with mental retardation may have poor quality of life

2**.** Socio demographic variables may influence quality of life (QOL) of parents with mental retardation

3. Different grades of mental retardation may influence the quality of life (QOL) of parents

**Conceptual framework:**
In the present context of the study Johnson's Behavioral model was used.

**Methods and materials:**

**Research Design:** Evaluative research, Descriptive study design.

**Research approach:** Cross sectional survey approach was used to evaluate the quality of life of parents of children with mental retardation.

**Sample and sample size:** The study enrolled 100 parents (now onwards referred as subjects) of mentally retarded children in Vikas Mandir Mental Retardation School, Nashik Road, Nashik. **Sampling technique:** Non probability, convenient sampling technique was used for selecting subjects from 08-Jan-2014 to 07-Feb-2014.

**Inclusion criteria:** children enrolled in Vikas Mandir School, able to understand and speak Marathi, willingness to participate in the study and availability during the period of data collection.

**Exclusion criteria:** Parents of children with less than 6 years and more than 18 years were excluded from the study.

**Ethical consideration:** The present study was approved by the Institutional Ethics Committee (IEC) and Institutional Research Committee (IRC) of Pravara Institute of Medical Sciences, Loni, (DU). Informed consent was obtained from the subjects who participated in the study.

**2. Method of data collection**
A semi structured interview schedule was prepared to collect data from subjects based on the study objectives. The tool was prepared in the form of rating scale to assess quality of life of parents of children with mental retardation the tool was modified from standardized WHO QOL 100 items scale. The semi structured interview schedule was prepared in two sections to collect the data.

**Section I** consisted of two parts with part I containing socio-demographic data of subjects like age, sex, educational qualification, occupation, annual income, marital status, term of delivery, type of delivery, source of information related to mental retardation and part II containing socio- demographic data of mentally retarded children like age, sex, duration of illness since diagnosed, grade of mental retardation, co morbid illness. **Section II** was modified quality of life scale (table 2) to assess the quality of life of parents of children with mental retardation, which included total 60 items out of which 19 items were to assess the physical aspect of quality of life of parents, 10 items of psychological aspect, social aspect consist of 7 items, financial aspect consists of 5 items, environment aspect consisted of 19 items. Each item has five alternatives like: never, seldom, quite often, very often, always with scores of 0, 1, 2, 3, 4 respectively. The maximum obtainable score was 240 (table 3). Except social aspect, all other four aspects consisted of some reverse questions with scores of 4, 3, 2, 1 and 0. Reverse questions for the present tool are as follows: Physical aspect: Item no. 1 to 7 and 9 to 14; Psychological aspect: Item no 20 to 22, 24; Financial aspect: Item no 37, 38 and Environmental aspect: Item no 58.

Table 2: Description of Modified WHOQOL scale

| SN | Areas | Number of items | Percentage |
|---|---|---|---|
| 1 | Physical aspect | Q1 to Q19 | 32% |
| 2 | Psychological aspect | Q20 to Q29 | 16% |
| 3 | Social aspect | Q30 to Q36 | 11% |
| 4 | Financial aspect | Q37 to Q41 | 9% |
| 5 | Environmental aspect | Q42 to Q60 | 32% |
| Total | | 60 | 100% |

Q: Question; WHOQOL: World Health Organization Quality of Life

Table 3: Scoring scheme for assessment of QOL

| SN | Actual score | Percentage | Scores |
|---|---|---|---|
| 1 | 0 – 80 | 0 – 33 | Poor |
| 2 | 81- 160 | 34 – 67 | Average |
| 3 | 161 – 240 | 68 – 100 | Good |

QOL: Quality of Life

**Validity and reliability of tool**

The content of validity of the semi structured interview schedule was established by consulting the experts from the various disciplines such as Department of Psychiatry, Department of Psychology, Department of Mental Health Nursing, and Statistics. The tool was modified according to the suggestion and recommendation of experts in consultation with guide. The reliability of the tool was tested by implementing the semi structured interview schedule on 10 parents of children with mental retardation enrolled in Ahmednagar Mental Retardation School, Ahmednagar. The test retest reliability method was used to test the reliability of tool and the r value was 0.95.

