

Master of Science in Public Health



**Assessment of Quality of Life in Mothers of
Visually Impaired Children in a Tertiary Care
Hospital, Rawalpindi**

By

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Pakistan (2023)**

*(Assessment of Quality of Life in Mothers of Visually
Impaired Children in a Tertiary Care Hospital,
Rawalpindi)*

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(362892 PIO/MSPH 2021)

Dissertation submitted in partial fulfilment of the requirement for the degree
of:

MASTER OF SCIENCE IN PUBLIC HEALTH (2023)

to

**Al-Shifa School of Public Health, PIO, Al Shifa Trust Eye Hospital,
Rawalpindi.
Quaid-I-Azam University, Islamabad.**

Word Count 11,186

Declaration

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This dissertation is the result of an independent investigation. Where my work is indebted to others, I have made acknowledgments.

I declare that this work has not been accepted in substance for any other degree, nor is it currently being submitted in candidature for any other degree.

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*This thesis is dedicated to my
beloved parents and my supportive
family.*

ABSTRACT

Background: Mothers of visually impaired children often deal with isolation, finances, caregiving, healthcare, education, and emotional stress, harming their quality of life (QOL).

Objectives: This study was aimed to assess the QOL of mothers of visually impaired children, to assess those factors that affect QOL of the mothers and the association of various socio demographic variables with QOL of the respondents.

Methodology: A cross-sectional study was carried at a tertiary care hospital of Rawalpindi. A total of 264 mothers of visually impaired children were selected through non-probability consecutive sampling. Data were entered and analyzed using SPSS version 26.0. WHOQOL-BREF was used to analyze the QOL of the respondents. Chi-square test of association was applied to determine the factors of QOL of the respondents.

Results: Out of total sample, majority of the visually impaired children were female (n=144, 54.5%) and belong to 5-8 years of age (n=115, 43.6%). It was also noted that majority of the children had mild level of visual impairment (n=182, 69%). More than half of the mothers of visually impaired children were married to their cousin (n= 144, 54.5%) and belonged to rural area (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%). A significant number of respondents had poor physical and psychological health (n=138, 52.3%). Overall, it was observed that mothers with poor QOL were slightly more in number as compared to those with good QOL (n=134, 51% vs n= 130, 49%).

Conclusion:

Mothers of visually impaired children exhibited a poor QOL in all four domains. Major child related factors associated with poor QOL of mothers are age of 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.

Keywords: Mothers, Quality of life, Rawalpindi, Tertiary care hospitals, visually impaired children.

ACKNOWLEDGMENTS

In the name of Allah, the most Merciful and Beneficent

First of all, I am thankful to Allah Almighty, the most merciful and beneficent, for making the journey of my life till this point, including the completion of my thesis, which is a blessing indeed. My utmost gratitude to my thesis supervisor, **Dr. Saman Waqar**, without her expertise and guidance this would not have been possible. In spite of her busiest and tiring routine, she had always provided me with her adroit guidance and worthy suggestions throughout this time. I would like to thank all my teachers who furthered my early and professional development during my education life. I would also like to pay my gratitude to the hospital administration who permitted me to collect data. My deepest gratitude to the patients who had spared their precious time and provided me required information for the completion of my study. I owe my supreme gratitude towards my parents for their unconditional love and support for me. They have always supported me in each and every phase of the life. Whatever I am and wherever I am, is just because of the altruistic love of my parents. Their prayers have made me strong enough to face every problem and difficulty of the life. I would also like to extend my gratitude to my dearest friends, who owe me a big time for their support throughout my research work. I humbly thanks to all the persons who have supported me in this regard.

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LIST OF ABBREVIATIONS

IRB	Institutional Review Board
MCD	Mothers of Children with Disabilities
O&M	Orientation and Mobility
PCG	Primary Congenital Glaucoma
QOL	Quality of Life
USDHHS	United States Department of Health and Human Services
VI	Visual Impairment
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life-BREF

CHAPTER I: INTRODUCTION

The visual system plays a crucial role in connecting individuals with their environment by processing incoming light through the eyes and interpreting this sensory input in the occipital lobe of the brain, ultimately enabling vision and perception (Getnet et al., 2021).

Visual impairment (VI) 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 like reading, writing, moving around, and participating in recreational pursuits (United States Department of Health and Human Services, 1996). 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 (Broek et al., 2017).

Around the world, approximately 2.2 billion individuals are affected by vision impairments, encompassing both near and distance vision issues (Yekta et al., 2022). Alarmingly, nearly half of these cases, amounting to 1 billion people, could have been prevented or managed (WHO, 2022). According to the statistics of the Global Burden of Disease (GBD) 2017 report, the third leading impairment was blindness and vision impairment that affected the greatest number of 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 (Hassan et al., 2019) When examining the prevalence of visual impairment, it becomes evident that low- and middle-income regions experience a significantly higher burden, with rates approximately four times higher than those observed in high-income regions. Rates

of unaddressed near vision impairment are significantly higher, exceeding 80%, in western, eastern, and central sub-Saharan Africa (Vishnuprasad et al., 2017). In contrast, the rates of unaddressed near vision impairment in high-income regions such as North America, Australasia, Western Europe, and the Asia-Pacific region are reported to be lower than 10%. This indicates a substantial disparity in access to vision correction services between these regions (Yekta et al., 2022). 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 (WHO, 2022). According to the Pakistan's National Census Report 2017, the population of Pakistan increased by 60% from 1998 to 2017, whereas the total burden of vision loss (all vision impairment categories inclusive) increased by 43% during this time (Hassan et al., 2019).

The causes of visual impairment in children differ significantly between regions, with the prevalence of cataract being lowest and macular degeneration being greatest in high-income regions (Alswailmi, 2018). Globally, the leading causes of blindness and moderate and severe visual impairment include uncorrected refractive error, cataract and macular degeneration (Küçük et al., 2019). In South Africa, the chief causes of childhood blindness include retinitis pigmentosa, albinism, cataract, glaucoma, nutritional causes, infections and inherited genetic disorders (other than retinitis pigmentosa and albinism) (Naipal & Rampersad, 2018).

While the focus in most diseases is primarily on providing care for the patient, it is important to recognize that the lives of parents or primary caregivers can be significantly impacted as well. The responsibilities and demands of caregiving can have a profound effect on their daily lives and overall well-being (Kantipuly et al., 2019). Caregivers play a crucial role in the management of a disease, and this responsibility can have significant

implications for the emotional and physical well-being of the caregiver and their family. The impact on the caregiver's overall health and the dynamics within their family should be recognized as important factors in the context of disease management (ToledanoToledano & Luna, 2020). It is found that parents of children with disabilities experience significant levels of burnout (Cin, Aydın & Ari, 2017). Consequently, they tend to blame themselves, feel like they have failed, struggle to cope with challenges, and may even try to avoid confronting the situation altogether. As a result, these challenges can have a detrimental impact on family relationships and overall quality of life (Aktan, Orakcı & Durnalı, 2020).

In recent years, the concept of quality of life has been extensively explored across various disciplines (Estoque et al., 2019). It encompasses several dimensions, including physical functions, mental well-being, social relations within and outside the family, environmental impact (Stoewen, 2017), as well as personal development, material well-being, and emotional and social aspects (Karimi & Brazier 2016). This overall measure indicates to what extent an individual can function optimally in their life. Parents of disabled children face numerous challenges in caregiving, education, treatment, and upbringing, which often lead to tensions within family relationships. Consequently, the quality of life of family members, including parents, may be adversely affected (Misura & Memisevic 2017), leading to reduced life satisfaction overall.

Various factors play a crucial role in determining the quality of life of the caregivers of the visually impaired children. Child behavior problems are an important predictor of caregiver psychological well-being, both directly and indirectly, through their effect on family function (Yıldız et al., 2016). Children's health problems, future concerns, children's

continuous need for care, children's education, caregiving demands and economic load of the disease are the leading causes of stress for family (Koch & Jones, 2018). Education level of the families is an important factor in the child's development and swift recovery of families' adaptation process to the disabled child. Higher-level education facilitates the process of information gathering and improves mothers' ability in more comprehensive problem-solving (Yıldız et al., 2016).

There is a major connection between the evaluation of the quality of parent's life and 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 personal welfare, the better are the evaluations for the quality of life of their children (Batool, Khan & Khanum, 2019).

