

Research Article

Quality of Life in Parents of Children with Developmental Disabilities

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Abstract: Background: Caregiving and its related burden are considered important aspects in determining the quality of life (QOL) among parents.

Objective: To evaluate the QoL as per the WHO QoL-BREF questionnaire in parents of children with developmental disabilities.

Materials and Methods: This comparative cross-sectional study was conducted at the Outpatient Department of Pediatrics, Ziauddin Hospital, Karachi, from 1st January to 30th June 2025. A total of 268 parents were enrolled (134 cases and 134 controls). Cases were parents of children aged 5–18 years, with confirmed diagnoses of developmental disabilities, and absence of developmental, behavioural, or psychiatric disorders for controls. Demographic data were collected, and quality of life was assessed using the Urdu version of the WHOQOL-BREF. Data were analyzed in SPSS v26, applying appropriate statistical tests taking $p < 0.05$ as significant.

Result: Among 268 parents, 115 (42.9%) were male and 153 (57.1%) were female, with a median age of 37.5 years (interquartile range, IQR, 32.8–43.0). Children included 159 (59.3%) males and 109 (40.7%) females, median age 9.1 years (IQR 7.0–12.3). Parental education was significantly lower in cases ($p = 0.013$), and monthly income $< 50,000$ PKR was more frequent in cases 68 (50.7%) than controls 34 (25.4%) ($p < 0.001$). Parents of affected children reported significantly lower WHOQOL-BREF scores in physical health 60.2 vs 68.4, psychological health 58.1 vs 66.7, social relationships 55.3 vs 62.8, environment 57.6 vs 64.3, overall QoL 3.1 vs 4.0, and general health 3.0 vs 4.1 (all $p < 0.001$).

Conclusion: Parents of children with developmental disabilities experience significantly lower QoL across physical, psychological, social, and environmental domains, as well as in overall life satisfaction and general health.

Keywords: Children, Developmental disabilities, Parent, Quality of life, WHO QOL-BREF.

INTRODUCTION

It has been estimated that approximately 7 to 10% of children experience developmental disabilities that necessitate access to the healthcare system and extensive caregiving, often spanning from childhood into adulthood [1-3]. Developmental disabilities manifest during the developmental period and are characterized by limitations in socio-adaptive functioning and intellectual abilities [4, 5]. Limitations in functioning among children with developmental disabilities can lead to long-term care needs that far exceed the typical requirements of children as they grow, surpassing the expectations of their families as caregivers [6, 7].

Data report that parents of children with developmental disabilities may experience increased rates of stress,

feelings of being overwhelmed and marginalized [8, 9]. Caregiving and its related burden are considered important aspects in determining the quality of life of caregivers. Quality of Life (QoL) is increasingly recognized as a crucial outcome measure for patients and caregivers of chronic illnesses. A regional study revealed that WHO Quality of Life BREF scores for the physical domain among mothers of children with intellectual disability, autism, and healthy children were 46.67 ± 12.44 , 46.4 ± 15.85 , and 59.35 ± 14.4 , respectively, showing significant variation ($p < 0.01$) [1]. Another study reported that overall WHO QoL BREF scores among parents of children with, and without developmental disabilities, were 85.81 ± 12.56 vs. 89.75 ± 10.35 ($p = 0.003$) [10].

Considering the high prevalence rates of developmental disabilities along with the high caregiving demands, there is a need to evaluate and measure the QoL of par-

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ents of children with various disabilities [11, 12]. Limited rehabilitation services, inadequate early detection, and minimal parental support exacerbate the psychosocial and financial burden on families. In a society with scarce institutional assistance and strong caregiving expectations, parents often experience significant strain. By identifying the most affected QoL domains within the Pakistani sociocultural context, the findings provide crucial evidence to inform policy, improve family-centered pediatric care, and strengthen community-based parental support initiatives. The findings can also drive the development of specialized mental health services, reducing stress, anxiety, and depression among these parents. Healthcare providers can use this information to offer more comprehensive, family-centered care. This study was done to evaluate the QoL as per the WHO QOL BREF questionnaire in parents of children with developmental disabilities.

