

# Quality of life of caregivers of children with psychiatric illnesses: a comparative study in a tertiary care hospital, Kolkata



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## ABSTRACT

**Background:** Childhood psychiatric morbidity is a serious issue in middle- and low-income countries. With the increasing prevalence of mental disorders among children, the role of caregivers has become vital. As a result of caregiving, caregivers experience financial difficulties, a reduction in social contact, emotional distress, and poor mental and physical health, which may lead to a low quality of life (QOL) among them. **Aims and Objectives:** This study aims to explore the QOL of caregivers attending the psychiatry OPD of a tertiary healthcare facility for their child's treatment and to compare it with that of caregivers of children without psychiatric problems. **Materials and Methods:** A cross-sectional observational-analytical study was conducted at a tertiary care center in Kolkata. The sample size was estimated to be 75 for each group. The WHOQOL-BREF questionnaire was used for the data collection. The data were analysed using IBM SPSS version 16. Mann Whitney U test was done to compare the scores between caregiver groups. **Results:** The QOL scores of caregivers of children with psychiatric illnesses in different domains were physical health ( $11.69 \pm 1.74$ ), psychological ( $9.78 \pm 2.72$ ), social relationships ( $11.12 \pm 2.86$ ), and environmental ( $11.66 \pm 2.13$ ). The overall QOL of caregivers attending psychiatry outpatient departments was found to be significantly affected as compared to caregivers of children without psychiatric illnesses, except for the environment domain. **Conclusion:** In this study, the most affected QOL domain in the case of caregivers of children attending psychiatry OPD was the psychological domain, followed by the social relationship domain. This finding highlighted the need for socio-psychological support and a better environment for improving QOL.

**Key words:** Quality of life; Caregivers; Psychiatry; Children

## INTRODUCTION

Psychiatric illnesses comprise a broad range of problems characterized by different symptoms such as abnormal thoughts, emotions, behavior, and relationships with others. One of the growing challenges nowadays to health-care systems around the globe is childhood psychiatric illness, which has been predicted to gradually increase with the increase in the population of children around the globe.<sup>1</sup> According to WHO factsheets on childhood

and adolescent mental health, presently, about 10–20% of children and adolescents experience mental disorders. Childhood psychiatric morbidity is a serious issue in middle- and low-income countries. Around 35–50% of the population in low- and middle-income countries are children and adolescents.<sup>2</sup> With recent changes both in the treatment of psychiatric illness as well as the delivery of psychiatric services, a shift has occurred from hospital-centered care to community-based services.<sup>3</sup> Nowadays, psychiatric patients receive relatively short inpatient care

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and early discharge from the hospital.<sup>4</sup> With the increasing prevalence of mental disorders among children, the role of caregivers has become very vital.

A caregiver is defined as the parent (either mother or father) or other family members (grandmother or grandfather, siblings, aunt or uncle, and adoptive parent) of the disabled child who are responsible for parenting or caring for the disabled child. A caregiver provides practical, day-to-day, unpaid support for a person unable to complete all the tasks of daily living.<sup>5</sup> As a result of caregiving, caregivers experience financial difficulties, a reduction in social contact, emotional distress, and poor mental and physical health, which may lead to lower life satisfaction and a low quality of life (QOL) among them.

QOL is a multi-dimensional concept that includes physical and mental health, relationships, and personal beliefs and values in relation to the environment. QOL is defined by WHO as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concern.”<sup>6</sup> Maintenance of the caregiver’s health is important for the caregiver’s own life as well as its possible impact on the child’s health. In India, the majority of psychiatric patients stay with their families. This is beneficial for the patients, as hospital services cannot replace a family environment, but on the other hand, caregivers face immense physical, social, emotional, and financial burden.<sup>7</sup> The contrast between the imagined caregiving experience of raising a typically developing child and the reality of caring for a child with a psychiatric disorder may lead to intense disappointment and an increasing caregiver burden.<sup>8</sup> Many studies have been done on the QOL of mentally ill patients and on the QOL of caregivers of adult mentally ill patients. However, till date, very few studies have been done to explore the QOL of caregivers of children with psychiatric problems in India, particularly in West Bengal.

