Assessment of Quality of Life in Mothers of Visually Impaired Children

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ABSTRACT

Objective: To assess the factors that affect mothers' quality of life (QOL) and the association of various demographic variables with QOL of the respondents.

Study Design: A cross-sectional survey.

Place and Duration of the Study: Al-Shifa Trust Eye Hospital, Rawalpindi, Pakistan, from April to September 2023.

Methodology: Mothers of visually impaired children were selected through non-probability consecutive sampling. WHO QOL-BREF was used to analyse the QOL of the respondents. The Chi-square test of association was applied to determine the factors of QOL of the respondents.

Results: Out of 264, the majority of the visually impaired children were females (n = 144, 54.5%) and belonged to 5-8 years of age (n = 115, 43.6%). It was also noted that the majority of children had mild levels of visual impairment (n = 182, 69%). More than half of the mothers of visually impaired children were married to their cousins (n = 144, 54.5%) and belonged to rural areas (n = 140, 53%). Most of the mothers perceived that they had a good quality of life (n = 96, 36%) and were satisfied with their health status (n = 107, 40%). Mothers with poor QOL were slightly more in numbers compared to those with good QOL (n = 134. 51% *vs*. n = 130. 49%).

Conclusion: Mothers of visually impaired children exhibited poor QOL in all four domains. Major related factors associated with poor QOL of mothers were the age of the child, cause of disability, duration of disability, and duration of caregiving. While mother's related factors included marital status, outside family marriage, education, income level, number of children, and residence.

Key Words: *Mothers, Quality of life, Rawalpindi, Tertiary care hospitals, Visually impaired children.*

How to cite this article: Rubab ZE, Tahir M, Zafar U, Rehman NU. Assessment of Quality of Life in Mothers of Visually Impaired Children. *J Coll Physicians Surg Pak* 2025; **35(01)**:116-121.

INTRODUCTION

The visual system plays a crucial role in connecting individuals with their environment by processing the incoming light through the eyes and interpreting this sensory input in the occipital lobe of the brain, ultimately enabling vision and perception.[1] Visual impairment refers to a condition where there is a decline in the functioning of an individual's visual system, resulting in various challenges such as decreased visual acuity, visual distortion, difficulties in perception, and a reduced ability to engage in everyday activities such as reading, writing, moving around, and participating in recreational pursuits. The loss of vision in children has a significant impact on their developmental trajectory, as well as their overall well-being. This not only affects the child's personal growth but also poses challenges to the family dynamics and quality of life for parents.[2]

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Received: January 01, 2024; Revised: March 28, 2024; Accepted: November 12, 2024
DOI: https://doi.org/10.29271/jcpsp.2025.01.116

Around the world, 2.2 billion individuals are affected by vision impairments, encompassing both near and distance vision issues.[3] According to the statistics of the Global Burden of Disease 2017 report, the third leading impairment was blindness and vision impairment which affected most people, with 1.34 billion cases worldwide. Globally as of 2017, 48.2 million people were blind, an additional 39.6 million had severe vision impairment, 279 million had moderate vision impairment, and 969 million had near vision impairment.[4] Specifically, in Pakistan, a survey conducted by the Blind Welfare Association in 2019 revealed that there are 1.9 million visually impaired children within the country.[5]

The causes of visual impairment in children differ significantly between regions, with the prevalence of cataracts being the lowest.[6] Globally, the leading causes of blindness and moderate and severe visual impairment include uncorrected refractive error and cataracts.[7]

It encompasses several dimensions, including physical functions, mental well-being, social relations within and outside the family, environmental impact[8] as well as personal development, and emotional and social aspects.[9-11] Parents of disabled children face numerous challenges in caregiving, education, and treatment, which often lead to tensions within family relationships. Consequently, the quality of life of family members, including parents, may be adversely affected,[9] leading to reduced life satis-

faction overall. Various factors play a crucial role in determining the quality of life of caregivers of visually impaired children. Child behaviour problems are an important predictor of caregiver's psychological well-being, both directly and indirectly, through their effect on family function.[10] Children's health problems, future concerns, children's continuous need for care, children's education, caregiving demands, and an economic load of the disease are the leading causes of stress for families.[11] Higher-level education facilitates the process of information gathering and improves mothers' ability to do more comprehensive problem-solving.[10] There is a major connection between the evaluation of the quality of a parent's life and the evaluation of the quality of their children's life. The more satisfied parents are with their quality of life, i.e., the better they estimate their welfare, the better the evaluations for the quality of life of their children.[12] The main aim of the current study was to assess the quality of life and those factors that affect the QOL in mothers of visually impaired children as well as to find out the association of various sociodemographic variables with QOL in mothers of visually impaired childrens. This subject has implications for mothers' well-being, and their children's development, as well as healthcare and social policies.