1.1. Rationale:

Visual impairment is a lifetime disability that can have serious consequences for a child's growth and functioning (Batool, Khan & Khanum, 2019). Mothers play an important role in their children's development and disability management. Mothers' quality of life can have a direct effect on their children's mental and physical health. Mothers of visually impaired children frequently face challenges such as social isolation, financial stress, care burden, managing their child's healthcare requirements, navigating educational institutions, and coping with emotional stress. These difficulties can result in increased stress, anxiety, and depression, which can have a negative effect on a mother's quality of life. However, the quality of life of mothers of visually impaired children is a neglected reality. Therefore, assessing these mothers' QOL is critical to identify their needs and create interventions that can improve their overall well-being, which can have a positive effect on their children's

development. Various studies have been conducted to assess the QOL of caregivers of disable children, yet little is known specifically about the QOL of mothers of visually impaired children.

Therefore, assessing the QOL of mothers of visually impaired children is an important and timely research subject. This subject has implications for mothers' well-being, their children's development, as well as healthcare and social policies. As a result, it is a valuable subject to investigate in current research.

1.2. Objectives:

- 1) To assess the quality of life in mothers of visually impaired children.
- 2) To assess those factors that affect the QOL in mothers of visually impaired children.
- 3) To find out the association of various socio demographic variables with QOL in mothers of visually impaired children.

CHAPTER II: LITERATURE REVIEW

Visual impairment has significant ramifications for the individual throughout their lifespan. The leading causes of vision impairment and blindness at a global level are refractive errors and cataracts. Many studies have been conducted worldwide to find out its causative factors. A review of related international as well as national literature has been conducted to highlight major findings in previous studies.

2.1. Prevalence of Visual Impairments in Children:

Globally, approximately 20,000–40,000 children are born with congenital or childhood cataract each year, leading to an estimated 200,000 children suffering from bilateral cataract and blindness. In the UK, childhood cataract affects about 2.5–3.5 per 10,000 children, with the majority of cases occurring during the first year of life. Genetic mutations are the primary cause of bilateral cataract, with autosomal dominant inheritance being the most common mode, observed in 44% of affected families. Among environmental factors, congenital infections such as toxoplasma, syphilis, varicella-zoster, parvovirus B19, coxsackievirus, rubella, cytomegalovirus (CMV), and herpes simplex virus I and II (TORCH) are significant considerations. While trauma and iatrogenic causes, such as medications and radiation exposure, are also relevant, they are rare in this age group (Suzannah Jo. Et al., 2020).

Approximately 14 million children worldwide are blind. In the past twenty years, due to the implementation of national programs focusing on vitamin A supplementation, vaccination, and sanitation improvements, the causes of childhood blindness in lower income settings have undergone a shift. Childhood glaucoma is responsible for approximately 5% of childhood blindness cases worldwide (Han et al., 2021).

Out of 207.7 million people in Pakistan, an estimated 1.12 million were blind, 1.09 million people had severe vision loss and 6.79 million people had moderate vision loss. Years lived with a disability (YLDs) count of blindness and vision impairment increased by 55% in 2017, which is the tenth highest increase among major health loss causes (such as dietary iron deficiency, headache disorders, low back pain etc.) in Pakistan. Moreover, it was observed that an increase in vision loss burden by 2025 for which Pakistan needs to make more efforts to encounter the growing burden of eye diseases (Hassan et al., 2019).

2.2. Types of Visually Impairment among Children:

The main conditions causing vision impairment or blindness are cataract, refractive errors & glaucoma. The life of a parent or primary caregiver can undergo significant changes, particularly when dealing with a severe or long-lasting condition. One such condition is primary congenital glaucoma (PCG), a relatively uncommon disease that affects different populations with prevalence rates ranging from 1 in 3,300 to 1 in 10,000. This condition is responsible for 4.2–5.0% of childhood blindness (Manju et al., 2019).

Traumatic cataract is a main cause of visual impairment in pediatric populations and is preventable. Untreated cataracts in children lead to tremendous social, economic, and emotional burden to the child, family, and society. Blindness related to pediatric cataract can be treated with early identification and appropriate management. The incidence ranges from 1.8 to 3.6/10,000 per year and the median prevalence is about 1.03/10,000 children (0.32–22.9/10,000). The prevalence of childhood cataract is higher in low-income economies (0.63–13.6/10,000) compared to that of high-income economies (0.42– 2.05/10,000) (Sudarshan et al., 2017).

The prevalence of refractive errors has been estimated in another study to be around 20% in school aged children of Pakistan. A school-based study among students aged 5-16 years from Rawalpindi reported prevalence of 3.35% (Muhammad Zahid et al., 2019).

2.3 Quality of Life of Mothers of Visual Impaired Children:

In numerous cultures, the mother holds the central role in interacting with and caring for her child, particularly during the early stages of growth and development. Mother-child interaction plays a fundamental role in the child's overall development and also brings a sense of fulfillment to the mothering role. The sense of vision is paramount in how human beings perceive the world, and in many societies, it is even regarded as the most precious gift bestowed upon humans by a higher power or considered a divine blessing (Behboodi et al., 2017).

In recent times, there has been an increased emphasis on evaluating the impact of a medical condition on a patient's functioning, participation, and overall quality of life. Quality of life comprises various dimensions, including physical, emotional, and social well-being. The International Classification of Functioning, Disability, and Health for Children and Youth (ICF-CY) has introduced the concept of participation, specifically for children. According to the ICF-CY, participation refers to a person's involvement in life situations, achieved through the execution of various tasks and activities (Ellen et al., 2021). Quality of life and participation differ from each other in that the former is more focused on subjective experiences, while the latter is concerned with objective tasks that a person can or cannot perform. Both aspects, quality of life and participation, are crucial outcomes to assess the impact of a medical condition or the effectiveness of an intervention on a patient's life. (Ellen et al., 2021).

The early stages of life, the parenting environment presents chances for children to cultivate effective stress and emotion regulation abilities, while also forming dependable perceptions of the social, emotional, and physical aspects of the world they interact with. Visual feedback plays a vital role in facilitating early parent-child interaction. In fact, the majority of early human interactions between two individuals rely heavily on visual contact. Infants, in particular, are highly responsive to visual stimuli, and they exhibit a keen sensitivity to how adults mirror their own behaviors through their responses (Serena et al., 2021).

Mothers of sensory impaired children face physical, psychological and social impact of their child's disability, including hopelessness and depression. Firdous et al. carried out research in Pakistan in 2019. Findings of the study showed that sensory impairment of children has a positive effect on the psychological health of mothers (p -value=0.01) (Firdous et al., 2019).

2.4. Risk Factors Associated with Poor QOL among caregivers of visually impaired children:

Parents of blind children shoulder additional parenting responsibilities, including efforts to enhance their children's learning about social activities, self-care, and independence. However, when these parents experience stress and psychological pressure, they may find it challenging to fulfill their parenting roles effectively, which could potentially hinder their children's social, psychological, and physical growth. In such situations, the well-being of both the parents and the children may be at risk. The combination of parenting stress and other factors, such as anger expression, can escalate into more severe parenting problems, including child abuse (Elham et al., 2016).

Caregivers face numerous problems, challenges and issues which affect their psychological wellbeing. The emotional and physical stress that they carry can take many forms like frustration, depression, fatigue, anger, guilt, loneliness, etc. According to United States Department of Health and Human Services Office on Women's Health, care-giving stress affects women more than men. Approximately, 75 percent cases of emotional, physical, or financial stress have been reported by women (Asima et al., 2015).