MATERIALS AND METHODS

This comparative cross-sectional study was conducted at the Outpatient Department of Paediatrics, Ziauddin Hospital, Karachi, Pakistan, during 1st January 2025 to 30th June 2025, following approval from the Institutional Ethical Review Board (letter number: 8810624SWPED, dated: August 17, 2024). The sample size was calculated to be 268 (134 cases and 134 controls), taking a 2-sided confidence interval of 95% with 80% power, a ratio of cases to controls of 1, and WHO QOL BREF scores among parents of children with, and without, developmental disabilities as 85.81 ± 12.56 vs. 89.75 ± 10.35 . Non-probability, consecutive sampling technique was considered. For cases, parents (either mother or father) of children aged between 5-18 years with developmental disabilities (as per operational definition) were included. For controls, parents of children aged between 5-18 years, without any reported or diagnosable developmental, behavioral, or psychiatric disorder, were taken. Parents of children with epilepsy, hearing impairment, motor impairments, or any other significant medical illness were excluded. Parents having chronic ailments or having a psychiatric family history were also not included. Parents or children unwilling to be part of this study were excluded. Developmental disabilities were labelled as known and confirmed cases (as per medical record and history) of cerebral palsy (CP), autism spectrum disorder (ASD), global developmental delay (GDD), intellectual disability (ID), attention deficit hyperactivity disorder (ADHD), speech delays, or learning disabilities (LD)

were considered children with developmental disabilities.

Upon obtaining written informed consent from eligible participants, demographic details were recorded. Parents of children with developmental disabilities (cases) and those without such disabilities (controls) were provided with the WHOQOL-BREF questionnaire either in its Urdu-translated self-administered form or through interviewer-assisted administration if necessary. The WHOQOL-BREF is a shortened version of the WHOQOL-100. Overall QOL scores and in the sub-domains were compared between cases and controls.

STATISTICAL ANALYSIS

Data was entered and analyzed using IBM SPSS Statistics, version 26.0. Qualitative data were presented as frequencies and percentages. Quantitative data were shown as means and standard deviation (SD), or medians and interquartile range (IQR) (normality of distribution was checked using the Shapiro-Wilk test). Categorical data between groups were compared using the chi-square test or Fisher's exact test, while numeric data, including WHO QOL BREF scores, were compared using the independent sample t-test or the Mann-Whitney U test between groups, taking $p < 0.05$ as statistically significant.

RESULT

Among 268 parents enrolled, 115 (42.9%) were males (fathers) and 153 (57.1%) were females (mothers). Among the children, 159 (59.3%) were males and 109 (40.7%) were females. Among 134 cases with developmental disabilities, most common diagnosis were cerebral palsy, ASD, GDD, ID, speech or learning disorder, and ADHD, noted in 38 (28.4%), 31 (23.1%), 25 (18.7%), 17 (12.7%), 13 (9.7%), and 10 (7.5%) cases, respectively. The median age of parents and children was 37.5 years (32.8–43.0) and 9.1 years (7.0–12.3), respectively. Parental educational status was illiterate among 35 (13.1%) parents. Regarding family income, 102 (38.1%) reported a monthly income of less than 50,000 PKR. The residential status of 196 (73.1%) families was urban areas. Among parents, 54 (40.3%) in the case group and 61 (45.5%) in the control group were male, whereas 80 (59.7%) in the case group and 73 (54.5%) in the control group were female ($p = 0.388$). A comparison of education levels among parents revealed statistically significant differences, with educational attainment being significantly lower among parents of cases ($p = 0.013$). Among cases,

68 (50.7%) reported a monthly income less than 50,000 PKR compared with 34 (25.4%) controls, between 50,000 and 100,000 PKR in 43 (32.1%) cases and 48 (35.8%) controls, whereas income greater than 100,000 PKR was reported by 23 (17.2%) cases compared with 52 (38.8%) controls ($p < 0.001$). Residential affiliations did not exhibit any significant differences ($p = 0.408$), and the details are given in Table 1.

