Quality of Life of Caregivers of Autistic Children and Adolescents Visiting Health Facilities in Lucknow City, Uttar Pradesh, India: A Cross-sectional Study

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Abstract

Background: The lifelong responsibility of the autistic children along with the lack of knowledge, lack of treatment, and if treatment is available, it is unaffordable leads to deterioration of quality of life of the parents in several domains. **Objectives:** The objective is to study the quality of life of principal caregivers of autistic children and adolescents visiting health facilities in Lucknow city. **Materials and Methods:** The sample included 90 principal caregivers (aged < 60 years) of autistic children and adolescents aged 3–19 years and diagnosed with autism, attending government and private health facilities providing treatment for autism in Lucknow, Uttar Pradesh, India. **Results:** The quality of life of principal caregivers was found to be influenced most in the physical health domain (with least score). The predictors of quality of life of principal caregivers were type of family and knowledge regarding child's problem. **Conclusion and Recommendations:** Thus, there is an immense need of increasing awareness through information, education, and communication materials, mass media, and discussions regarding autism.

Keywords: Autistic children, predictors of quality of life, quality of life of caregivers

Introduction

Autism is a neurodevelopmental disorder, which in most people (with the condition) has a lifelong impact. Its core features include impaired social interaction, impaired communication, and restricted and repetitive interests and activities.[1]

Parents of children with autistic disorder may find themselves burdened with a lifelong responsibility of caring for their children and diminished attention to their own health.[2] Other than this, lack of knowledge about autism, lack of treatment, and if treatment is available, it is unaffordable, adds on the stress. This leads to deterioration of quality of life of parents in different domains such as economic, social, educational, and psychological.[3]

Studies have been conducted to determine the quality of life of principal caregivers of autistic children and adolescents, but there is a paucity of studies providing the sociodemographic predictors of quality of life of principal caregivers of autistic

children and adolescents. The objectives of this study were to study the quality of life and its predictors of principal caregivers of autistic children and adolescents visiting health facilities in Lucknow city.

Materials and Methods

Treatment facilities for autism are at its developing stages in Northern India. Uttar Pradesh is conventionally classified into Eastern Uttar Pradesh and Western Uttar Pradesh. On Google search, for the treatment centers for autism, only a few cities were found to have treatment facilities for autism, especially in the Eastern Uttar Pradesh. These cities include Varanasi,

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Jaunpur, and Lucknow (government facilities such as the King George's Medical College, private centers such as Creative Mind, Genius Lane, Autism Awareness and Action). While the Western Uttar Pradesh was found to have better treatment facilities, especially in cities such as Noida, Ghaziabad, and Agra (all these cities shares their borders with New Delhi). Due to the lack of treatment facilities in the Eastern Uttar Pradesh, many parents in search of better treatment modalities come to Lucknow for the treatment of their children.

Among the 90 caregivers included in this study, 26 caregivers belonged to districts of Uttar Pradesh other than Lucknow and from different adjacent states as well (including Madhya Pradesh and Orissa).

It was a cross-sectional study conducted at the child and adolescent psychiatry outpatient department at a tertiary care government center and four private centers for autism in Lucknow. The study participants were principal caregivers (<60 years of age) of diagnosed children/adolescents with autism spectrum disorder, aged 3–19 years, and not having any behavioral disorders/medical comorbidities requiring priority management.

Nonrandom (Purposive) sampling technique was used in this study. Taking the standard deviation of the mean of quality of life 0.96,[4] and the acceptable deviation from the mean 0.2, and using the formula: $N = (Z_{1-\alpha/2})^2 * (SD)^2/d^2$, the sample size calculated was 88. Thus, a total of 90 principal caregivers of the autistic children and adolescents were included in the study.

Owing to ethical considerations, permission was obtained from the Institutional Ethical Committee of the King George's Medical University, Uttar Pradesh, Lucknow, before commencing the study. Written permission (duly signed by the head of the department) was taken from the private centers included in the study. Written informed consent was taken from each selected patient to confirm willingness after explaining the survey purpose. Affirmation for freedom to withdraw at any point was also given. Privacy and confidentiality of collected information were ensured throughout the process.

Data were tabulated and analyzed using the software IBM - SPSS version 16 (Bangalore, Karnataka, India). The categorical variables were represented in the form of frequency tables. Median was used as the measure of central tendency for the continuous variables as the data were not normal. Nonparametric test of significance such as Chi-square test, Mann–Whitney U-test, and Kruskal–Wallis tests was used for determining any difference between medians of two (or more than two) groups of a particular independent variable. Further, binary logistic regression analysis was done to determine the predictors of quality of life of principal caregivers.