METHODOLOGY

A cross-sectional survey was carried out at the Al-Shifa Eye Trust Hospital, Rawalpindi, from April to September 2023. A total of 264 mothers of boys and girls aged 5-17 years who met the inclusion criteria were consecutively included in this study. Those children who did not have a parent or caregiver with them were excluded from the study. The sample size was calculated using the proportion formula for sample size calculation in Open-Epi menu, version 3.01 software. Data were collected through an interview-based questionnaire which consisted of sociodemographic characters of children and mothers along with the questions regarding the QOL of their mothers. QOL was assessed using an adapted WHO QOL-BREF Australian version questionnaire. It is a five-point Likert Scale ranging from 1 = very poor to 5 = very good. The scale contained a total of 26 questions covering different aspects of health such as physical, psychological, social, and environmental. Pilot testing was performed before starting the formal data collection procedure by including 10% of the actual sample size (n = 26). The questionnaire was tested for any future changes; no major changes were made after pilot testing. The reliability of the scale was checked through the value of Cronbach's alpha using SPSS version 26. The overall reliability of the scale was 0.91. Reverse coding was done for the desired scale items before proceeding with further analysis. The computed response for QOL was calculated for each respondent by adding the individual responses in SPSS. Computed scores for all domains of the scale (physical, psychological, social interaction, and environment) were also calculated. Continuous variables were categorised to proceed with the analysis.

Data were analysed using SPSS version 26. Descriptive analysis was carried out through frequencies and percentages while the Pearson's Chi-Square test of independence was used to determine the association between QOL and the sociodemographic characteristics of the respondents. A p-value less than 0.05 was considered statistically significant.

RESULTS

A total of 264 respondents were included in this study. The majority of the visually impaired children were females (n = 144, 54.5%) and belonged to the age group of 5-8 years (n = 115, 43.6%). The major cause of visual impairment in most of the children was congenital abnormality (n = 147, 55.7%) while refractive error was the most common visual impairment observed among children (n = 91, 34.5%). The findings of the study showed that the majority of the children had mild level of visual impairment (n = 182, 69%) while blind children were 11% (n = 29), and most of the children had some kind of visual impairment for more than 5 years (n = 85, 32.2%).

WHO QOL-BREFF measured QOL in four domains of physical health, psychological health, environment, and social relations. It was noted that a significant number of respondents had poor physical and psychological health (n = 138, 52.3%). Environmental domain and social relations also depicted that most of the mothers exhibit poor QOL in these domains. Findings of the study revealed that the overall QOL of the mothers of visually impaired children showed mothers with poor QOL were slightly more in number as compared to those with good QOL (n = 134, 51% *vs.* n = 130, 49%).

The physical health of the mothers was significantly affected by the age of the child (p = 0.042), cause of impairment (p = 0.028), and duration of impairment (p = 0.002). Results revealed that the physical health of the mothers of 9-11 years of children was comparatively poor as compared to mothers of other children. Similarly, mothers whose children had congenital visual impairment reported relatively good physical health as compared to those whose children were affected with non-congenital visual impairment. Likewise, mothers whose children were visually impaired for more than 5 years reported relatively good physical health as compared to those mothers whose children were recently diagnosed with visual impairment. Results are given in Table I.

The association of the psychological health of the mothers with sociodemographic characteristics of the visually impaired children was determined and noted that the psychological health of the mothers was significantly influenced by the age of the child (p <0.001). Findings suggested that mothers whose children were above 12 years, reported relatively good psychological health as compared to those whose children were of young age group (Table II).

The association of environmental health of the mothers with sociodemographic characteristics of the visually impaired children was determined that mothers whose children were 15-17 years of age presented relatively poor environmental health as compared to mothers of other children, (p = 0.014). Similarly, mothers whose children were congenitally visually impaired, presented good environmental health as compared to those whose children were diagnosed with some visual impairment later in life (p <0.001). Likewise, mothers whose children were visually impaired for more than 5 years, reported relatively good environmental health as compared to others (p = 0.002).

Table I: Association of physical health of mothers with sociodemographic characters of mother.