### Aims and objectives

This study aims to explore the QOL of caregivers attending the psychiatry OPD of a tertiary healthcare facility for their child’s treatment and to compare it with that of caregivers of children without psychiatric problems.

## MATERIALS AND METHODS

This was an observational, analytical, study cross-sectional in design conducted at the child guidance clinic of the department of psychiatry and the OPD of the department of pediatrics of a tertiary care center in Kolkata, West Bengal. The study population comprised caregivers

of children with psychiatric disorders attending the psychiatry OPD and caregivers of children attending the pediatrics OPD of that tertiary care center during the data collection period of 6 months. The participating caregivers were children’s family members, providing care for them for at least 1 year before data collection without any employment agreement or compensation. Caregivers of children aged 1–11 years and 11 months were included in the study.

### Exclusion criteria

(a) Caregivers with ages <18 years (b) Unwilling to participate (c) Caregivers having diagnosed psychiatric morbidity (d) In the case of caregivers of children attending pediatrics OPD, where the child has been suffering from any illness for more than fourteen days, e) the child had a serious ailment.

Based on a study conducted by Malhotra et al.,<sup>9</sup> on the QOL of parents having children with developmental disabilities assessed by WHOQOLBREF and considering the groups to be of equal number of participants, at a power of 80%, considering the difference in group means to be 9, the sample size was estimated to be 75 for each group at a confidence level of 99% ( $Z=2.576$ ).

### Sampling technique

One study group was taken from caregivers of children attending the pediatric OPD within the data collection period (group 1). Another study group was taken from caregivers of children with psychiatric disorders attending psychiatry OPD (group 2). If caregivers denied consent, the next person was immediately interviewed.

### Tools of data collection

The WHOQOL-BREF questionnaire was used for the data collection. The study tool was developed by WHO and later translated and validated by WHO for use by Bengali-speaking population. Another schedule was used for sociodemographic parameters like sex, age, literacy status, monthly income of the family, occupation, and marital status.

The World Health Organization (WHO), with the help of 40 collaborating centers around the world, has developed two instruments for measuring QOL (the WHOQOL100 and the WHOQOL-BREF), that can be used in a variety of cultural settings while allowing the results from different populations and countries to be compared. The WHOQOL-BREF contains two individually scored items about an individual’s overall perception of QOL and general health (Q1 and Q2). WHOQOL-BREF has four domains of QOL: physical,

psychological, social relationships, and environment. The four domain scores are scaled in a positive direction, with higher scores denoting higher QOL. The items are scaled in a positive direction, with a score range of 1–5, with higher scores denoting higher QOL except for three items, which should be reversed before scoring. The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. The first transformation method converts scores to a range between 4 and 20, comparable with the WHOQOL-100. The next step involves transforming each raw score to a 0–100 scale. This transformation converts the lowest and highest possible scores to zero and a hundred. The WHOQOL scoring programs have used this transformation to provide comparative data for interpretation.

Considering the busy OPD setup, as well as a convenience of caregivers, interview technique was used, and the questions were read out to them in the language they were convenient with. Prescriptions were reviewed only for the purpose of knowing the child's diagnosis. In the case of more than one diagnosis, the most important one was noted as per discussion with the treating doctor. After data collection, the data were entered into Microsoft Excel and analyzed using SPSS version 16.

Descriptive statistics were expressed in terms of frequency, percentage for categorical data, mean along with standard deviation for normally distributed data, median with interquartile range for non-normally distributed data, and were presented using tables and figures. Appropriate statistical tests were applied as and where required. Data entry was done in Microsoft Excel 2007, and statistical analysis was done in IBM SPSS version 16. Ethical clearance was taken from the institutional ethics committee. This study was completely academic in nature and was done after getting consent from the study participants. All the data provided by the participants were kept confidential.