Following tools were used in this study:
1. A predesigned and pretested semi-structured questionnaire to determine, the sociodemographic characteristics of the principal caregivers and their knowledge regarding autism

2. Indian Scale for Assessment of Autism (ISAA)

The ISAA has been developed for assessing the extent of disability for persons with autism based on which the disability certificate is issued.[5] ISAA consists of 40 items rated on a 5-point scale ranging from 1 (never) to 5 (always).[6] Further, the levels of disability are classified into no autism (score <70), mild autism (score 70–106), moderate autism (score 107–153), and severe autism (score >153)

3. World Health Organization Quality of Life-BREF (WHOQOL-BREF).[7]

The WHOQOL-BREF contains a total of 26 questions, in Likert response scale ranging from 1 to 5. Of which, two items were the overall quality of life and general health facet, and the rest 24 were divided into four domains which includes physical health, psychological health, social health, and environmental health domains. The obtained raw score of each domain was transformed manually to a 0–100 range score. For logistic regression analysis, good quality of life was taken as total quality of life score ≥50 and poor quality of life as total quality of life score <50.

RESULTS

As shown in Figure 1, the Box and Whisker plot shows that among the domains of quality of life, the minimum score was in the "physical health" domain which was 38.00 median with an interquartile range of 31.00–50.00. The maximum score was in the "environmental health" domain with the median score of 50.00 with an interquartile range of 38.00–56.00.

As shown in Table 1, among the caregivers, who belonged to districts other than Lucknow, 17.8% stayed in Lucknow for their child's treatment. Majority (87.8%) of the principal caregivers were mothers, and in spite of 77.8% being graduate and postgraduate 73.3% were unemployed. The male-to-female ratio in this study was around 4.98. The caregivers who had knowledge about the child's problem, autism, and the care modalities of autism had statistically significant better "environmental health" as compared to caregivers who did not have the knowledge. No difference in quality of life was seen among caregivers with children with different levels of disability [Figure 2].
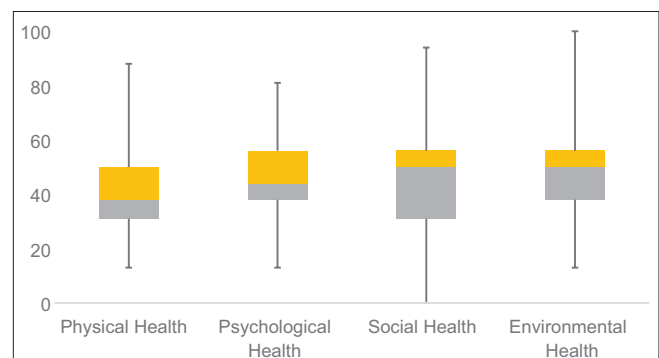

Figure 1: Quality of life scores in different domains

Table 1: Comparison of medians of different domains of the World Health Organization Quality of Life scale with respect to the sociodemographic characteristics