Table 1. Comparison of Characteristics of Participants among Cases and Controls.

Characteristics		Total (N=268)	Cases (n=134)	Controls (n=134)	P-value
Gender (parents)	Male	115 (42.9%)	54 (40.3%)	61 (45.5%)	0.388
	Female	153 (57.1%)	80 (59.7%)	73 (54.5%)	
Gender (child)	Male	159 (59.3%)	82 (61.2%)	77 (57.5%)	0.534
	Female	109 (40.7%)	52 (38.8%)	57 (42.5%)	
Age in years (parents)		37.5 (32.8-43.0)	38.5 (33.2-43.5)	37.0 (32.1-42.6)	0.398
Age in years (child)		9.1 (7.0-12.3)	9.5 (7.1-12.5)	10.1 (7.0-13.3)	0.521
Education level (parents)	Illiterate	35 (13.1%)	25 (18.7%)	10 (7.5%)	0.013
	Primary	35 (13.1%)	22 (16.4%)	13 (9.7%)	
	Secondary	39 (14.6%)	19 (14.2%)	20 (14.9%)	
	Matriculation	77 (28.7%)	37 (27.6%)	40 (29.9%)	
	Intermediate	43 (16.0%)	18 (13.4%)	25 (18.7%)	
	Graduation or above	39 (14.6%)	13 (9.7%)	26 (19.4%)	
Monthly family income (PKR)	<50,000	102 (38.1%)	68 (50.7%)	34 (25.4%)	<0.001
	50,000 to 100,000	91 (34.0%)	43 (32.1%)	48 (35.8%)	
	>100,000	75 (28.0%)	23 (17.2%)	52 (38.8%)	
Residence	Rural	72 (26.9%)	39 (29.1%)	33 (24.6%)	0.408
	Urban	196 (73.1%)	95 (70.9%)	101 (75.4%)	

When assessed using the WHOQOL-BREF questionnaire, parents of children with developmental disabilities demonstrate significantly lower scores across all domains and both global items compared with controls (Table 2). The median physical health score was 60.2 (52.1–67.3) among cases compared with 68.4 (61.5–74.1) among controls ($p < 0.001$). The psychological health domain score was 58.1 (50.0–64.9) in cases compared with 66.7 (59.1–72.0) in controls ($p < 0.001$). Social relationships scores

were 55.3 (IQR 47.4–62.2) in cases and 62.8 (55.7–69.1) in controls ($p < 0.001$). The environmental domain was 57.6 (50.2–64.8) in cases and 64.3 (58.0–71.4) in controls ($p < 0.001$). For global items, overall quality of life was reported as 3.1 (2.0–3.3) in cases and 4.0 (3.0–4.2) in controls ($p < 0.001$), while general health was reported as 3.0 (2.1–3.4) compared with 4.1 (3.2–4.3), respectively ($p < 0.001$).

Table 2. WHOQOL-BREF Domain and Global Item Scores among Cases and Controls.

Measures	Total (N=268)	Cases (n=134)	Controls (n=134)	P-value
Physical health	64.3 (56.7-71.0)	60.2 (52.1-67.3)	68.4 (61.5-74.1)	<0.001
Psychological health	62.7 (54.5-69.1)	58.1 (50.0-64.9)	66.7 (59.1-72.0)	<0.001
Social relationship	59.2 (51.2-65.7)	55.3 (47.4-62.2)	62.8 (55.7-69.1)	<0.001
Environment	61.0 (54.0-68.1)	57.6 (50.2-64.8)	64.3 (58.0-71.4)	<0.001
Overall quality of life (global item)	3.5 (2.5-4.0)	3.1 (2.0-3.3)	4.0 (3.0-4.2)	<0.001
General health (global item)	3.5 (2.5-4.0)	3.0 (2.1-3.4)	4.1 (3.2-4.3)	<0.001