2.5 Conceptual Framework:

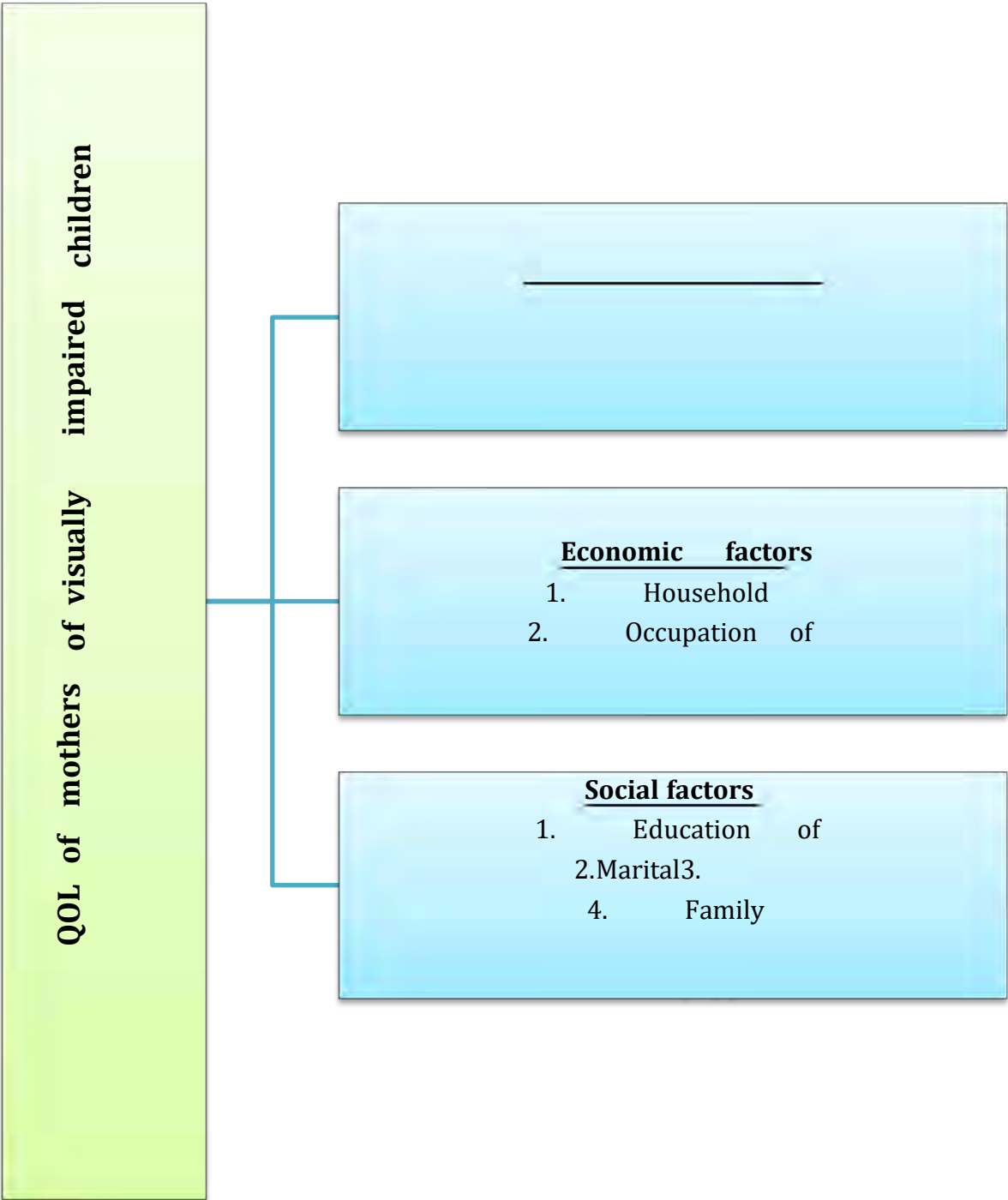


Figure 1: Conceptual framework of QOL of the mothers of visually impaired children

Operational Definitions:

- **QOL** _ The subjective well-being and satisfaction with different aspects of life, such as physical, emotional, social, and psychological functioning, are referred to as quality of life. The QOL in mothers is measured through WHOQOL-BREF questionnaire tool. This validated tool assesses the physical, psychological, social, and environmental domains of QOL. It consists of 26 items that are scored on a 5point Likert scale, with higher scores indicating better QOL (WHO, 2012). Mothers showing QOL below median (256) were considered to have poor overall QOL while those with score above median (256) were considered to have good QOL.
- **Visual impairment** – lowers the ability to see objects or unable to correct at normal levels. It causes severe problems for children’s because normal vision is essential to carry out routine-based activities and tasks. Congenital and non-congenital both are causes of visual impairment in the children. Types of visual impairment includes cataract, glaucoma, refractive errors, blind and others (any eye infection, injury or allergy).
- **WHOQOL-BREF** (World Health Organization Quality of Life-BREF) is a validated questionnaire tool that can be used to measure the QOL of mothers of visually impaired children. This tool assesses the physical, psychological, social, and environmental domains of QOL. It consists of 26 items that are scored on a 5point Likert scale, with higher scores indicating better QOL (WHO, 2012).
- **Social Health:** Social health can be defined as ability of an individual to interact

and form meaningful relationships with others. Mothers with social health score below median (56) were considered as having poor social health while those with score above median were considered as having good social health.

- **Psychological Health:** Psychological health is a state of psychological wellbeing that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. Mothers having scores below median (67) were considered in poor psychological health group while those with scores higher than median were considered as having good psychological health.
- **Environmental Health:** Environmental health is concerned with all aspects of the natural and built environment affecting human health. Women with scores lower than median (44) were considered as having poor environmental health while those with higher scores were considered as having good environmental health.
- **Physical Health:** Physical fitness is a state of health and well-being and, more specifically, the ability to perform various sports, occupations and daily activities. Women with scores lower than median (71) were considered having poor physical health while those having higher scores were considered as having good physical health.

CHAPTER III: METHODOLOGY

3.1 Study design

A quantitative research approach using cross-sectional study design was used for the current study.

3.2. Study Duration:

Study period for the current research was six months from April 2023-September 2023.

3.2. Study Setting:

The study was carried out at Al-Shifa Eye Trust Hospital Rawalpindi.

3.3. Study Participants:

Mothers of male and female visually impaired children visiting Al-Shifa Eye Trust Hospital were included in the study.

3.3.1. Inclusion Criteria:

1. All mothers of children with aged 5 years to 17 years were included.
2. Mothers of both male and female children were included.
3. Those mothers who give consent to participate in the study.

3.3.2. Exclusion Criteria:

1. Those children who do not have parent caregiver with them were excluded from the study.

3.3. Sample Size Calculation:

Sample size was calculated using proportion formula for sample size calculation in Open-Epi menu, Version 3.01 software. Previous prevalence of anxiety among mothers of visually impaired children in District Sheikhpura, Pakistan was taken as 78% (Ramzan & Minhas, 2022). Calculated sample size was 264 with 95% confidence interval (C.I) and 5% margin of error.

Sample Size for Frequency in a Population	
Population size(for finite population correction factor or fpc)(<i>N</i>):	1000000
Hypothesized % frequency of outcome factor in the population (<i>p</i>):	78%+/-5
Confidence limits as % of 100(absolute +/- %)(<i>d</i>):	5%
Design effect (for cluster surveys- <i>DEFF</i>):	1
Sample Size(<i>n</i>) for Various Confidence Levels	
ConfidenceLevel(%)	Sample Size
95%	264
80%	113
90%	186
97%	324
99%	456
99.9%	743
99.99%	1039

Figure 2: Sample size for the current study

3.5. Sampling Strategy:

Desired sample was collected using non-probability consecutive sampling.