## RESULTS

The average age of children belonging to caregivers attending pediatrics outpatient departments was  $8.49 \pm 2.20$  years, and those children of caregivers attending psychiatry outpatient departments was  $8.41 \pm 2.33$  years. The average income of caregivers in two groups was Rs.  $13333.33 \pm 4852.78$  and Rs.  $16733.33 \pm 7859.12$ . Table 1 shows the sociodemographic distribution of study participants belonging to two groups: Group 1 represents caregivers of children attending

pediatric OPD, and Group 2 represents caregivers of children with psychiatric morbidities attending psychiatric OPD.

Most of the participants, 56.0% of caregivers attending the pediatrics outpatient department and 70.7% of caregivers attending the psychiatry outpatient department were homemakers. Of caregivers in group 1, 21.3% and 13.3% were into service and business, respectively, whereas only 2.7% were teachers and 6.7% were maids. While among caregivers in group 2, 9.3% and 6.7% were into service and business, respectively. Other occupations that caregivers in group 2 had teachers (4.0%), maids (8.0%), and nursing staff (1.3%).

21.3% of caregivers in group 1 and 30.7% of caregivers in group 2 had health problems. It was found that 12% of the caregivers in group 1 were suffering from joint pain, followed by hypertension (9.3%), hypothyroidism (9.3%), diabetes mellitus (8%), menstrual problems, and migraine. Among caregivers in group 2, 9.3% had joint pain, 9.3% had hypertension, 8.0% were suffered from hypothyroidism, and 8.0% had diabetes mellitus. Among the different childhood psychiatric illnesses, the most frequent psychiatric morbidity that was encountered was that of childhood depressive episodes (26.7%), followed by attention deficit hyperkinetic disorder (22.6%). Table 2 shows the distribution of caregivers of children according to the predominant psychiatric morbidity of the child.

Table 3 shows the mean scores of study participants belonging to groups 1 and 2 in domain-specific questions of the WHO QOL-BREF. Observations on scores obtained by caregivers of both groups against items from all domains, except the physical health domain of caregivers belonging to Group 1, did not follow a normal distribution pattern ( $P \leq 0.05$ ). Hence, Mann Whitney U test was applied for comparing averages between two groups across each domain. Table 4 shows the comparison of QOL scores between groups 1 and 2 across different domains.

## DISCUSSION

The study was conducted in a hospital setting. It was observed that most of the caregivers were female (70.7% in group 1 and 89.3% in group 2). A similar observation was made in a study conducted by Daltro et al.,<sup>10</sup> in Brazil on the QOL of caregivers of children with mental disorders, where it was observed that 93.8% of caregivers were female. The mean ages of participants in our study in the two groups were  $34.45 \pm 4.52$  and  $35.60 \pm 4$ . As regards the

**Table 1: Sociodemographic distribution of study participants**

Variables	Group 1 n1=75 No. (%)	Group 2 n2=75 No. (%)	Total n=150
Sex			
Female	53 (70.7)	67 (89.3)	120 (80.0)
Male	22 (29.3)	8 (10.7)	30 (20.0)
Age			
≤30	10 (13.3)	6 (8.0)	16 (10.7)
>30–≤35	40 (53.3)	35 (46.7)	75 (50.0)
>35	25 (33.4)	34 (45.3)	59 (39.3)
Education			
Illiterate	4 (5.3)	4 (5.3)	8 (5.3)
Primary school	20 (26.7)	16 (21.4)	36 (24.0)
Secondary school and above	51 (68.0)	55 (73.3)	106 (70.7)
Income			
≤10000	25 (33.3)	20 (26.7)	45 (30.0)
>10000–≤20000	46 (61.4)	40 (53.3)	86 (57.3)
>20000–≤30000	4 (5.3)	11 (14.7)	15 (10.0)
>30000	0 (0.0)	4 (5.3)	4 (2.7)
Marital status			
Married	72 (96.0)	70 (93.3)	142 (94.7)
Widowed	2 (2.7)	3 (4.0)	5 (3.3)
Separated	1 (1.3)	2 (2.7)	3 (2.0)
Relationship with the child			
Mother	51 (68.0)	66 (88.0)	117 (78.0)
Father	22 (29.3)	8 (10.7)	30 (20.0)
Grandmother	2 (2.7)	1 (1.3)	3 (2.0)
Other family members requiring care			
Yes	27 (36.0)	33 (44.0)	60 (40.0)
No	48 (64.0)	42 (56.0)	90 (60.0)
Caregivers having pre-existing physical morbidity			
Yes	16 (21.3)	23 (30.7)	39 (26.0)
No	59 (78.7)	52 (69.3)	111 (74.0)
Received help with child care			
Yes	59 (78.7)	54 (72.0)	113 (75.3)
No	16 (21.3)	21 (28.0)	37 (24.7)