**Statistical analysis**

Descriptive and inferential statistics was planned for data analysis. The collected data was organized, tabulated and analyzed by using descriptive statistics i.e. percentage, mean, mean percentage and standard deviation. The Chi-square test was used to find out the association between the quality of life (QOL) and socio demographic variables. Co-efficient of correlation test was used to test the relationship between grades of mental retardation and quality of life of parents.

## 3. Results

The study enrolled subjects with varied demographics detailed in table 4. The analysis also showed that the female subjects gave birth to mentally retarded children by normal delivery (93%) and caesarean method (7%). Out of them 89% were full-term delivery followed by post-term (7%) and pre-term (4%). Majority of subjects (84%) received the information related to mental retardation from healthcare professional followed by media (3%). Detailed information related to mentally retarded children is provided in table 5.

Table 4: Socio- demographic variables of parents of children with mental retardation.

| Variables | Demographic variables | Percentage of subjects |
|---|---|---|
| Gender | Female | 78 |
| | Male | 22 |
| Age (Year) | <25 | 0 |
| | 26-35 | 43 |
| | 36-45 | 56 |
| | 46-55 | 1 |
| | >55 | 0 |
| Education | Illiterate | 0 |
| | Primary | 4 |
| | Secondary | 26 |
| | Higher Secondary | 61 |
| | Graduate/Postgraduate | 9 |
| Occupation | Daily Wages | 4 |
| | Farmer | 9 |
| | Private Job | 14 |
| | Govt. | 0 |
| | Business | 7 |
| | Housewife | 66 |
| Socioeconomic status (Income in Rs) | <3000 | 0 |
| | 3000-6000 | 4 |
| | 6000-9000 | 11 |
| | 9000-12000 | 61 |
| | >12000 | 24 |

Table 5: Description of socio demographic data of children with mental retardation

| Variables | Demographic variables | Frequency | Percentage |
|---|---|---|---|
| 1. Age of MR child | 6 to 10 yrs | 38 | 38% |
| | 11 to 14 yrs | 40 | 40% |
| | 15 to 18 yrs | 22 | 22% |
| 2. Sex of MR child | Male | 68 | 68% |
| | Female | 32 | 32% |
| 3. Grade of MR child | Mild | 27 | 27% |
| | Moderate | 35 | 35% |
| | Severe | 37 | 37% |
| | Profound | 1 | 1% |
| 4. Duration of illness since diagnosed | Less than 3 yrs | 6 | 6% |
| | 3 to 4 yrs | 0 | 0 |
| | 4 to 5 yrs | 8 | 8% |
| | 5 to 6 yrs | 17 | 17% |
| | 6 to 7 yrs | 19 | 19% |
| | More than 7 yrs | 50 | 50% |
| 5. Co- morbid illness | Learning disorder | 8 | 9% |
| | Developmental disorder | 10 | 11% |
| | Muscular disorder | 0 | 0 |
| | Communication disorder | 7 | 8% |
| | Epilepsy | 25 | 28% |
| | Combined | 40 | 44% |

In addition to mental retardation, co-morbid illness in the subjects included epilepsy, communication disorder, developmental disorder and learning disorder (fig 1).

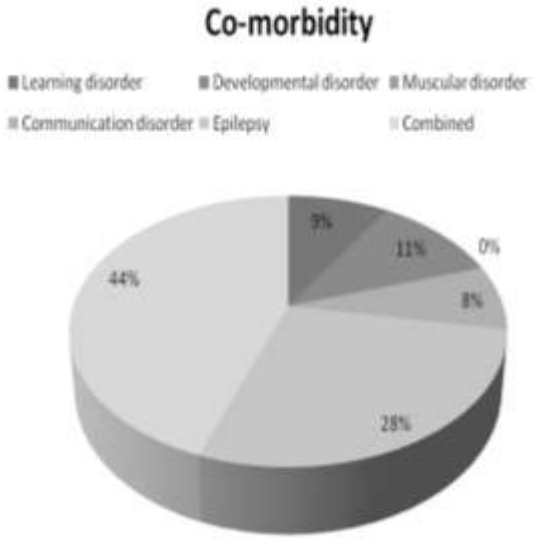


Fig 1: Pie diagram showing co-morbidities in the subjects.