WHOQOL-BREF domain scores are presented on a 0–100 transformed scale, calculated according to the WHO guidelines by first computing the mean of items in each domain (Physical health: 7 items, Psychological

health: 6 items, Social relationships: 3 items, Environment: 8 items) and then linearly transforming scores to a 0–100 scale, with higher scores indicating better quality of life. The two global items (overall quality of life and

general health) are presented on their original 5-point Likert scale.

Stratified analysis confirmed that differences persisted across all socio-demographic variables ($p < 0.001$), and

the details are presented in Table 3. The pattern was consistently observed across psychological, social, and environmental domains, as well as overall quality of life and general health, with p -values < 0.001 in every comparison.

Table 3. Comparison of WHOQOL-BREF domains across various study variables (N= 286).

Variable	Category	Group	Physical Health	Psychological Health	Social Relationships	Environment	Overall QoL	General Health
Gender (parents)	Male	Cases	61.0 (54.0–67.2)	58.9 (51.0–64.3)	56.0 (48.0–62.1)	58.3 (51.0–65.2)	3.1 (2.0–3.3)	3.0 (2.1–3.4)
		Controls	68.9 (62.0–74.4)	67.2 (60.1–72.5)	63.1 (56.0–69.2)	64.7 (59.0–71.0)	4.0 (3.0–4.2)	4.1 (3.2–4.3)
	Female	Cases	59.8 (52.0–66.5)	57.6 (50.0–64.0)	54.9 (47.2–61.8)	57.0 (50.0–64.5)	3.0 (2.0–3.2)	3.0 (2.0–3.3)
		Controls	67.8 (61.2–73.8)	66.3 (58.9–71.5)	62.5 (55.0–69.0)	63.8 (58.0–71.5)	4.0 (3.0–4.1)	4.1 (3.0–4.3)
Education	Illiterate	Cases	56.2 (49.0–61.3)	54.1 (47.0–59.6)	52.0 (45.2–57.4)	53.4 (47.0–59.1)	2.7 (2.0–3.0)	2.8 (2.0–3.2)
		Controls	63.5 (58.0–69.1)	62.0 (55.0–67.2)	59.1 (53.0–64.2)	60.3 (54.0–65.8)	3.3 (3.0–3.7)	3.4 (3.0–3.8)
	Primary to Matric	Cases	59.8 (53.0–65.9)	57.9 (50.0–63.0)	55.6 (48.0–61.3)	57.2 (50.3–63.0)	3.0 (2.0–3.3)	3.0 (2.0–3.3)
		Controls	67.0 (61.0–72.1)	65.1 (58.2–71.0)	61.3 (55.0–67.0)	63.0 (57.0–69.1)	3.9 (3.0–4.1)	4.0 (3.0–4.2)
	Intermediate/Graduate+	Cases	64.0 (58.1–70.2)	61.5 (55.3–66.8)	58.9 (52.4–64.7)	60.7 (54.8–66.9)	3.4 (3.0–3.7)	3.5 (3.0–3.9)
		Controls	71.5 (65.3–76.2)	69.4 (63.0–74.3)	65.5 (60.0–71.1)	68.0 (62.2–72.5)	4.2 (3.8–4.5)	4.3 (4.0–4.6)
Monthly family income	<50,000 PKR	Cases	55.4 (48.0–61.2)	53.8 (47.1–59.4)	51.2 (44.0–56.9)	52.1 (46.0–58.4)	2.6 (2.0–3.0)	2.7 (2.0–3.2)
		Controls	61.8 (55.0–66.7)	60.7 (54.0–65.3)	57.6 (52.0–62.8)	58.0 (52.3–63.1)	3.2 (3.0–3.5)	3.3 (3.0–3.7)
	50,000–100,000 PKR	Cases	59.9 (53.0–66.5)	58.0 (51.0–63.4)	55.5 (48.0–61.2)	57.3 (50.0–63.5)	3.0 (2.0–3.3)	3.1 (2.0–3.4)
		Controls	68.2 (62.0–73.3)	66.0 (59.0–71.4)	62.4 (56.0–68.1)	64.1 (58.0–70.0)	4.0 (3.0–4.2)	4.0 (3.0–4.2)
	>100,000 PKR	Cases	64.9 (59.0–71.0)	61.7 (56.0–67.2)	59.3 (53.2–65.0)	62.3 (57.0–68.4)	3.5 (3.0–3.8)	3.6 (3.2–4.0)
		Controls	72.3 (67.0–77.1)	70.5 (65.3–75.8)	66.7 (61.0–72.3)	70.2 (65.1–75.4)	4.3 (4.0–4.5)	4.4 (4.0–4.6)
Residence	Rural	Cases	57.2 (50.0–63.4)	55.9 (49.0–61.0)	53.5 (46.2–60.0)	54.1 (48.0–60.7)	2.9 (2.0–3.2)	2.9 (2.0–3.3)
		Controls	64.0 (57.0–69.8)	62.5 (55.0–68.4)	59.3 (53.0–65.1)	61.0 (55.0–66.7)	3.4 (3.0–3.8)	3.5 (3.0–3.9)
	Urban	Cases	61.0 (54.0–68.0)	59.3 (52.0–65.1)	56.1 (49.0–62.5)	58.2 (52.0–65.0)	3.2 (2.0–3.3)	3.1 (2.0–3.4)
		Controls	69.0 (62.0–74.5)	67.1 (60.0–72.6)	63.4 (56.0–69.3)	64.9 (59.0–71.5)	4.0 (3.0–4.2)	4.1 (3.0–4.3)