Sociodemographic characteristics of the mothers	Physical health of mothers		χ^2 (df)	p-value
	Poor n (%)	Good n (%)		
Marital status			1.83 (2)	0.399
Married	116 (53)	102 (47)		
Divorced	9 (39)	14 (61)		
Widow	13 (56)	10 (44)		
Husband			3.12 (2)	0.210
First / Second cousin	75 (52)	69 (48)		
Distant relative	22 (43)	29 (57)		
Out of family	41 (59)	28 (41)		
Residences			0.617 (1)	0.432
Urban	68 (55)	56 (45)		
Rural	70 (50)	70 (50)		
Education of mothers			4.63 (4)	0.327
Illiterate	39 (57)	29 (43)		
Primary	22 (50)	22 (50)		
Secondary	35 (60)	23 (40)		
Diploma	17 (47)	19 (53)		
Graduation	25 (43)	33 (57)		
Occupation of mothers			7.72 (3)	0.052
Housewife	87 (53)	77 (47)		
Day labourer	30 (56)	24 (44)		
Govt. employee	16 (39)	25 (61)		
Others	5 (100)	0 (0)		
Monthly income			6.87 (3)	0.076
Less than 20,000	25 (68)	12 (32)		
21,000-50,000	70 (56)	58 (44)		
51,000-100,000	22 (44)	29 (56)		
More than 100,000	21 (44)	27 (56)		
Family type			0.860 (1)	0.354
Nuclear	67 (55)	54 (45)		
Joint	71 (49)	72 (51)		
Total number of children			2.02 (2)	0.363
1-3	74 (53)	66 (47)		
4-5	48 (56)	38 (44)		
More than 5	16 (42)	22 (58)		
Number of disabled children			3.61 (2)	0.164
1-2	118 (51)	112 (49)		
More than 2	20 (63)	12 (73)		

Pearson's Chi-square test of association was applied to determine the factors of QOL of the respondents.

Table II: Association of sociodemographic characters of children with psychological health of mothers.

Sociodemographic characteristics of the mothers	Psychological health of mothers		χ^2 (df)	p-value
	Poor n (%)	Good n (%)		
Marital status			10.65 (2)	0.005
Married	115 (53)	103 (47)		
Divorced	6 (26)	17 (74)		
Widow	17 (74)	6 (26)		
Husband			6.84 (2)	0.033
First / Second cousin	71 (49)	73 (51)		
Distant relative	22 (43)	29 (57)		
Out of family	45 (65)	24 (35)		
Residences			5.87 (1)	0.015
Urban	55 (44)	69 (56)		
Rural	83 (59)	57 (41)		
Education of mothers			2.34 (4)	<0.001
Illiterate	48 (71)	20 (29)		
Primary	26 (59)	18 (41)		
Secondary	30 (52)	28 (48)		
Diploma	16 (44)	20 (56)		
Graduation	18 (31)	40 (39)		
Occupation of mothers			2.01 (3)	<0.001
Housewife	90 (55)	74 (45)		
Day labourer	36 (67)	18 (43)		
Govt. employee	9 (22)	32 (78)		
Others	3 (60)	2 (40)		
Monthly income				
Less than 20,000	29 (78)	8 (22)		

Pearson's Chi-square test of association was applied to determine the factors of QOL of the respondents.

The association of the environmental health of the mothers with their sociodemographic characteristics was determined and noted that the environmental health of the mothers who were widows was poor as compared to those who were married or divorced (p = 0.005). Similarly, mothers living in urban areas reported good environmental health as compared to those living in rural areas (p <0.001). Likewise, mothers with no education reported poor environmental health as compared to those who received some formal education (p <0.001). Furthermore, mothers who were government employees reported good environmental health as compared to those who were housewives or day labourers (p <0.001). Likewise, mothers whose monthly income was poor also reported poor environmental health as compared to those who were higher in the social ladder (p <0.001). Similarly, mothers living in a joint family system reported poor environmental health as compared to those who were living in a nuclear family (p = 0.007). Furthermore, mothers with more than 5 children reported good environmental health as compared to those who had a smaller number of children (p = 0.026). It was also observed that mothers who were giving care to visually impaired children for a longer time reported relatively good environmental health as compared to those with less duration of caregiving (p = 0.012). Pearson's Chi-square test of association was applied to determine the factors of QOL of the respondents.

The association of social health of the mothers with sociodemographic characteristics of the visually impaired children was determined that mothers whose children were in the 9-11 years of age range, reported relatively poor social health as compared to others (p = 0.026). Likewise, mothers with children having congenital visual impairment reported good social health as compared to those whose children developed visual impairment later in life (p <0.001). It was also noted that mothers whose children were diagnosed with glaucoma reported poor social health as compared to those whose children had other visual impairments (p <0.001). Similarly, it was also found that mothers whose children had visual impairment for a long duration reported good social health as compared to those whose children had less duration of visual impairment (p = 0.039).