**Table 2: Distribution of caregivers of children attending psychiatry outpatient department according to the predominant psychiatric morbidity of the child**

Psychiatric morbidities	Frequency No.	Percentage
Childhood depressive episode	20	26.7
ADHD	17	22.6
Mental retardation	14	18.7
Behavioural problems	9	12.0
ASD	5	6.7
Anxiety disorder	4	5.3
Oppositional defiant disorder	3	4.0
Epilepsy	2	2.7
Conversion disorder	1	1.3
Total	75	100.0

ADHD: Attention deficit hyperkinetic disorder, ASD: Autism spectrum disorder

age of the caregivers of children participating in various studies, it was observed that the median age was 38.92 years in a study by Daltro et al. among caregivers of children in Brazil.<sup>10</sup> In another study, on QOL of caregivers of children with intellectual disabilities, the average age of caregivers was 43.6±8.57 years.<sup>11</sup> The average age of children belonging to caregivers attending pediatrics outpatient

departments was 8.49±2.20 years, and those children of caregivers attending psychiatry outpatient departments was 8.41±2.33 years. In the study by Daltro et al. in Brazil, the average age of children and adolescents participating in the study was 10.6±3.7 years.<sup>10</sup> It has been found in many literatures that caregivers with higher educational status have better QOL.<sup>12</sup> This might be because of better knowledge about their relative's psychiatric illness and better coping strategies. 68.0% of caregivers attending pediatric outpatient departments and 73.3% of caregivers of children attending psychiatry outpatient departments had a literacy status of secondary school or above. In this study, the monthly family income of caregivers of children with psychiatric morbidities was found to be better in comparison with the other group. Evidence shows that paid work is an important factor that can alleviate the suffering of individuals to a great extent.<sup>13</sup> The fact that caregivers with an active professional life have more time for social activities and spend less time with the mentally ill has a positive effect on their QOL.<sup>14</sup> Jeyagurunathan et al.,<sup>15</sup> also found that caregivers who were employed reported better QOL. Most of the study participants were presently



**Table 3: Mean scores of study participants of Group 1 and Group 2 in domain specific questions of WHO QOL-BREF**

Domains	Groups	Mean±SD (4–20 scale)	Mean±SD (0–100 scale)
Overall QOL and General health questions	Group 1	12.53±2.718	53.33±16.99
	Group 2	10.88±3.123	43.00±19.52
Physical health domain	Group 1	13.34±2.419	58.38±15.12
	Group 2	11.69±1.738	48.09±10.86
Psychological domain	Group 1	12.17±2.608	51.11±16.30
	Group 2	9.78±2.724	36.17±17.03
Social relationship domain	Group 1	12.83±2.655	55.22±16.60
	Group 2	11.12±2.862	44.56±17.89
Environmental domain	Group 1	12.05±2.338	50.33±14.62
	Group 2	11.67±2.129	47.92±13.31

**Table 4: Comparison of quality-of-life score across among two groups**

Domains	Groups	Mean score	Mann Whitney U value	P*
Overall QOL and general health questions	Group 1	12.53±2.718	1949.500	0.001
	Group 2	10.88±3.123		
Physical health domain	Group 1	13.34±2.419	1642.500	0.000
	Group 2	11.69±1.738		
Psychological domain	Group 1	12.17±2.608	1461.000	0.000
	Group 2	9.78±2.724		
Social relationship domain	Group 1	12.83±2.655	1866.000	0.000
	Group 2	11.12±2.862		
Environmental domain	Group 1	12.05±2.338	2624.500	0.478
	Group 2	11.67±2.129		