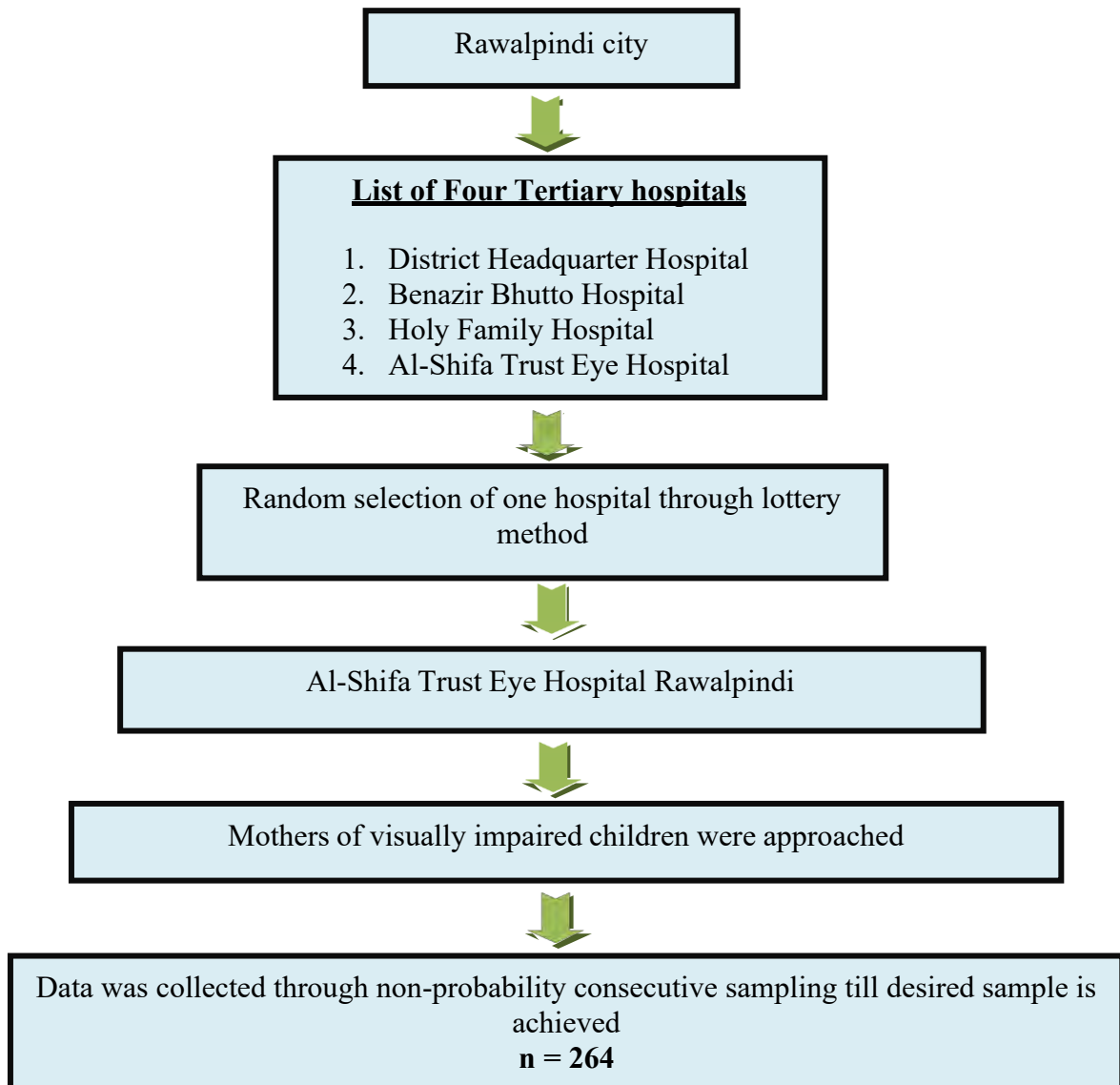


Figure 3: Non-Probability Consecutive Sampling Strategy

3.4. Data Collection Tool:

3.4.1. Questionnaire Design:

Data was collected using an interview-administered questionnaire. A Performa was developed to collect data regarding sociodemographic characters of children and mothers, along with questions regarding QOL of their mothers. QOL was assessed using an adapted WHOQOL – BREF Australian version questionnaire (WHO, 2012).

3.5.1. Content of the Questionnaire:

The questionnaire consisted of three sections:

1. **Section one** included questions related to sociodemographic characteristics of the children such as age, gender etc. This section contained a total of six questions.
2. **Section two** included sociodemographic characteristics of mothers of visually impaired children education of mother, occupation of mother etc. This section contained a total of eleven questions.
3. **Section three** included questions for assessment of QOL of mothers of visually impaired children. For this purpose, WHOQOL-BREF Australian version was adapted (WHO, 2012). 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.

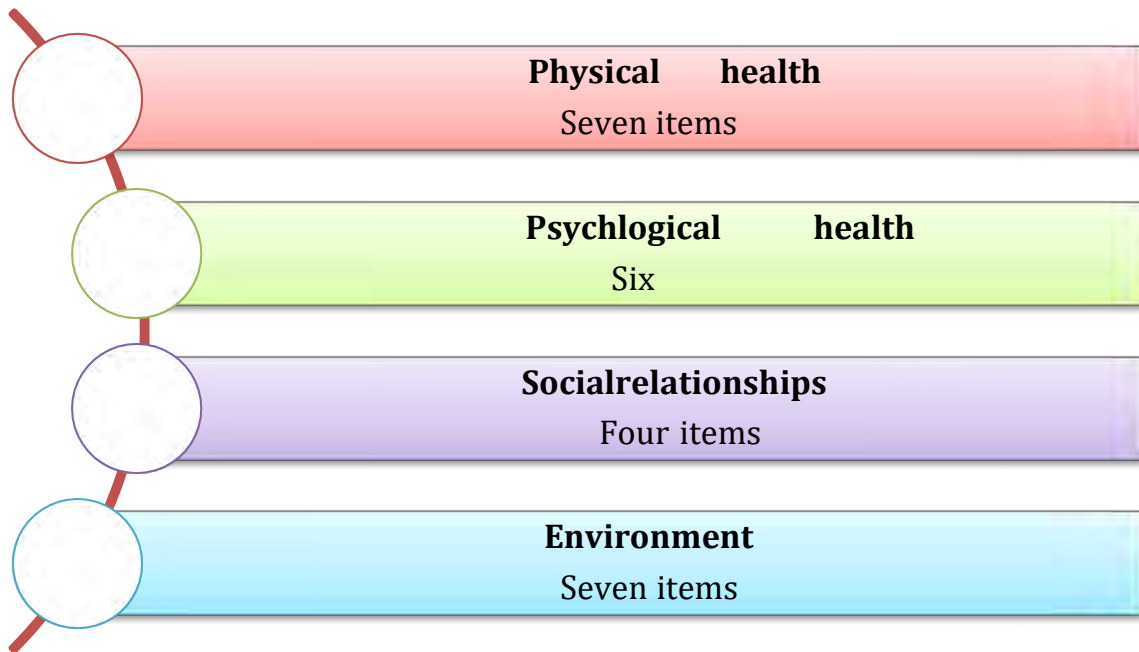


Figure 4: Dimensions of WHOQOL-BREF

3.4.2. Study Variables:

3.7.3.1. Outcome Variable:

QOL in mothers of visually impaired children was taken as outcome variable in current study. QOL was assessed using WHOQOL-BREF Australian version.

3.7.3.2. Independent Variable:

Data on independent variables was collected through a structured Performa that is constructed after international and national literature review. The Performa included sociodemographic variables of mother and children.

3.5. Data Collection Process:

3.5.1. Pilot Testing:

Pilot testing was performed before starting the formal data collection procedure by including 10% of the actual sample size ($n = 26$). Questionnaire was tested for any future

changes; no major changes were done after pilot testing. Reliability of the scale was checked through the value of Cronbach's alpha using SPSS version 26. The value of alpha for physical domain was 0.88, for psychological domain it was 0.87, for social relations it was 0.81 and for environment the value of alpha was 0.87. Overall reliability of the scale was 0.91. (Appendix F).

3.5.2. Data Collection:

All the mothers of visually impaired children visiting Al-Shifa Trust Eye Hospital were approached. Consent was taken from the mothers and they were informed about the purpose of the research. Only those mothers were selected who agreed to take part in the research process and fulfill the inclusion criteria. After taking the consent, the respondents were interviewed and their responses were recorded by the researcher. Data collection was completed in approximately one month.

3.6. Data Analysis Procedure:

Code book was developed and data was entered in Statistical Package for Social Sciences (SPSS) version 26. After careful data entry, data was checked for any error before proceeding to the further analysis.

3.6.1. Data Cleaning:

After careful data entry, data was checked for any missing values and any error that could possibly affect the further analysis. Double entries were eliminated before continuing the further analysis.

3.9.1. Data Transformation:

Reverse coding was done for the desired scale items before proceeding further analysis. 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, environment) were also calculated. Continuous variables were categorized in order to proceed the analysis. QOL computed variable was further categorized in to two categories: poor and good. Similarly, all computed variables of all dimensions were also categorized in to poor and good. Scores of the individual domains were calculated as per the instructions mentioned in WHO manual given in table 1.

Table 1: Scoring of WHOQOL-BREF items

Domain	Scoring
Physical health	$((6 - \text{Question3}) + (6 - \text{Question4}) + \text{Question10} + \text{Question15} + \text{Question16} + \text{Question17} + \text{Question18}) \times 4$
Psychological health	$(\text{Question5} + \text{Question6} + \text{Question7} + \text{Question11} + \text{Question19} + (6 - \text{Question26})) \times 4$
Social relations	$(\text{Question20} + \text{Question21} + \text{Question22}) \times 4$
Environment	$(\text{Question8} + \text{Question9} + \text{Question12} + \text{Question13} + \text{Question14} + \text{Question23} + \text{Question24} + \text{Question25}) \times 4$

To transform score on a 0-100 scale, following formula was used.