**Item analysis:** shows under physical aspects of quality of life maximum of subjects (98%) were under 'very often' grade. 95% subjects were able to carry out their regular duties, 90% subjects were satisfied with the work they did. In response with psychological aspect of quality of life, 60% subjects said they feel alone in their life. 59% subjects said that personal beliefs give meaning to life and 55% said personal beliefs helps to understand difficulties in life. In social aspect of quality of life, 69% subjects were satisfied with the social care activities. 68% subjects were satisfied with their sex life. 63% subjects got family support and satisfied with their support and 61% parents said that they felt happy about the relationship with the family members. Item wise comparison of environmental aspect of quality of life of parents of children with mental retardation responses showed that highest percentage (91%) parents responded as they get social services for their children. (67%) parents said that they get opportunity for leisure activity. (62%) parents responded as they are having adequate means of transport (table 6).

Table 6: Aspects of quality of life

| S. No. | Aspects of QOL | Maximum score | Mean ± SD | Mean % |
|---|---|---|---|---|
| 1 | Physical | 76 | 45.27 ± 7.86 | 59.56 |
| 2 | Psychological | 40 | 24.69 ± 4.84 | 61.7% |
| 3 | Social | 28 | 16.47 ± 3.31 | 58.82 |
| 4 | Financial | 20 | 5.97 ± 1.87 | 29.95 |
| 5 | Environmental | 76 | 40.87 ± 5.63 | 53.77 |
| 6 | Total | 240 | 133.27 ± 18.17 | 55.52 |

The study also demonstrated that there was no association between demographic variable with quality of life; however, sex of mentally retarded child and duration of illness since diagnosis was associated with quality of life ($p<0.05$) (table 7 and 8).

Table 7: Association between quality of life with socio demographic variables of parents

| SN | Variables (Parents) | Chi square | Level of significance |
|---|---|---|---|
| 1 | Age | 0.103 | Not significant |
| 2 | Sex | 0.905 | Not significant |
| 3 | Education | 3.362 | Not significant |
| 4 | Occupation | 0.014 | Not significant |
| 5 | Marital status | 1.231 | Not significant |
| 6 | Monthly Income | 1.016 | Not significant |
| 7 | Type of delivery | 0.011 | Not significant |
| 8 | Term of delivery | 0.598 | Not significant |

Table 8: Association between quality of life and socio demographic variables of mentally retarded child

| SN | Variables | Chi square | Level of significance |
|---|---|---|---|
| 1 | Age of MR child | 0.167 | Not significant |
| 2 | Sex of MR child | 4.358 | Significant |
| 3 | Grade of mental retardation | 0.692 | Not significant |
| 4 | Duration of illness (since diagnosed) | 6.822 | Significant |
| 5 | Co-morbid illness | 1.687 | Not significant |

The calculated co-efficient of co-relation test value revealed that relationship between mild mental retardation and severe mental retardation shows negative co-relation (r= -0.18, r= -0.06) and moderate mental retardation shows positive co-relation (r= 0.06) with quality of life of parents. Hence the stated assumption, different grades of mental retardation may influence the quality of life (QOL) of parents, is accepted.

**4. Discussion**

The study revealed that the parents of children with mental retardation having poor quality of life in financial aspect (5.97± 1.87) (29.95%) and average quality of life in physical (45.27± 7.86) (59.56%), psychological (24.69± 4.84) (61.72%), social (16.47± 3.31) (58.82%) and environmental aspect (40.87± 5.63) (53.7%). Chi square test showed that there was no significance association between quality of life and demographic variables. However significant association was found between socio demographic variables of mental retardation children with quality of life of parent such as sex of mental retardation child and duration of illness since diagnosed.