married (96% of group 1 and 93.3% of group 2). Parental educational level and marital status have been found to be significantly related to health and QOL outcomes in various literatures. Divorced or widowed mothers had higher parenting stress and lower QOL and family functioning compared to married mothers.<sup>16</sup> High educational levels and living with a partner were correlated with better QOL indirectly via emotional support and holidays.<sup>17</sup> In this study, 78.7% of caregivers of children attending pediatrics outpatient departments and 72.0% of caregivers of children attending psychiatry outpatient departments reported to have received help from other family members in rendering care to the diseased child, which is quite a good finding as this may alleviate the caregiver's burden to some extent and may have some positive effects on their QOL. Again the presence of other family members at home who require care, like old, debilitated, or paralyzed people who cannot take care of themselves, may sometimes add up to a caregiving burden and may adversely affect their QOL. In this study, 44.0% in caregivers of group 2 and 36% of caregivers in group 1 had additional caregiving activities apart from caring for the affected child. Among the different childhood psychiatric illnesses, the most frequent diagnosis that was encountered was that of childhood depressive episodes (26.7%), followed by attention deficit hyperkinetic disorder (22.6%). In the study by Daltro et al., the most common diagnosis encountered was that of mental retardation. But in this study, childhood depressive

episodes were found to be the most common diagnosis, followed by ADHD and mental retardation. This may be due to the fact that depression may accompany a lot of other psychiatric conditions. A study on depression in children and adolescents showed that the point prevalence of depression among children ranges from 1.2% to 21% in clinic-based studies.<sup>18</sup> The lowest mean score was that of participants in Group 2 across psychological domains, with a mean score of 9.78±2.72. On a scale of 0–100, this score will be 36.17±17.03. This was followed by scores in the social relationship domain with 44.56±17.89, the environment domain with 47.92±13.31, and the physical health domain with 48.09±10.86. This finding was similar to that of Daltro et al.,<sup>10</sup> although the scores of participants in this study were lower as compared to Brazilian caregivers. The result of WHOQOL BREF assessment scores in their study showed that the lowest score was found in the psychological domain with 40.1, followed by the social relationships domain with 49.2, 51.4 in the environment, and a physical domain score of 54.3. Another study done in Taiwan<sup>11</sup> found that the mean scores in each domain of WHOQOL-BREF of the caregivers were the following: Physical health was 13.71±2.35, psychological health was 12.21±2.55, social relationships were 12.99±2.43, and the environment was 12.32±2.38. These scores were better than those of our study participants, which were physical health 11.69±1.74, psychological 9.78±2.72, social relationships 11.12±2.86, and environmental 11.66±2.13.

Thus, the overall QOL of caregivers attending psychiatry outpatient departments was found to be significantly affected as compared to caregivers attending pediatrics outpatient departments, except for the environment domain. The lowest score was in the psychological domain for caregivers of children with psychiatric illnesses, which implies these caregivers had negative perceptions about their body image and appearance, negative feelings, decreased self-esteem, decreased thinking and learning capabilities, along with poor memory and concentration. Their personal relationships, social support, and sexual life are also affected, as evident from low scores in the social relationships domain.

### Limitations of the study

Considering the busy OPD setting and health condition of the affected child, as well as the varying literacy status of the study participants, interviewer-assisted administration of WHOQOL-BREF was done. The good side was that all the questions were answered and not a single assessment was discarded, but the response of the participants may have been affected to some extent due to this technique. Again, the findings of the study are difficult to generalize, as group 2 was a heterogeneous entity regarding diagnosis and severity or chronicity of disease or disability percentage was not taken into account. Moreover, it was solely an institution-based study, and the study population included only those caregivers who visited the pediatrics and psychiatry outpatient department during the data collection period. In this study, only the sociodemographic factors that may influence the QOL of individuals were described for both study groups, and scores obtained in different domains were compared.

## CONCLUSION

In this study, the most affected QOL domain in the case of caregivers of children attending psychiatry OPD was the psychological domain followed by the social relationship domain. This finding highlighted the need for socio-psychological support and a better environment for improving QOL among those caregivers.

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