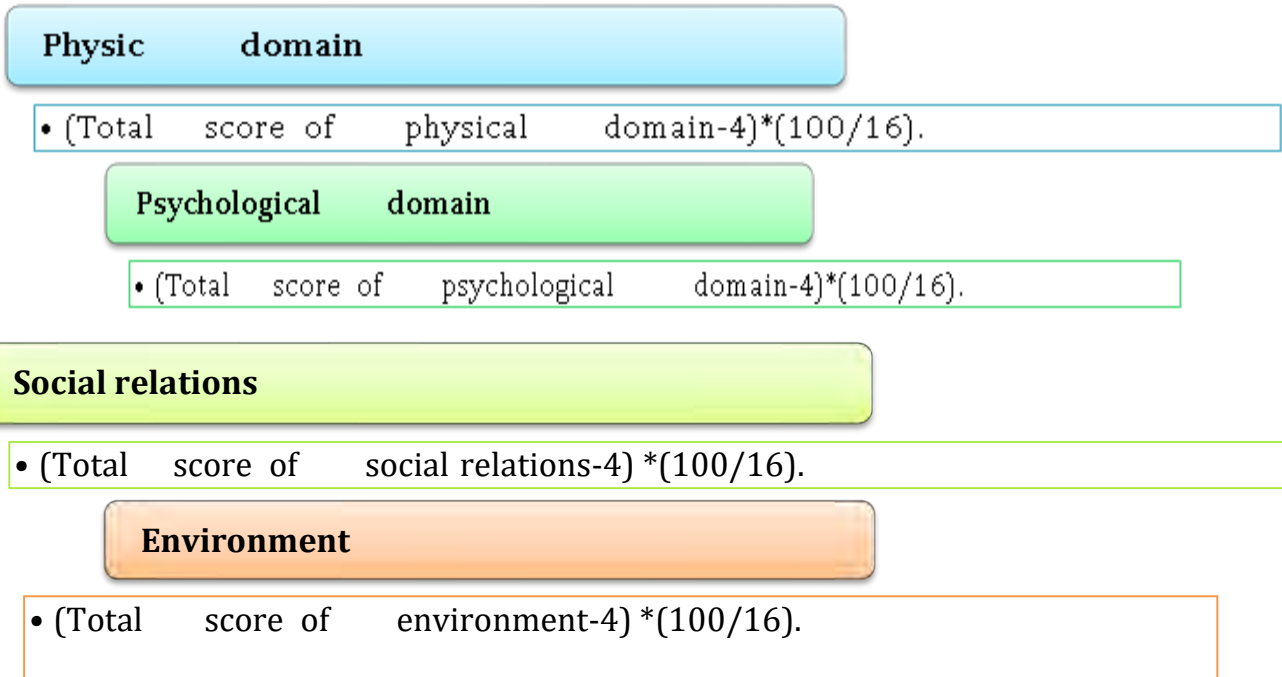


Figure 5: Conversion of WHOQOL-BREFF Score on 0-100 scale The overall score ranges between 0-100. Individuals with higher score were considered having good QOL.

3.9.2. Descriptive Analysis:

Descriptive statistics were generated for sociodemographic characteristics and outcome variable. Data was summarized in the form of frequencies and percentages and presented in table form, Bar chart and Pie chart.

3.9.3. Inferential Analysis:

Pearson Chi Square test of Independence was used to determine the association between QOL and socio-demographic characteristics of the respondents. P value less than 0.05 was considered statistically significant.

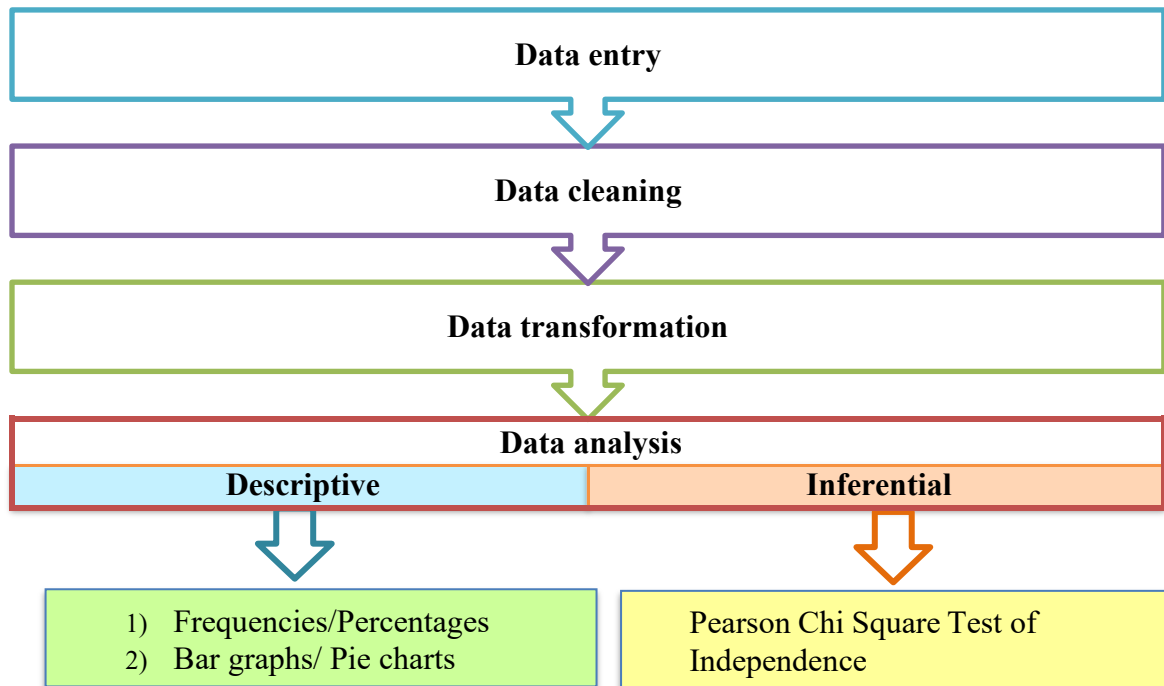


Figure 6: Data Analysis Plan

3.7. Ethical Considerations:

Before starting formal data collection, approval from Institutional Review Board (IRB) of Al-Shifa School of Public Health Rawalpindi, Pakistan has been taken. Permission letter from the Head of Department of Al-Shifa School of Public Health was obtained regarding access to the tertiary health facilities. Permission was taken from hospital for conducting research. Respondents were explained the purpose of the research and oral consent was taken from each participant before collecting the data. Data was collected from only those respondents who had agreed to participate in the research process voluntarily. Participants were assured for the confidentiality of their data. Data collected from the respondents was kept anonymous and was not shared with anyone. Data was entered in SPSS anonymously. After data entry, hard copies of collected were kept at a safe place.

CHAPTER IV: RESULTS

4.1. Demographic characteristics:

A total of 264 respondents were included in the study. Majority of the visually impaired children were female (n=144, 54.5%) and belong to the age group of 5-8 years (n=115, 43.6%). Major cause of visual impairment in most of the children was congenital abnormality (n=147, 55.7%) while refractive error was most common visual impairment observed among children (n=91, 34.5%). A summary of sociodemographic variables of children is given in table 2.

Table 2: Sociodemographic variables of the visually impaired children

S. No	Variable	Frequency (n)	Percentage (%)
1.	Children Age		
	5-8 years	115	43.6
	9-11 years	66	25.0
	12-14 years	32	12.1
	15-17 years	51	19.3
2.	Child's Gender		
	Male	120	45.5
	Female	144	54.5
3.	Cause of Visual Impairment		
	Congenital	147	55.7
	Non-congenital	117	44.3
4.	Types of visual impairment		
	Cataract	61	23.1
	Glaucoma	11	4.2
	Refractive errors	91	34.5
	Blind	29	11.0
	Others	72	27.3

