Mental retardation (MR) is one of the most prevalent developmental disabilities.[1] Family is the main source of support for the persons with disabilities in any society. Those who are closest to the persons with MR and care for them bear the brunt of their disability.[2-4] Caregivers experience enormous physical and emotional burden while caring for such relatives. In a country like India where care provided for MR is mainly home based and alternate support systems such as day-care centers, weekend care, and special schools are meager, the impact of care on caregivers can be enormous.[5,7]

Similarly, in early-onset psychosis (EOP), a nonspecific symptomatic disorder with onset in adolescent age, patients as well as their caregivers are often devastated by this illness, and this is equally taxing to the caregivers but has not received much attention.

Both MR and EOP are developed in the same age group, i.e., before the age of 18 years, affect normal development of child, have chronic course, and require long-term extraordinary care by their caregivers. Despite the increasing interest in understanding the quality of life (QOL) among caregivers, research in this area has been mainly restricted to schizophrenia. The problems associated with rearing of such children can be multifold, and problems such as disturbance of routine, family leisure, family health, work absenteeism, and physical and emotional stress can have a negative impact on quality of life (QOL).

Context: In India, patients with mental illness and mental retardation (MR) are cared by their families. In caregiving, problems such as disturbance of routine, family leisure, family health, and emotional stress can have a negative impact on quality of life (QOL). Aims: The purpose of this study is to assess and compare the QOL of the caregivers of children of early-onset psychosis (EOP) with caregivers of MR children and also to find out the correlation between sociodemographic variables and QOL. Settings and Design: A prospective study was carried out in the outpatient and inpatient unit of a tertiary care center teaching hospital of North India. Materials and Methods: Thirty caregivers each of two groups, i.e., children with EOP and mentally retardation, between the ages of 13 and 18 years with minimum 1 year of illness and fulfilling the inclusion and exclusion criteria, were compared with a well-matched control group. QOL was assessed using the World Health Organization QOL-BREF (Hindi version). Statistical analysis was done using SPSS (version 16.0). Results: QOL was significantly affected in most of its dimensions in the caregivers of both EOP and MR groups in comparison to the control group but more deterioration was noted in caregivers of children with MR. Sociodemographic factors such as domicile, education, family type, and family size were important determinants of QOL. Conclusion: Multiple factors seem to be responsible for poor QOL of caregivers of children with MR and EOP.

Keywords: Early-onset psychosis, mental retardation, quality of life

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stress not only result in increased economic costs, but also have a negative impact on the QOL of caregiver.[8,9] Thus, it is important that the QOL is needed to be adequately researched and studied in the caregivers of children with MR and EOP. This will ensure the sensitivity while dealing comprehensively with not only children suffering from MR or EOP, but also the sufferings of caregivers.

Thus, this study was planned to assess and compare QOL of caregivers of EOP with caregivers of children with MR and also to study the correlation between sociodemographic variables and QOL. To the best of our knowledge and review of the current Indian literature, no study has yet compared the QOL of the caregivers of children with MR and EOP.

**SUBJECTS AND METHODS**

This study was conducted in the outpatient and inpatient unit of a tertiary care center teaching hospital of North India. Institute's Ethical Committee’s approval and written informed consent from the participants were obtained. The study comprised of three groups – thirty caregivers of children with MR and thirty caregivers of children with EOP, where the primary caregiver was identified as an adult relative living with the patient in the same environment for at least 1 year and was involved directly in giving care and felt responsible for the care of the patient. The third group comprised of thirty healthy individuals not directly involved in the caregiving of the patient. The inclusion criteria for the participants were children of either sex, aged between 13–18 years. Diagnosis of EOP and MR was made as per WHO ICD 10 criteria and same was confirmed by consultant Psychiatrist. For EOP group those who had psychotic illness for at least 1 year of duration and for MR group those who were diagnosed at least 1 year before the study were included in the study. Caregivers of children with comorbid MR and any other psychotic illness or comorbid major medical or surgical illness or substance abuse were not included in the study. Caregivers who were illiterate, who were suffering from any major psychiatric, medical, and/or surgical illness; and who had family history of MR, major mental illness, or incapacitating medical/surgical illness in more than one family member were also excluded.

