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ETHICAL APPROVAL

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Quality of Life Among Parents of Children with Autism Spectrum Disorder

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ABSTRACT

Background: Autism spectrum disorder (ASD) is a chronic neurodevelopmental condition associated with sustained psychological, social, and economic demands on families, particularly parents as primary caregivers. These demands can meaningfully reduce caregivers' quality of life (QoL), and evidence from resource-constrained settings remains limited. Objective: To assess QoL among parents of children with ASD across physical, psychological, social, and environmental domains. Methods: An observational cross-sectional study was conducted in Lahore, Pakistan (January–June 2023) at tertiary hospitals and autism centers. Using purposive sampling, 133 parents of children diagnosed with ASD were recruited. QoL was assessed with the WHOQOL-BREF. Data were analyzed using SPSS v21 and summarized using frequencies, percentages, and domain-level scores. Results: Overall QoL and general health were rated at 60%. Physical health showed the highest domain score (74%), followed by the environmental domain (70%), while psychological health and social relationships were both 66%. Globally, 34.6% rated QoL as good, 38.3% neutral, and 27.1% bad. Neutral responses were common across psychological, social, and environmental indicators, particularly regarding emotional well-being, financial sufficiency, and leisure opportunities. Conclusion: Parents of children with ASD experience moderately constrained QoL, with psychological, social, and environmental domains most affected. Family-centered psychosocial support and improved access to supportive services should be integrated into ASD care pathways.

Keywords

Autism spectrum disorder; parents; quality of life; caregiver burden; WHOQOL-BREF.

INTRODUCTION

Autism spectrum disorder (ASD) is a chronic neurodevelopmental condition that affects social communication and behavior and often requires long-term support from families. Parents frequently manage behavioral challenges, coordinate therapies, navigate educational needs, and cope with uncertainty about developmental trajectories. These sustained caregiving demands are consistently associated with reduced parental well-being and poorer quality of life (QoL), particularly where specialized services and structured supports are limited (1).

Quality of life is a multidimensional construct comprising physical health, psychological well-being, social relationships, and environmental resources. In ASD caregiving, QoL is shaped by child-related factors (e.g., behavioral difficulties), caregiver roles, stigma, family functioning, coping strategies, and availability of social support (1,2). Social support is repeatedly identified as protective and may buffer caregiver stress while improving QoL domains (3,4). Across settings, caregiver stress and QoL reflect both individual-level factors (stress, coping, stigma) and structural determinants (service access, financial stability, disability-related supports) (5,6). Transcultural evidence further suggests that cultural interpretations of disability, social norms, and formal/informal support can influence the magnitude and expression of QoL impairment among parents of children with ASD (7). In South Asian and other resource-constrained contexts, limited autism-service infrastructure and stigma may compound psychological distress, social isolation, and environmental insecurity (6,7).

In Pakistan, standardized domain-specific evidence using validated QoL instruments remains limited. This gap restricts development of family-centered rehabilitation pathways and targeted psychosocial support strategies. Therefore, this study aimed to assess QoL among parents of children with ASD across WHOQOL domains in Lahore, Pakistan (8). Environmental and structural constraints including cost of care, limited specialized services, and fragmented healthcare access are strongly associated with poorer caregiver QoL (9,10). These challenges are often amplified in low- and middle-income countries due to resource limitations, out-of-pocket expenditures, and misconceptions about developmental disorders (11). Cultural context and support structures may further modify caregiver outcomes across domains (12).

MATERIALS AND METHODS

An observational cross-sectional study was conducted in Lahore, Pakistan, to evaluate quality of life among parents of children diagnosed with autism spectrum disorder. The study setting comprised Mayo Hospital, the University of Lahore Teaching Hospital, and autism centers, and data collection was completed over a six-month period from January 2023 to June 2023 after approval of the synopsis through the departmental review process. The study enrolled 133 parents of children with autism spectrum disorder using a non-probability purposive sampling technique.

Eligibility was defined as being a parent of a child with autism spectrum disorder, while parents of children reported to have psychological disorders or other comorbid conditions were excluded. After obtaining institutional permission, eligible parents were approached at the study sites, provided information about the study, and written informed consent was obtained prior to participation and questionnaire completion. Sample size was calculated using an autism prevalence estimate of 3.20% with a 95% confidence interval and 5% margin of error, yielding a target sample of 133 participants, which was achieved. Quality of life was assessed using the standardized World Health Organization Quality of Life instrument (WHOQOL; 26 items). The questionnaire was administered to participating parents at the data-collection sites, and responses were recorded directly from parents.