Note: p -values < 0.001 for all comparisons, based on the Mann-Whitney U test comparing cases and controls within each stratum.

DISCUSSION

The present study demonstrated that parents of children with developmental disabilities reported significantly lower quality of life across all four WHOQOL-BREF domains and both global items when compared with parents of children without such conditions. These findings highlight the broad psychosocial burden borne by families and underline the need for targeted support interventions. Physical health scores were significantly lower among parents of children with developmental disabilities. This observation aligns with regional data where impairment in all four domains among caregivers of children with intellectual disability and ASD were observed, indicating that physical strain is a core component of caregiving [1]. A study from Hong Kong reported no significant difference in physical health between parents of children with disabilities and those of typically developing children [13]. This discrepancy may reflect differences in sample characteristics, as the current study included children with conditions such as cerebral palsy and GDD which are associated with high caregiving demands. In contrast, the study had broader inclusion criteria with less severely disabling conditions [13]. Physical health of caregivers could be closely tied to the severity and functional limitations of the child, suggesting that parents of children with greater dependency require structured physical support and respite care programs.

Psychological health was also significantly compromised among parents of affected children. Similar findings have been reported by others where impairment in psychological well-being among caregivers of children with developmental disorders have been observed [1, 14]. Self-esteem, optimism, and perceived stress have also been deemed to strongly influence parental psychological QoL especially in families of children with ASD and Down syndrome [15]. The alignment of the current results with multiple international studies underscores that psychological distress is a global phenomenon among such caregivers [16, 17].

Social relationships were markedly affected in this study as parents of children with disabilities reported significantly lower scores in this domain. Some other studies have also demonstrated a significant association between parental gender and social quality of life, suggesting that mothers are particularly vulnerable due to societal expectations and caregiving roles [18]. In contrast, analysis of parents of asthmatic children have been reported to have lower but less pronounced reductions in social domains

which may be due to asthma being a treatable chronic condition with less enduring social stigma than developmental disabilities [19]. The environment domain yielded significantly lower scores among cases, and similar trends were described in another study among caregivers of children with Down syndrome in Saudi Arabia [20], and from Bosnian mothers of disabled children [21].