**Instruments**

A specially designed pro forma was used for the patients and their caregivers that included sociodemographic data sheet and clinical profile sheet (for patients only). To assess the QOL of the caregivers, the World Health Organization (WHO)-QOL BREF Hindi version was used. In order to carry out QOL evaluation, the WHO QOL Group was created and a collaborative multicentric research project was developed, resulting in the WHO QOL-100. Based on this tool, the WHOQOL-BREF was developed, containing 26 questions. Hindi version of the WHOQOL-BREF was developed by Saxena et al.[10] and had also been used in Indian settings.[11,12] Its primary aim is to assess one's subjective perception of his or her QOL. The scale consists of 26 items, which uses a Likert-type 5-point scale. These items are distributed in four domains including (a) physical health, (b) psychological health, (c) social relationships, and (d) environmental health. There are also two items that are examined separately: one which asked about the individual's overall perception of QOL and the other which asked about the individual's overall perception of his or her health. Domain scores are scaled in a positive direction (higher scores denote higher QOL). The scale produces four domain scores that correlate at around 0.9 with the WHO-QOL 100 domain scores. The transformed score is calculated as follows:

\[
\text{Transformed score} = \left( \frac{\text{actual raw domain score} - \text{lowest possible raw domain score}}{\text{possible raw domain score range}} \right) \times 100.
\]

Where more than 20% data were missing from an assessment, the assessment was discarded. In addition, where up to two items were missing from a domain, the domain scores were not calculated with the exception of social relationship domain, where the domain was not calculated even if one item is missing.[10]

All the participants in the group were randomly recruited and selected using the exclusion and inclusion criteria laid down for the purpose of this study. All participants were explained about the study and proper written informed consent was taken. The participants in the three groups were well matched. The patients were evaluated and the QOL scale was applied by a qualified psychiatrist in a single sitting. Statistical analysis was done using SPSS version 16.0 for Windows (Chicago, Illinois, USA).

**RESULTS**

The mean age of caregivers was 42.8 years. The female-to-male ratio was 1:1.4. All the respondents were married; majority of them were Hindus, belonged to nuclear family, were educated up to secondary level, lived in the urban area, and were farmers/skilled or unskilled workers/laborers. Their family income ranged from Rs. 1500 to Rs. 25,000 per month, with majority of them falling in the category of <Rs. 5000. There was no
significant difference among the study groups with respect to various sociodemographic variables including age, religion, family type, education, domicile, occupation, and family income [Table 1].

In our study, caregivers had significant poor QOL in all the domains, i.e., physical health, psychological health, social relationship, environmental health, and total QOL as compared to healthy controls. On comparing QOL of caregivers of mentally retarded children and EOP patients, those of MR were found to have poorer QOL in all domains [Table 2].

A statistically significant correlation was found between QOL domains and domicile, education level of the caregiver, family size, and family type. It was observed that caregivers who were living in rural area (all domains), were better educated (all domains), and belonged to joint family (psychological and environment domains) with more number of family members (physical domain) had better QOL [Table 3].

**DISCUSSION**

In our study, caregivers of EOP and MR children had significant poor QOL in all the domains, i.e., physical health, psychological health, social relationship, environmental health, and total QOL as compared to healthy controls. On comparing QOL of caregivers of mentally retarded children and EOP patients, those of MR were found to have poorer QOL in all domains. This difference cannot be attributed to sociodemographic factors as both groups were comparable. Possibly, longer duration of illness and treatment led to the difference in QOL among the caregivers of children with MR.

Our results as well as previous evidence also suggests that continued physical, emotional, and economic burden affects caregivers life negatively.[13–17] Earlier, the focus of QOL research has been restricted to the relatives of adult patients with schizophrenia[18,19]; little attention has been paid to the caregivers of children with EOP. Extensive research work