Variables (N = 90)	n (%)	Domains of WHOQOL Scale, median (interquartile range)			
		Physical health	Psychological health	Social relationships	Environmental health
Religion					
Hindu	74 (82.2)	38 (31-50)	44 (38-56)	50 (31-56)	50 (38-56)
Muslim	14 (15.6)	38 (31-50.25)	44 (42.5-56.5)	44 (31-56)	47 (36.25-56)
Sikh	2 (2.2)	62.5 (56-)	66 (63-)	62.5 (50-)	-
Permanent residence					
Lucknow	64 (71.1)	41 (31-56)	44 (38-56)*	50 (31-65.75)	50 (39.5-61.25)*
District other than Lucknow	26 (28.9)	38 (31-44)	44 (23.5-45.5)*	44 (31-51.5)	44 (36.25-56)*
Domicile					
Urban	81 (90)	38 (31-53)	44 (38-56)	50 (31-56)	50 (38-56)*
Rural	9 (10)	38 (31-38)	44 (38-44)	50 (44-62.5)	38 (28-23)*
Type of family					
Nuclear	51 (56.7)	38 (31-44)	44 (38-50)	50 (31-56)	50 (38-56)*
Joint	39 (43.3)	38 (31-56)	44 (38-56)	50 (31-69)	56 (44-69)*
SES**					
Upper class	64 (71.1)	41 (31-56)	44 (38-56)	50 (31-75)	50 (44-56)
Upper middle class	15 (16.7)	31 (25-50)	38 (25-56)	44 (25-56)	44 (31-56)
Lower middle class	7 (7.8)	38 (31-38)	44 (38-44)	50 (31-56)	38 (25-56)
Lower class	3 (3.3)	38 (31-)	44 (44-)	50 (44-)	38 (31-)
Relation					
Father	9 (10)	50 (37.5-59.5)	50 (41-56)	50 (37.5-56)	50 (34.5-59.5)
Mother	79 (87.8)	38 (31-44)	44 (38-56)	50 (31-56)	50 (38-56)
Age of principal caregivers (years)					
20-29	18 (20)	38 (31-39.5)	44 (38-44)	47 (29.5-59.25)	44 (36.25-56)
30-39	58 (64.4)	44 (31-56)	44 (38-56)	50 (31-56)	50 (38-63)
40-49	11 (12.2)	38 (31-50)	44 (19-56)	50 (31-50)	44 (38-50)
50-59	3 (3.3)	38 (31-)	56 (44-)	50 (50-)	56 (50-)
Education					
Illiterate	4 (4.4)	38 (38-47)	44 (39.5-53)	50 (45.5-54.5)*	34.5 (26.5-47)
Middle school, high school, intermediate	9 (9.9)	38 (34.5-44)	44 (41-50)	44 (44-56)*	44 (25-56)
Graduate and postgraduate	70 (77.8)	38 (31-56)	44 (38-56)	50 (31-56)*	50 (38-56)
Profession and honors	7 (7.8)	38 (19-56)	44 (25-50)	56 (31-81)*	56 (50-69)
Occupation					
Unemployed	66 (73.3)	38 (31-44)	44 (38-50)	44 (31-56)	50 (38-56)
Unskilled, semiskilled, skilled worker	6 (6.6)	38 (31-48.5)	44 (22-54.5)	53 (34.25-75)	41 (28.25-63)
Clerical, shop owner, farmer	7 (7.8)	59 (50-67.5)	59.5 (42.5-73.5)	53 (45.5-75)	62.5 (45.5-69)
Profession	11 (12.2)	44 (25.25-48.5)	56 (32.75-56)	50 (35.75-50)	47 (39.5-50)
Age of child (years)					
3-7	48 (53.3)	38 (31-50)	44 (38-50)	50 (31-56)	50 (38-56)
7-11	36 (40)	38 (25-47)	44 (19-50)	56 (49-72)	50 (31-59.5)
11-15	4 (4.4)	56 (32.75-61.25)	62.5 (23.75-73.50)	59.5 (11-79.5)	53.5 (20.75-67.5)
15-19	2 (2.2)	41 (38-)	-	47 (44-)	47 (38-)
Sex					
Male	75 (83.3)	38 (31-50)	44 (38-56)	44 (31-56)	50 (38-56)
Female	15 (16.7)	38 (31-56)	44 (44-63)	50 (44-69)	44 (38-56)
Siblings					
0	41 (45.6)	38 (31-44)	44 (38-53)	50 (31-56)	50 (38-56)
1	39 (43.3)	44 (38-56)	44 (38-56)	50 (44-69)	50 (38-63)
2	8 (8.9)	41 (28.25-58.25)	44 (25.25-54.5)	44 (44-48.5)	44 (31-50)

Contd...

Variables (n=90)	n (%)	Domains of WHOQOL Scale, median (interquartile range)			
		Physical health	**Psychological health**	**Social relationships**	**Environmental health**
Knowledge about the child's problem					
Yes	69 (76.7)	38.00 (31.00-56.00)	44.00 (38.00-56.00)	50.00 (31.00-56.00)	50.00 (44.00-56.00)*
No		38.00 (31.00-44.00)	44.00 (38.00-50.00)	44.00 (44.00-56.00)	38.00 (25.00-53.00)*
Knowledge about autism					
Yes	69 (76.7)	38.00 (31.00-56.00)	44.00 (38.00-56.00)	50.00 (31.00-56.00)	50.00 (44.00-59.50)*
No		38.00 (31.00-44.00)	44.00 (38.00-50.00)	44.00 (44.00-56.00)	38.00 (25.00-53.00)*
Knowledge about the care modalities of autism					
Yes	68 (75.6)	38.00 (31.00-56.00)	44.00 (38.00-56.00)	50.00 (31.00-56.00)	50.00 (44.00-56.00)*
No		38.00 (31.00-44.00)	44.00 (38.00-50.00)	44.00 (44.00-56.00)	41.00 (29.50-56.00)*

Table 1: Contd...