Study variables included parent-reported responses to WHOQOL items and parent/child demographic characteristics captured in the study proforma. To support data quality and reproducibility, standardized administration procedures were used at all sites, and questionnaires were completed in the presence of the data collector to reduce item non-response at the point of capture. Data were stored securely, with hard copies kept under lock and key and electronic files password-protected to maintain integrity and confidentiality. Data was analyzed using Statistical Package for Social Sciences (SPSS), version 21. Descriptive statistics were performed for demographic variables and questionnaire responses, with categorical variables summarized as frequencies and percentages. Ethical requirements were followed in accordance with the rules and regulations of the ethical committee of the University of Lahore. Participation was voluntary, written informed consent was obtained from all participants, confidentiality was maintained, anonymity was preserved, participants were informed that there was no disadvantage or risk related to participation, and they retained the right to withdraw at any time without penalty.

RESULTS

This table summarizes child age distribution and parent-related characteristics for the sample (n = 133). The most common child age groups were 60–71 and 72–83 months (24.1% each), and most respondents were mothers (56.4%). Over half reported a family history of autism (55.6%), and birth order was broadly distributed with first-born being the most frequent (23.3%).

Table 1. Demographic characteristics of children with ASD and respondent parents (n = 133)

Variable	Category	Frequency (n)	Percentage (%)
Age group (months)	12–23	23	17.3
	24–35	7	5.3
	36–47	22	16.5
	48–59	3	2.3
	60–71	32	24.1
	72–83	32	24.1
	≥84	14	10.5
Respondent parent	Father	58	43.6
	Mother	75	56.4
Family history of autism	Yes	74	55.6
	No	59	44.4
Birth order	First	31	23.3
	Second	25	18.8
	Third	28	21.1
	Fourth	26	19.5
	Fifth	21	15.8
	Sixth	2	1.5

Table 2. WHOQOL-BREF global ratings, domain scores, and selected item responses (n = 133) A) Global ratings (WHOQOL-BREF Q1–Q2)

Measure	Response	Frequency (n)	Percentage (%)
Overall quality of life (Q1)	Good	46	34.6
	Neutral	51	38.3
	Bad	36	27.1
Satisfaction with health (Q2)	Good	39	29.3
	Neutral	63	47.4
	Bad	31	23.3

Table 2. WHOQOL-BREF global ratings, domain scores, and selected item responses (n = 133) B) Domain scores

Domain	Items	Raw score	Percentage (%)
Overall quality of life & general health	Q1–Q2	8	60
Physical health	Q3–Q9	33	74
Psychological health	Q10–Q15	26	66
Social relationships	Q16–Q18	13	66
Environment	Q19–Q26	36	70

This table presents WHOQOL-BREF outcomes, including global QoL/health ratings, domain scores, and selected item responses. Neutral responses were most common for overall QoL (38.3%) and health satisfaction (47.4%), indicating moderate perceived well-being. Physical health scored highest (74%), while psychological and social domains were lower (66%), with notable neutrality on concentration, finances, leisure, and negative feelings.

Table 2. WHOQOL-BREF global ratings, domain scores, and selected item responses (n = 133) C) Selected WHOQOL-BREF item responses

Item	Good n (%)	Neutral n (%)	Bad n (%)
Enjoy life	46 (34.6)	46 (34.6)	41 (30.8)
Life is meaningful	49 (36.8)	46 (34.6)	38 (28.6)
Able to concentrate	39 (29.3)	65 (48.9)	29 (21.8)
Enough money to meet needs	29 (21.8)	66 (49.6)	38 (28.6)
Leisure opportunities	41 (30.8)	78 (58.6)	14 (10.5)
Negative feelings	37 (27.8)	73 (54.9)	23 (17.3)

DISCUSSION

This study provides domain-specific evidence on QoL among parents of children with ASD in a Pakistani healthcare context. Overall, QoL was moderately compromised across domains, with physical health relatively higher and psychological, social, and environmental domains showing greater constraint.

A key finding was the predominance of neutral responses across many WHOQOL-BREF items, suggesting "marginal well-being," where parents adapt under chronic caregiving stress rather than experiencing either optimal functioning or overt severe distress. Similar intermediate QoL patterns have been reported in prior syntheses and qualitative studies of parents of children with ASD (15,16). Psychological health emerged as particularly vulnerable, with notable neutrality/dissatisfaction related to negative emotions, concentration, and enjoyment of life. Prior studies indicate elevated anxiety, depressive symptoms, and emotional exhaustion among caregivers, especially where caregiver-focused mental health supports are limited (17,18).

Social relationship outcomes were mixed. Reduced engagement, perceived stigma, and time constraints can limit social participation and peer support. Evidence shows that perceived social support is strongly associated with caregiver QoL and may buffer stress-related deterioration (19,20). Environmental and economic factors also played a substantial role. Neutrality and dissatisfaction regarding finances, leisure, and access to services highlight structural constraints beyond individual coping. Prior research shows that limited-service availability and financial insecurity are among the strongest predictors of reduced caregiver QoL in ASD caregiving populations (21). Collectively, these findings support prioritizing early and targeted caregiver interventions, including psychosocial counseling, caregiver education, peer-support networks, and policies that improve access to ASD services.