The association of social health of the mothers with their sociodemographic characteristics was determined and results of the Chi-square test revealed that mothers who were widowed reported poor social health as compared to married or divorced (p = 0.001). Similarly, mothers who were married out of family reported poor social health as compared to those who were married to a distant relative or their first cousin (p = 0.047). It was found that mothers with high education levels reported poor social health as compared to those with low education levels (p = 0.028). Likewise, it was also found that mothers who were living in a nuclear family reported poor social health as compared to those living in a joint family (p = 0.011). It was also found that mothers who had a smaller number of children (1-3 children) reported good social health as compared to those with a greater number of children (p = 0.003). Pearson's Chi-square test of association was applied to determine the factors of QOL of the respondents.

DISCUSSION

In the present study, the QOL of the mothers of visually impaired children was assessed using the WHO QOLBREF along with finding the factors that affect their QOL. Moreover, an association of QOL of the mothers of visually impaired children with sociodemographic characteristics was also determined. Results of the study showed that the majority of the mothers of visually impaired children were satisfied with their health status (n = 107, 40%) and perceived that they had a good quality of life (n = 96, 36%). It was also observed that a considerable proportion of participants (n = 138, 52.3%) experienced poor physical and psychological well-being. The environmental aspect and social interactions similarly indicated that the majority of the mothers demonstrated low quality of life. The findings of the present study are consistent with the literature previously available. A study conducted in Saudi Arabia in 2021 revealed that social well-being and environmental well-being reported by mothers of disabled children were significantly lower.[6]

The findings of the current study also indicated that the mothers with overall poor QOL were slightly more in number as compared to those who have good QOL. Previous studies also confirm the current findings regarding the QOL of mothers. The study's findings demonstrated a notable association between the QOL of mothers and the ages of their children across various dimensions. Specifically, the physical health of mothers exhibited a significant association with the age of their children. Mothers with children aged 9-11 years (n = 44, 67%) showed notably poor physical health as compared to other groups. Similarly, the psychological health of mothers showed a significant relationship with the age of visually impaired children. A significant majority of mothers with children in the 9-11-year age group (n = 42, 64%) reported experiencing poor psychological health compared to those in other age groups. Furthermore, the social health of mothers displayed a significant link to the ages of their children. Mostly, the mothers having children from the age group of 9-11 years (n = 41, 62%) were facing poor social health as compared to the other group. In addition, the environmental health of mothers was also significantly connected to the ages of their children. Mothers with children aged 9-11 years showed a notably low level of environmental health, accounting for (n = 44, 67%) of cases. These findings are somehow consistent with the previous studies. A study that was conducted by Yu *et al.* in 2017 in China also found that the quality of life of mothers of visually impaired children is significantly affected by the age of the child concerning all four domains of QOL: Physical health, psychological health, social health, and environmental

health.[12] On the contrary, a study that was conducted by Hanif *et al*. in 2023, showed that a child's age does not have a significant association with the parents' QoL.[13]

The present study also revealed that the specific types of visual impairment were notably linked to the social health of mothers. Particularly, mothers with children diagnosed with glaucoma tended to experience a lower QOL. These findings are associated with the previous ones. AlQurashi *et al*. carried out research in 2017 in Saudi Arabia. The study aimed to evaluate the QOL measures of mothers of children with glaucoma. The findings of the study showed poor QOL with mother caregivers.[14] Another research was conducted by Basilious *et al.* in 2022. The study aimed to describe the caregiver burden and QOL of caregivers of paediatric glaucoma patients. Results of the study indicated a significantly higher burden and poor QOL in caregivers.[15]

This cross-sectional study limits the establishment of a causal relationship. However, recall bias of mothers may be another limitation which can affect the results of the study. This study was conducted on a specific population with a small sample size. Therefore, the results of the current study cannot be traced to a larger context without further investigation as well as time constraints were also considered as a limitation in this study.

CONCLUSION

Most of the mothers of visually impaired children exhibited poor QOL in all four domains. The major factors that are affecting the QOL of mothers include the age of the child, congenital visual impairment in the child, less than 1-year duration of impairment, and caregiving while other factors include women being a widow, outside family marriage, illiteracy, low-income level, involvement in day labour, rural residence, and large number of children. It was noted that mothers who were educationally and financially empowered and living in urban localities reported relatively good QOL in all four domains.

ETHICAL APPROVAL:

The study was conducted after obtaining approval from the IRB of Al-Shifa School of Public Health, Pakistan Institute of Ophthalmology Al-Shifa Trust, Rawalpindi, Pakistan (MSPH-IRB/15-13).

PATIENTS' CONSENT:

Informed consent was obtained from all the paticipants before conducting the study.

COMPETING INTEREST:

The authors declared no conflict of interest.

AUTHORS' CONTRIBUTION:

ZER: Conception, data analysis, and data interpretation.
MT, UZ, NUR: Data collection, data entry, and manuscript formatting.
ZER, MT, UZ, NUR: Methodology.
All authors approved the final version of the manuscript to be published.

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