**Table 1: Sociodemographic profile of caregivers (n=60)**

| Variables                        | n (%) |
|----------------------------------|-------|
| Age (years)                      |       |
| <35                              | 8 (13.3) |
| 36-40                            | 15 (25.0) |
| 41-45                            | 13 (21.7) |
| 46-50                            | 20 (33.3) |
| 51-55                            | 4 (6.7) |
| Mean age (years)±SD              | 42.88±6.31 |
| Relation                         |       |
| Mother                           | 25 (41.7) |
| Father                           | 30 (50.0) |
| Others (all male members)        | 5 (8.3) |
| Religion                         |       |
| Hindu                            | 43 (68.3) |
| Muslim                           | 19 (31.7) |
| Education                        |       |
| Primary                          | 13 (21.7) |
| Middle                           | 9 (15.0) |
| Secondary and senior secondary   | 31 (51.7) |
| Graduate and above               | 7 (11.6) |
| Domicile                         |       |
| Urban                            | 35 (58.3) |
| Rural                            | 25 (41.7) |
| Marital status                   |       |
| Married                          | 60 (100) |
| Unmarried                        | 0 |
| Family size                      |       |
| <5                               | 28 (46.7) |
| 5-10                             | 28 (46.7) |
| >10                              | 4 (6.7) |
| Family type                      |       |
| Nuclear                          | 37 (61.7) |
| Extended nuclear                 | 5 (8.3) |
| Joint                            | 18 (30.0) |
| Occupation                       |       |
| Service                          | 16 (26.7) |
| Homemaker                       | 14 (23.3) |
| Farmer/skilled/unskilled worker/labor | 18 (30.0) |
| Businessperson                   | 12 (20.0) |
| Monthly family income (Rs.)      |       |
| <5000                           | 27 (45.0) |
| 5001-15,000                     | 16 (26.7) |
| 15,001-25,000                   | 17 (28.4) |

**Table 2: Mean quality-of-life scores of caregivers of mental retardation, early-onset psychosis, and control groups**

| QOL domain          | Variables | n  | Mean±SD | SEM |
|---------------------|-----------|----|---------|-----|
| Physical health     | MR        | 30 | 36.10±5.85 | 1.06 |
|                     | EOP       | 30 | 47.07±12.70 | 2.31 |
|                     | Control   | 30 | 60.53±10.53 | 1.92 |
| Psychological health| MR        | 30 | 44.10±8.82 | 1.62 |
|                     | EOP       | 30 | 50.27±7.07 | 1.29 |
|                     | Control   | 30 | 61.27±7.11 | 1.40 |
| Social relationship | MR        | 30 | 41.67±11.16 | 2.03 |
|                     | EOP       | 30 | 48.77±16.68 | 3.04 |
|                     | Control   | 30 | 74.43±15.28 | 2.79 |
| Environmental health| MR        | 30 | 42.73±12.87 | 2.35 |
|                     | EOP       | 30 | 51.02±11.10 | 2.02 |
|                     | Control   | 30 | 69.42±10.96 | 2.00 |
| Total QOL           | MR        | 30 | 40.43±7.67 | 1.40 |
|                     | EOP       | 30 | 49.03±5.58 | 1.74 |
|                     | Control   | 30 | 66.70±6.66 | 1.21 |

MR – Mental retardation; EOP – Early-onset psychosis; QOL – Quality of life; SEM – Standard error of mean; SD – Standard deviation
also highlights that caregivers of children and adolescents with MR seem to display a lower QOL than the general population, probably from a combination of stress, health, and household income factors.[12,13,15,20]

Unlike other reports, our study had predominantly males as the main caregiver in most of the patients. Previously, studies have shown the mother, i.e., the female, as the main caregiver of the patient and thus females have poorer QOL in comparison to other family members.[21] Better education level of the caregiver was a protective factor in our study and was found to be positively correlated with the QOL, which is similar to previous studies.[22] However, some studies could not establish a similar correlation between education level and QOL.[23] Socioeconomic status appears to be inversely related to the QOL of the caregivers as reported previously.[19,23] Lower socioeconomic status along with the continued economic burden could explain the correlation. According to a study, the strongest predictors of caregivers’ QOL were the caregiver’s family income along with other factors such as the caregivers’ health.[24] Like previous studies,[16,17] we observed better QOL in caregivers who had good social support (i.e., belonging to joint family, having more family members and were from rural background) compared to those having poor levels of perceived social support.

The results of the current study should be interpreted in the background of certain limitations, which may have affected the observations: first, the study is exclusively hospital based with a small sample size. Second, factors related to caregivers such as duration of caregiving, comorbid physical illness, substance abuse in caregivers, and traits such as neuroticism that influence the perception of the caregivers were not taken into account.

**CONCLUSION**

Living with and caring for a child with MR and psychosis is stressful and negatively affects QOL. Multiple sociodemographic variables influence the QOL of these caregivers.

The authors propose that respite care, psychoeducation, and skills’ training to the caregivers can help them to deal effectively with children with MR and EOP. More studies need to be planned in the future that will help policymakers to carefully consider the position of caregivers while designing and implementing support measures.