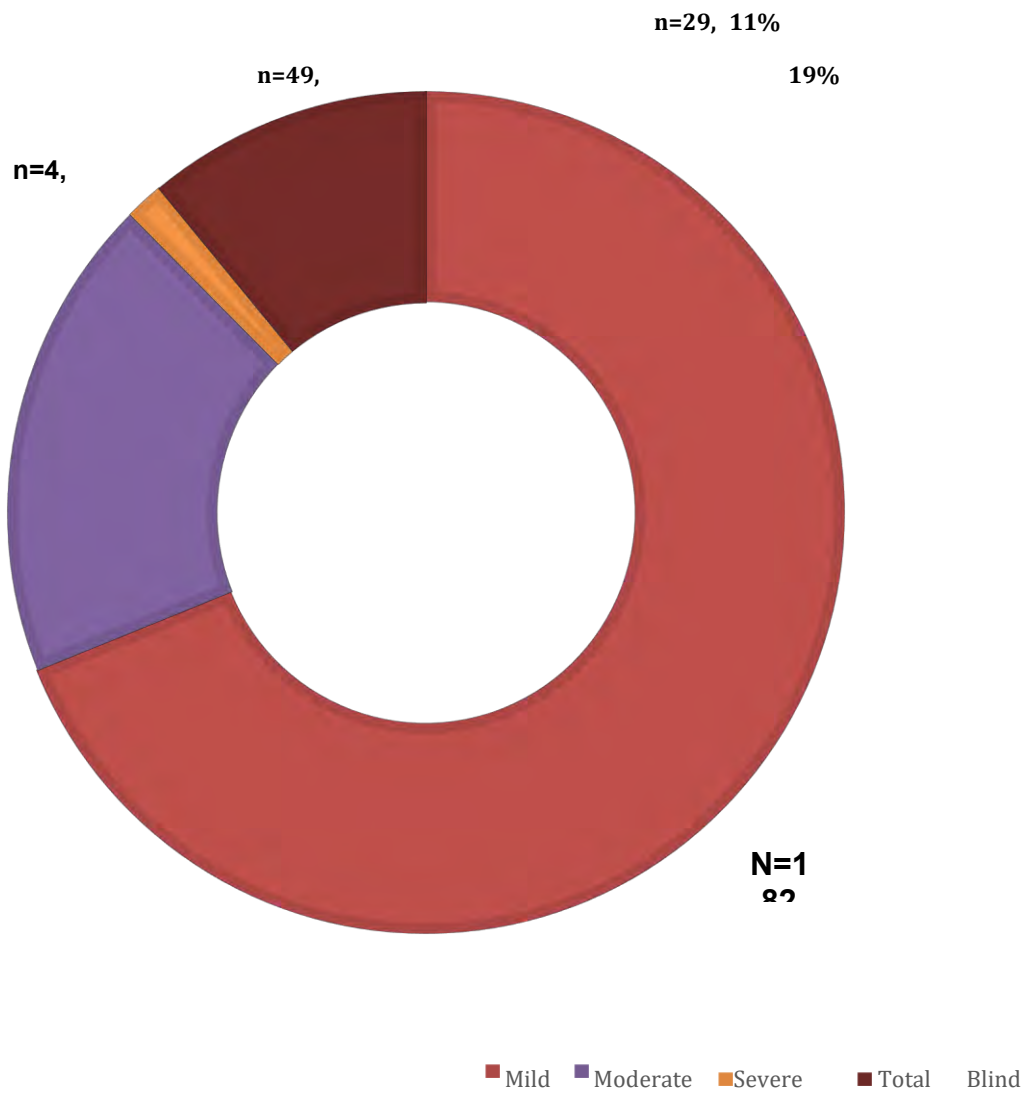


Figure 7: Level of Visual Impairment in Children

Findings of the study showed that majority of the children had mild level of visual impairment (n=182, 69%) while totally blind children were 11% (n= 29) as given in figure 7.

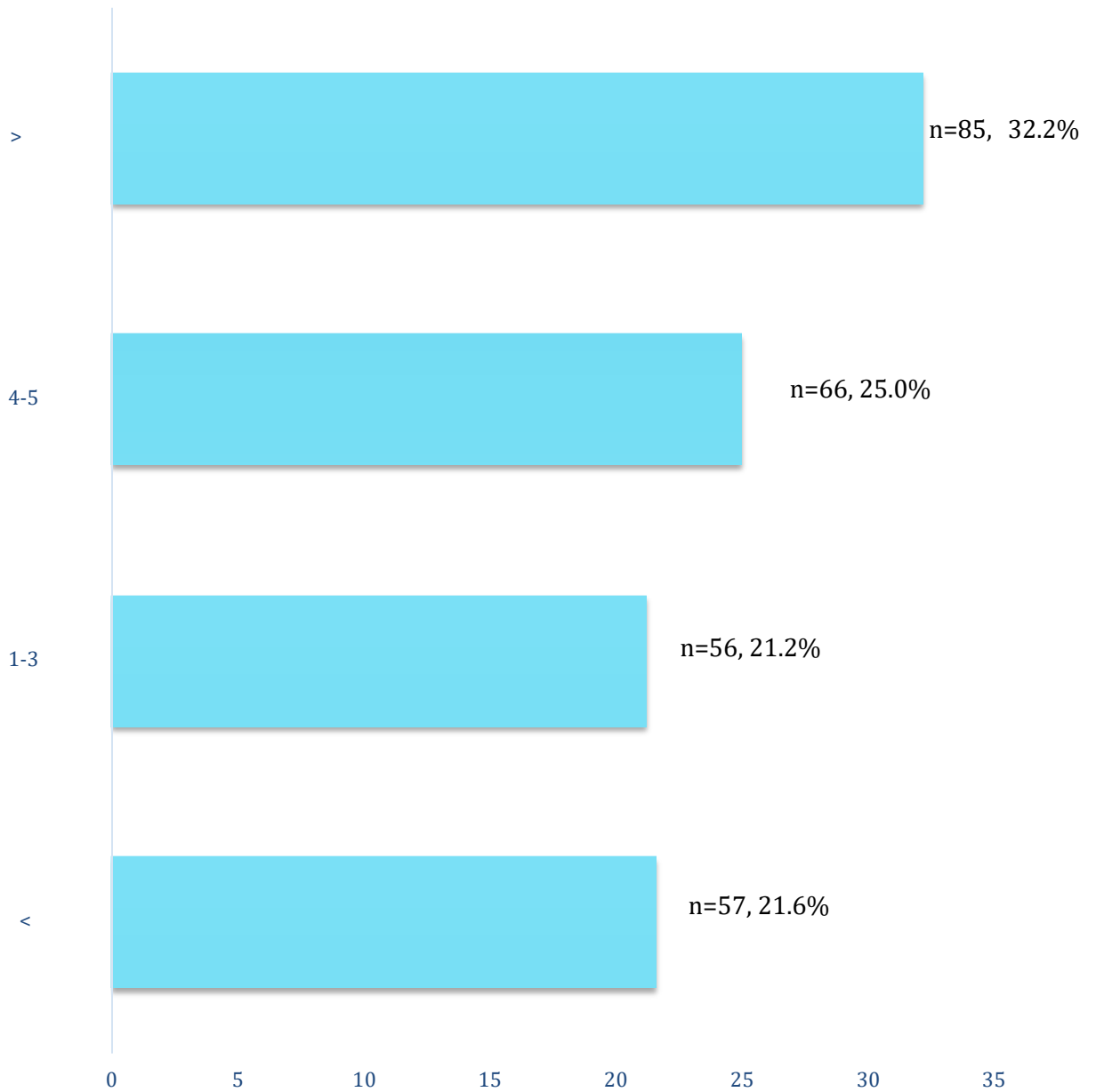


Figure 8: Child's Duration of Visual Impairment

It was noted that most of the children had some kind of visual impairment for more than 5 years (n=85, 32.2%) as given in figure 8.

4.2. Demographic Characteristics of Mothers of Visually Impaired Children:

Sociodemographic characters of mothers of the visually impaired children were also determined. It was noted that majority of the mothers were married to their first or second cousins (n=144, 54.5%) and more than half of the mothers belonged to rural areas (n=140, 53%). A detailed summary of sociodemographic characters of mothers of the visually impaired children is given in table 3.

Table 3: Sociodemographic characters of mothers of visually impaired children

S. No	Variables	Frequency (n)	Percentage (%)
1.	Mother's marital status		
	Married	218	82.6
	Divorced	23	8.7
	Widow	23	8.7
2.	Mother's husband		
	First/second cousin	144	54.5
	Distant relative Outside the family	51 69	19.3 26.1
3.	Mother's residence		
	Urban Rural	124 140	47.0 53.0
4.	Mother's level of education		
	Illiterate	68	25.8
	Primary	44	16.7
	Secondary	58	22.0
	Diploma Graduation	36 58	13.6 22.0
5.	Mother's occupation		
	Housewife	164	62.1
	Day Laborer	54	20.5
	Govt employee Other	41 05	15.5 1.9
6.	Monthly household income		
	< 20,000	37	14.0
	20,000 - 50,000	128	48.5
	51,000-100,000 > 100,000	51 48	19.3 18.2

7.	Family system		
	Nuclear	121	45.8
	Joint	143	54.2

■ 1-3 chi
■ 4-5 ch
■ > 5

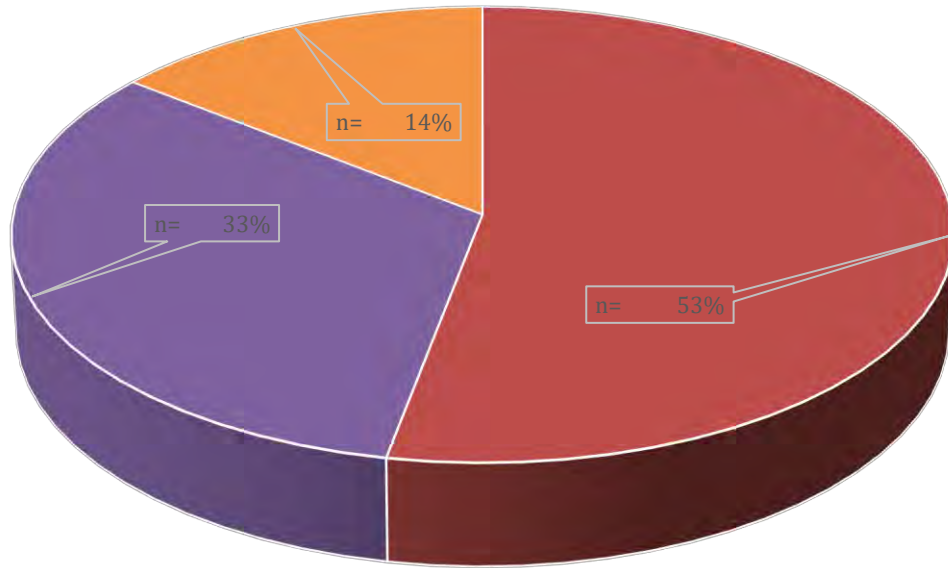


Figure 9: Total number of children in the family

Majority of mothers had 1-3 children (n=140, 53%) while those with more than 5 children were only 14% (n= 38) as shown in figure 9.