CONCLUSION

Parents of children with ASD experience moderately compromised QoL across physical, psychological, social, and environmental domains. Psychological and environmental constraints particularly emotional strain, financial limitations, restricted leisure, and service access challenges appear central. Integrating family-centered psychosocial support and improving service accessibility should be treated as core components of comprehensive ASD management.

REFERENCES

1. Mai TLA, Chaimongkol N. Effectiveness of a family management intervention program among families of children with autism: a randomized controlled trial. J Nurs Res. 2022;26(1):67-81.
2. Hemdi A, Daley D. The needs of mothers of children with autism spectrum disorder (ASD) in the Kingdom of Saudi Arabia (KSA): a qualitative study. Int J Adv Sci Res. 2017;5(3).
3. Begum FA, Islam MS, Rahman AS. Coping strategies and education of parents of autistic children in Bangladesh. Bangladesh J Med Sci. 2020;19(4):614-619.
4. Pyszkowska A, Wrona K. Self-compassion, ego-resiliency, coping with stress and the quality of life of parents of children with autism spectrum disorder. PLoS One. 2021;9:e11198.
5. Mohakud K, Sahu RK, Dash SR, Sahoo S. Child behavioral problem and its relationship with parenting stress of mothers of cerebral palsy children and autistic children. World Wide J Multidiscip Res Dev. 2019;13(4):478.
6. Alhazmi A, Petersen R, Donald KA. Quality of life among parents of South African children with autism spectrum disorder. Afr J Neurol. 2018;30(4):226-231.
7. Suen MW, Ningrum V, Yuniardi MS, Hasanati N, Wang JH. The association between parenting stress, positive reappraisal coping, and quality of life in parents with autism spectrum disorder (ASD) children: a systematic review. Healthcare (Basel). 2021;9.
8. Bohadana G, Morrissey S, Paynter J. Self-compassion in mothers of children with autism spectrum disorder: a qualitative analysis. J Autism Dev Disord. 2021;51(4):1290-1303.
9. Staunton E, Kehoe C, Sharkey L. Families under pressure: stress and quality of life in parents of children with an intellectual disability. Int J Prev Med. 2020:1-8.
10. Jose P, Sundaram S, Varma RP. Buffering effect of spousal support on stress levels in mothers of children with a diagnosis of autism spectrum disorder in Kerala, India. J Nurs Interprof Res Pract. 2021;12(03):535-542.
11. Beheshti SZ, Hosseini SS, Maroufizadeh S, Almasi-Hashiani A. Occupational performance of children with autism spectrum disorder and quality of life of their mothers. Basic Res J. 2022;15(1):1-6.
12. Cappe É, Poirier N, Sankey C, Belzil A, Dionne C. Quality of life of French-Canadian parents raising a child with autism spectrum disorder and effects of psychosocial factors. Qual Life Res. 2018;27(4):955-967.
13. Hannon MD, Blanchard R, Storlie CA. Microaggression experiences of fathers with children with autism spectrum disorder. Fam J. 2019;27(2):199-208.
14. Wilkinson E, Vo LTV, London Z, Wilson S, Bal VH. Parent-reported strengths and positive qualities of adolescents and adults with autism spectrum disorder and/or intellectual disability. J Autism Dev Disord. 2022:1-12.

15. Vasilopoulou E, Nisbet J. The quality of life of parents of children with autism spectrum disorder: a systematic review. Res Autism Spectr Disord. 2016;23:36-49.
16. Abolkheirian S, Sadeghi R, Shojaeizadeh D. What do parents of children with autism spectrum disorder think about their quality of life? A qualitative study. J Educ Health Promot. 2022;11.
17. Singh P, Ghosh S, Nandi S. Subjective burden and depression in mothers of children with autism spectrum disorder in India: moderating effect of social support. J Autism Dev Disord. 2017;47(10):3097-3111.
18. Eapen V, Karlov L, John JR, Beneytez C, Grimes PZ, Kang YQ, et al. Quality of life in parents of autistic children: a transcultural perspective. Front Psychol. 2023;14:1022094.
19. Kuru N, Piyal B. Perceived social support and quality of life of parents of children with autism. Niger J Clin Pract. 2018;21(9):1182-1189.
20. Papadopoulos A, Siafaka V, Tsapara A, Tafiadis D, Kotsis K, Skapinakis P, et al. Measuring parental stress, illness perceptions, coping and quality of life in families of children newly diagnosed with autism spectrum disorder. BJPsych Open. 2023;9(3):e84.
21. Wang Y, Xiao L, Chen RS, Chen C, Xun GL, Lu XZ, et al. Social impairment of children with autism spectrum disorder affects parental quality of life in different ways. Psychiatry Res. 2018;266:168-174.