*$P<0.05$, **Modified B G Prasad Scale. QOL: Quality of Life, IQR: Interquartile range, WHO: World Health Organization, SES: Socioeconomic status
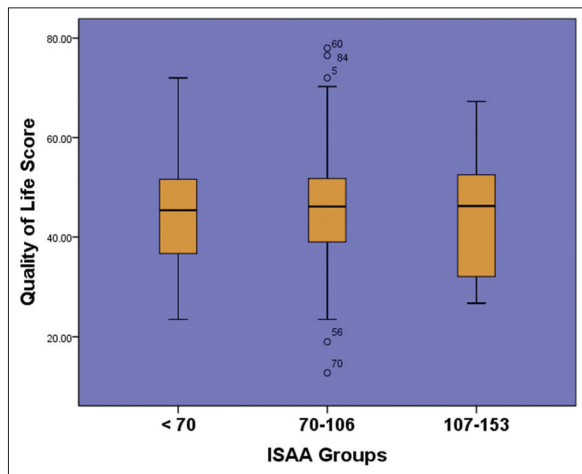
Figure 2: Distribution of quality of life scores with respect to the level of disability scores by the Indian Scale for Assessment of Autism

As shown in Table 2, on binary logistic regression analysis, caregivers belonging to nuclear families were found to predict poor quality of life, while caregivers who had knowledge about the child's problem had lesser chances of having a poor quality of life thus showing a protective effect.

Discussion

Autism is mostly considered as the disability of higher classes. Similar representation was observed in this study too [Table 1]. Moreover, this over-presentation of autism in higher classes and people belonging to urban areas is primarily due to the easy accessibility of autism treatment services by the people living in urban areas and affordability of the expensive treatment of autism at private centers by higher socioeconomic classes. In addition, families belonging to higher socioeconomic status (SES) may be more likely to persist in finding a diagnosis and to obtain services for their children.[8] A similar reason was concluded in a study, in which the author stated that "social, cultural, and economic factors" played a significant role in their ability to access appropriate diagnosis, treatment, and intervention. Furthermore, many families, due to their own

SES are unable to access what few resources and services are available."[9]

Majority of the caregivers in the present study were mothers. Among the caregivers, majority (~ 77%) were highly educated (graduate and postgraduate). Despite this higher education, they preferred to be unemployed as one among the parents had to constantly look after the child. The indirect out of pocket expenditure occurring due to the nonworking parents poses a great problem for the economy of the particular nation.

Among the four domains of quality of life, least median score (thus the poorest quality of life) was found in the physical health domain followed by psychological health domain. Similar findings were observed in studies by Malhotra *et al*.,[10] Perumal *et al*.,[11] and Khan *et al*.,[12] in which least scores were in the physical and psychological health domains.

The median scores and interquartile ranges of psychological and environmental health were found significantly lower of the caregivers who belonged to districts other than Lucknow as compared to scores of the caregivers who belonged to Lucknow district. As told by the caregivers (belonging to districts other than Lucknow), the treatment facilities were better in Lucknow as compared to that in their own cities.

The caregivers who knew about the child's problem, about "Autism" and about its treatment, had a significantly better environmental health as compared to those who lacked the knowledge due to better accessibility of resources.

The quality of life of caregivers of autistic children was not affected by the level of disability among the children [Figure 2]. Furthermore, median scores of different QOL scale domains for other variables such as the relationship of principal caregiver, education of principal caregiver, the occupation of principal caregiver, the age of the child, and duration of present treatment were found similar for different groups in each variable.

Conclusion

Knowledge regarding autism and type of family predicted the

Table 2: Predictors of Quality of Life (poor/good) of principal caregivers

Variables	Univariate analysis			Multivariate analysis		
	OR	95% CI	*P*	AOR	95% CI	*P*
Domicile						
Urban	0.22	0.03-1.88	0.168	-	-	-
Rural	Reference	Reference	Reference	-	-	-
Type of family						
Nuclear	3.45	1.38-8.64	0.008	3.53	1.12-11.14	0.032
Joint	Reference	Reference	Reference	Reference	Reference	Reference
Knowledge about the child's problem						
Yes	0.26	0.07-0.96	0.044	0.17	0.03-0.88	0.034
No	Reference	Reference	Reference	Reference	Reference	Reference
Knowledge about "What is Autism"						
Yes	0.26	0.07-0.96	0.044	-	-	-
No	Reference	Reference	Reference	-	-	-
Knowledge about the treatment of Autism						
Yes	0.36	0.11-1.18	0.091	-	-	-
No	Reference	Reference	Reference	-	-	-

OR: Odds ratio, AOR: Adjusted odds ratio, CI: Confidence interval

quality of life of parents. The quality of life of caregivers was not found to be affected by the level of disability of the child.

The limitation of this study includes that as the sampling method is nonrandom, thus the study results lacks external generalizability.

Recommendations

The quality of life of principal caregivers of autistic children and adolescents can be improved by improving their knowledge regarding autism. Thus, there is an immense need of increasing awareness among general population through information, education, and communication materials, mass media, and discussions regarding autism. The study also depicts importance of joint families in improving the quality of life of caregivers.

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Conflicts of interest

There are no conflicts of interest.

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