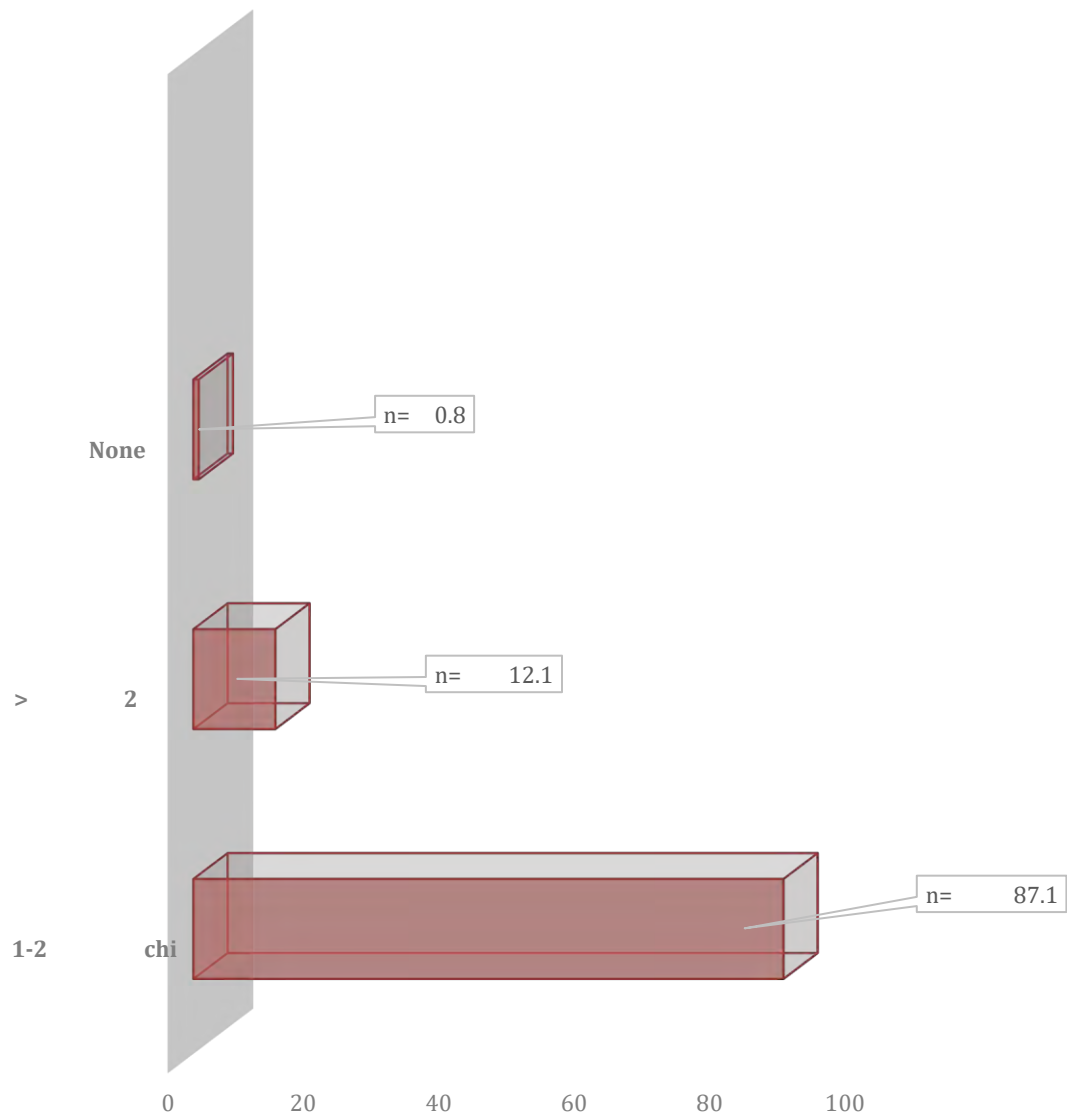


Figure 10: Number of disable children

Majority of mothers had at least 1-2 children with disability (n=230, 87.1%) in the family as given in figure 10.

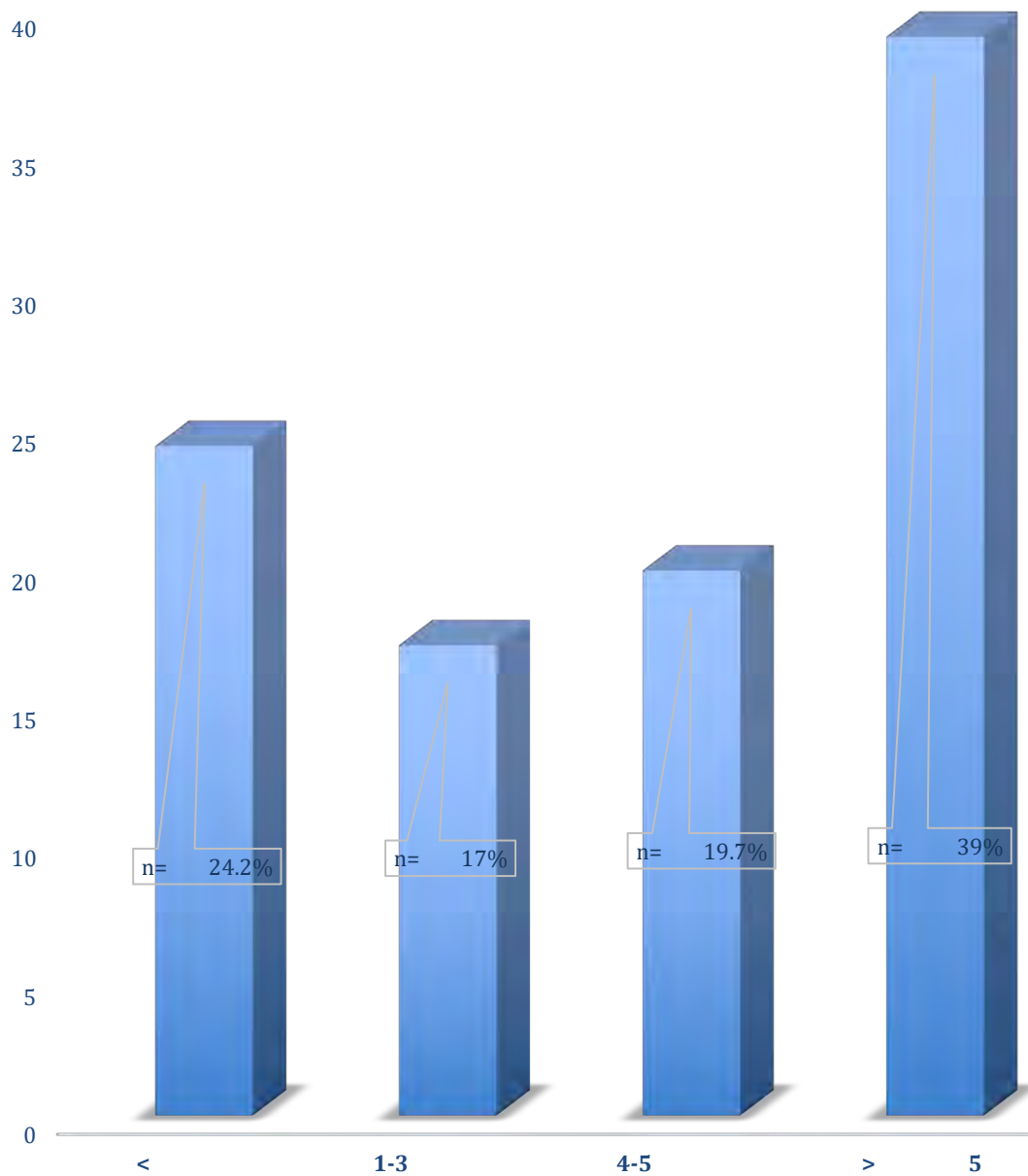


Figure 11: Duration of Caregiving to Disable Children

The study's findings revealed that majority of mothers were providing care to their disabled children for more than 5 years (n=103, 39%) as shown in figure 11.

4.3. Quality of life of the mothers of visually impaired children:

In present study, QOL of the mothers of visually impaired children was determined using WHOQOL-BREFF.