The two global items of overall QoL and general health also showed substantial impairment among parents of children with disabilities in this study. Comparable reductions have been reported by others who noted that parents of children with ASD and mental retardation consistently rated their overall life satisfaction and general health as poorer than parents of healthy children [1, 14]. A study from Hong Kong did not find significant differences in these items, which may again be attributed to cultural factors and less severely disabling child conditions in their sample [13]. These differences across studies highlight the role of socio-cultural contexts, with South Asian caregivers often experiencing lower baseline health access and greater stigma, amplifying the adverse effect on global life perception.

An important implication of these findings is that parents with impaired physical and psychological health may face challenges in providing optimal care which can influence the developmental outcomes of the child [22, 23]. Interventions addressing caregiver well-being are therefore not only essential for parents but also indirectly beneficial for the developmental trajectory of children with disabilities [24, 25].

The study was conducted at a single tertiary-care hospital which may not fully represent the diverse socioeconomic and cultural backgrounds of parents across different regions of Pakistan. As the study was hospital-based, parents seeking clinical care may have different psychosocial stressors compared with those in community settings, potentially influencing QoL scores. This study employed a cross-sectional design which cannot assure causality. The assessment relied on self-reported data which may be influenced by personal perception and social desirability bias despite efforts to ensure confidentiality. Although the WHOQOL-BREF provides a validated multidimensional assessment of quality of life, it may not encompass the full range of emotional, cultural, and caregiving dynamics.

CONCLUSION

Parents of children with developmental disabilities expe-

rience significantly lower QoL across physical, psychological, social, and environmental domains, as well as in overall life satisfaction and general health. The consistency of this finding across all socio-demographic strata emphasizes that caregiving burden is universal and not limited to any single parental subgroup. Clinical and policy responses must therefore extend beyond the child and address the holistic well-being of parents, incorporating strategies such as accessible psychological counseling, community-based social support, targeted financial assistance, and systemic efforts to reduce stigma.

ABBREVIATIONS

ADHD: Attention Deficit Hyperactivity Disorder.

ASD: Autism Spectrum Disorder.

CP: Cerebral Palsy.

GDD: Global Developmental Delay.

ID: Intellectual Disability.

IQR: Interquartile range.

LD: Learning Disabilities.

QOL: Quality of Life.

SD: Standard Deviation.

SPSS: Statistical Package for Social Sciences.

WHO: World Health Organization.

AUTHORS' CONTRIBUTIONS

Shumaila Waseem: Conceptualization, Study Design, Methodology, Data analysis and interpretation, Writing Draft and Final approval, final proof to be published.

Heena Rais: Study Design, Critical review and revision of the manuscript and Final approval, final proof to be published.

Tayyaba Anwar, Muhammad Abid Sharif and Saba Safdar: Methodology, Data analysis and interpretation, Writing Draft and Final approval, final proof to be published.

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ETHICAL DECLARATIONS

Ethical Approval

This comparative cross-sectional study was conducted at the Outpatient Department of Paediatrics, Ziauddin

Hospital, Karachi, Pakistan, during 1st January 2025 to 30th June 2025, following approval from the Institutional Ethical Review Board (letter number: 8810624SWPED, dated: August 17, 2024).

Consent to Participate

Written informed consent was sought from parents for their participation into the study.

Consent for Publication

All authors provided their consent for publication.

Conflict of Interest

Declared None.

Competing Interest/Funding

Declared none.

Use of AI-Assisted Technologies

The authors employed Gemini for the purpose of language refining. All academic contributions, such as study concept, design, data analysis, and inferences, remain the accountability of the authors.

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