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**Conflicts of interest**

There are no conflicts of interest.

**REFERENCES**

1. Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena S. Prevalence of intellectual disability: A meta-analysis of population-based studies. Res Dev Disabil 2011;32:419-36.
2. Seshadari M. Impact of the mentally handicapped on the family. Indian J Clin Psychol 1983;10:473-8.
3. Tunali B, Power TG. Creating satisfaction: A psychological perspective on stress and coping in families of handicapped children. J Child Psychol Psychiatry 1993;34:945-57.
4. Wishart MC, Bidder RT, Gray OP. Parents’ report of family life with a developmentally delayed child. Child Care Health Dev 1981;7:267-79.
5. Girimaji SC, Sinirth S, Seshadri S, Krishna D. Family interview for stress and coping in mental retardation (FISC-MR): A tool to study stress and coping in families of children with mental retardation. Indian J Psychiatry 1999;41:341-9.
6. Kumar I, Akhtar S. Rate of anxiety in mothers of mentally retarded children. Indian J Psychiatry 2001;43:27-30.
7. Blacher J, Shapiro J, Lopez S, Diaz L, Fusco J. Depression in Latin mothers of children with mental retardation: A neglected concern. Am J Mental Retard 1997;101:483-96.
8. Chauverdey SK, Malhotra S. A follow up study of mental retardation focusing on parental attitudes. Indian J Psychiatry 1984;26:370-6.
9. Rastogi CK. Attitude of parents towards their mentally retarded children. Indian J Psychiatry 1981;23:206-9.
10. Saxena S, Chandiramani K, Bhargava R, WHOQOL-Hindi: A questionnaire for assessing quality of life in health care settings in India. World Health organization quality of life. Natl Med J India 1998;11:160-5.
11. Purkayastha M, Chavan BS, Kumar S. Quality of life in caregivers of persons with mental retardation and chronic schizophrenia: A comparative study. J Ment Health Hum Behav 2012;17:53-9.
12. Navnit K, Santosha C, Priya DJ. Quality of life of parents of individual with autism, cerebral palsy and mental retardation in India. Indian J Health Wellbeing 2013;4:765-71.
13. Rimmerman A, Duvdevani I. Parents of children and adolescents with severe mental retardation: Stress, family resources, normalization, and their application for out-of-home placement. Res Dev Disabil 1996;17:487-94.
14. Yarrow M, Schwart C, Murphy H, Deasy L. The psychological meaning of mental illness in the family J Soc Issues 1955;11:12-24.
15. Lin JD, Hu J, Yen CF, Hsu SW, Lin LP, Loh CH, et al. Quality of life in caregivers of children and adolescents with intellectual disabilities: Use of WHOQOL-BREF survey. Res Dev Disabil 2009;30:1448-58.
16. Avasthi A. Preserve and strengthen family to promote mental health. Indian J Psychiatry 2010;52:113-26.
17. Sethi BB, Manchanda R. Socioeconomic, demographic and cultural correlates of psychiatric disorders with special reference to India. Indian J Psychiatry 1978;20:199-211.
18. Jungbauer J, Angermeyer MC. Living with a schizophrenic patient: A comparative study of burden as it affects parents and spouses. Psychiatry 2002;65:110-23.
19. Kuipers L. Family burden in schizophrenia: Implications for services. Soc Psychiatry Psychiatr Epidemiol 1993;28:207-10.
20. Chou YC, Lin LC, Chang AL, Schalock RL. The quality of life of family caregivers of adults with intellectual disabilities in Taiwan. J Appl Res Intellect Disabil 2007;20:200-10.
21. Tsai SM, Wang HH. The relationship between caregiver’s strain and social support among mothers with intellectually disabled children. J Clin Nurs 2009;18:539-48.
22. Beckman PJ. Influence of selected child characteristics on stress in families of handicapped infants. Am J Ment Defic 1983;88:150-6.
23. Ohaeri JU. Caregiver burden and psychotic patients’ perception of social support in a Nigerian setting. Soc Psychiatry Psychiatr Epidemiol 2001;36:86-93.
24. Roick C, Heider D, Bebbington PE, Angermeyer MC, Azorin JM, Brugha TS, et al. Burden on caregivers of people with schizophrenia: Comparison between Germany and Britain. Br J Psychiatry 2007;190:333-8.