In present study, highest percentage (56%) of parents were in the age group of 36 to 45 years and (43%) of parents were 26 to 35 years. The finding supported by Mungo *et al* reported that average age of parents of mental retarded children was (40± 13.5) (20 to 38 years) in their study. [9] Majority (78%) parents were females, data consistent with Chaturvedi reported that majority (91%) subjects were predominantly female. Majority (93%) of subjects had normal delivery. [10] It is also consistent with the study done by Singh et al also observed that (75%) samples had normal delivery. [11] Most (89%) parents had full term delivery (4%) had pre term delivery (7%) had post term delivery. It has been supported findings by Ramey et al also found that (85%) samples were full term delivery, (6%) samples were pre term delivery and (9%) samples post term delivery. [12]

Majority (37%) were severely mentally retarded children, (35%) moderately mentally retarded (27%) mild and (1%) were found to be profound mentally retarded children. It is contradictory with the study done by Koirala *et al* reported that (35%) mild, (27%), moderate, (12%) severe and (8%) profound mental retarded children. [13] Majority of the mentally retarded children observed in the duration of illness of more than 7 years were (50%), which is consistent with the study reported that duration of illness from 6 to 10 years were (50%). [13] Majority (28%) mental retarded children suffering from epilepsy (Fig no 12), It is similar with the study done by Arshad *et al* also observed that (33%) of mental retarded children suffering from epilepsy. [14] Assessment of quality of life of parents of children with mental retardation showed average quality of life in physical (45.27± 7.86). It is similar with the study done by Shahzadi et al reported impairment in domains of quality of life in physical (46.67± 12.44) aspects. [15]

The relationship between severe mental retardation and quality of life of parents of mental retardation shows negative co-relation (r= -0.06), It is similar with the study done by Yatsugi et al reported negative relationship (r= -0.30) between severe intellectual disability with quality of life. [16]

**Conclusion**

The study concluded that the parents of children with mental retardation had average quality of life in physical, psychological, social and environmental aspects and poor quality of life in financial aspect. This emphasizes parents of children with mental retardation face financial burden and also diminished quality of life in social aspect. Thereby health care professional especially nurses must focus on improving the quality of life and their survival.

**Implications of the study**

**Nursing Practice**

Findings of this study will help the nursing professional working in mental health services, rehabilitation centers, hospitals and community for reinforcing their knowledge as nurses plays a major role in caring the mental retarded children so nurses can give more emphasis on prevention of mental illness and provide rehabilitation services. Nurses can give more emphasis on counseling services to parents regarding stress management, improving coping strategies etc. These findings will also help the nursing professionals to plan the nursing care, supportive services, and problem solving skills and help nurse practitioners to develop insight in to the importance of quality of life of parents of children with mental retardation in their clinical practice in maintaining the health of the society.

**Nursing education**

Nursing personals can deduct the causes of mental retardation and take necessary actions prior to prepare modules or educational material to educate the parents with mental retardation regarding promotion of health, prevention of illness. Nurse educator should educate the student nurses and other health care workers to improve the knowledge and create awareness regarding mental retardation. Community psychiatry nurse should do surveys in the rural areas to find out the cases of mental illness and provide appropriate services for them. Awareness programs should be conducted in the community regarding prevention of mental illness, services available for mentally ill client,

rehabilitation services. The study findings explain the importance of quality of life of parents of children with mental retardation more theoretical and practical aspect of quality of life should be included in the curriculum.

**Nursing Research**

The study focuses on evaluating quality of life of parents of children with mental retardation. These findings help the nurse researcher to develop conceptual framework, carry out research activities on various aspects of quality of life of parents of children with mental retardation. Long term research with intervention also can be done in future.

**Recommendations**

On the basis of findings of the present study recommends the following: conduct of studies in large subjects and in different settings with various areas of quality of life. Experimental studies can also be conducted to assess the effects of counseling on quality of life of parents of children with mental retardation. In future, studies can be conducted to find out the effectiveness of nursing interventions of specific symptoms to improve the quality of life.

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