4.3.1. Self-rated QOL of the mothers of visually impaired children:

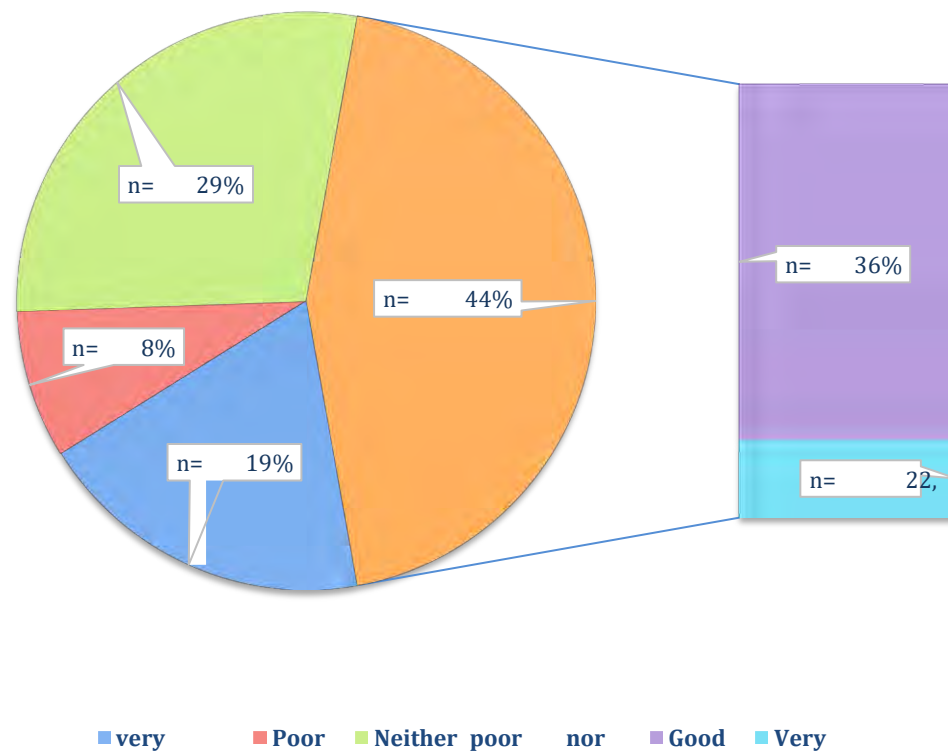


Figure 12: Self-rated QOL of the mothers of visually impaired children

It was noted that most of the mothers of visually impaired children perceived that they had a good quality of life (n=96, 36%) while only 19% mothers perceived their QOL as very poor (n= 50) as shown in figure 12.

4.3.2. Satisfaction of mothers of visually impaired children with their health status:

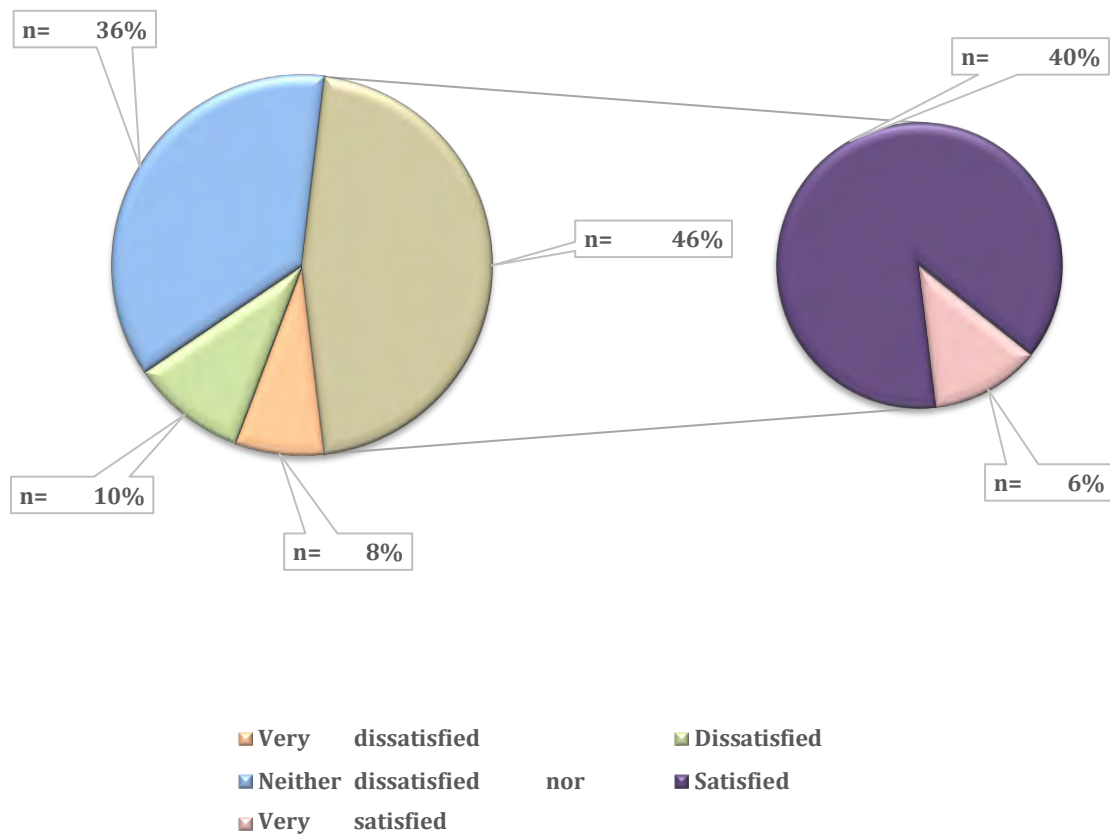


Figure 13: Satisfaction of Mothers with their Health status

Findings of the study revealed that majority of the mothers of visually impaired children were satisfied with their health status (n=107, 40%) as shown in figure 13.

4.3.3. Domains of QOL as measured by WHOQOL-BREFF:

WHOQOL-BREFF measured QOL in four domains; physical health, psychological health, environment and social relations. All these domains were independently assessed for determining QOL of the mothers.

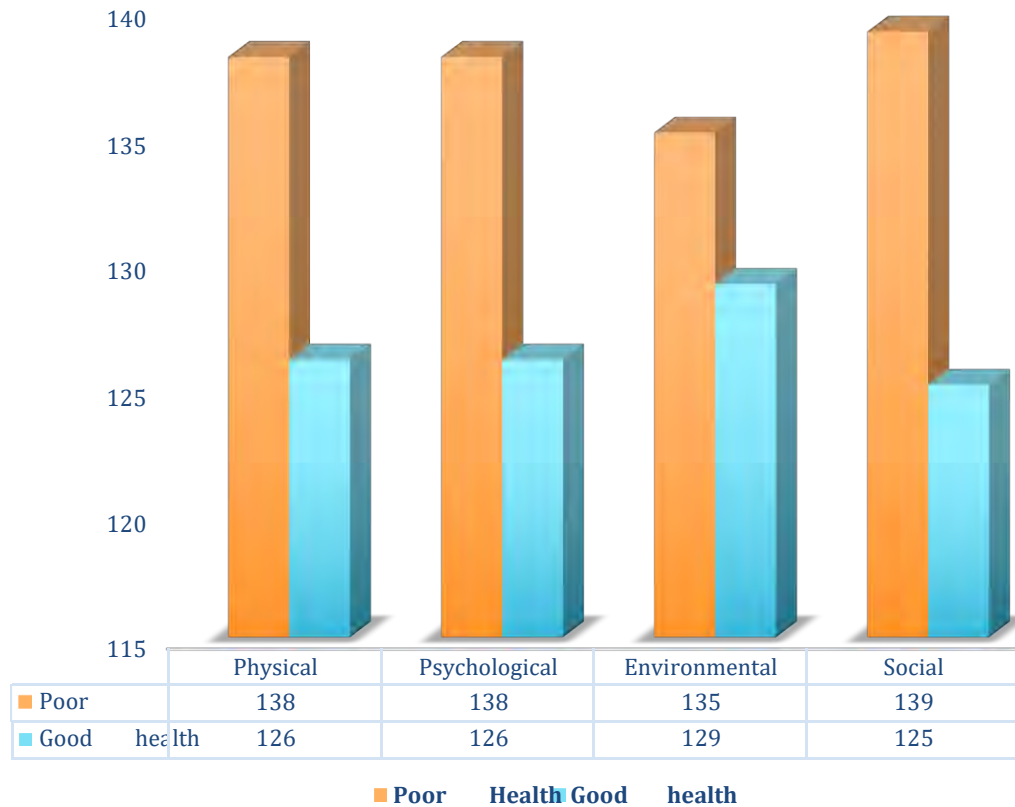


Figure 14: Domains of WHOQOL-BREFF

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 as given in figure 14.

4.3.4. Calculated QOL of mothers of visually impaired children:

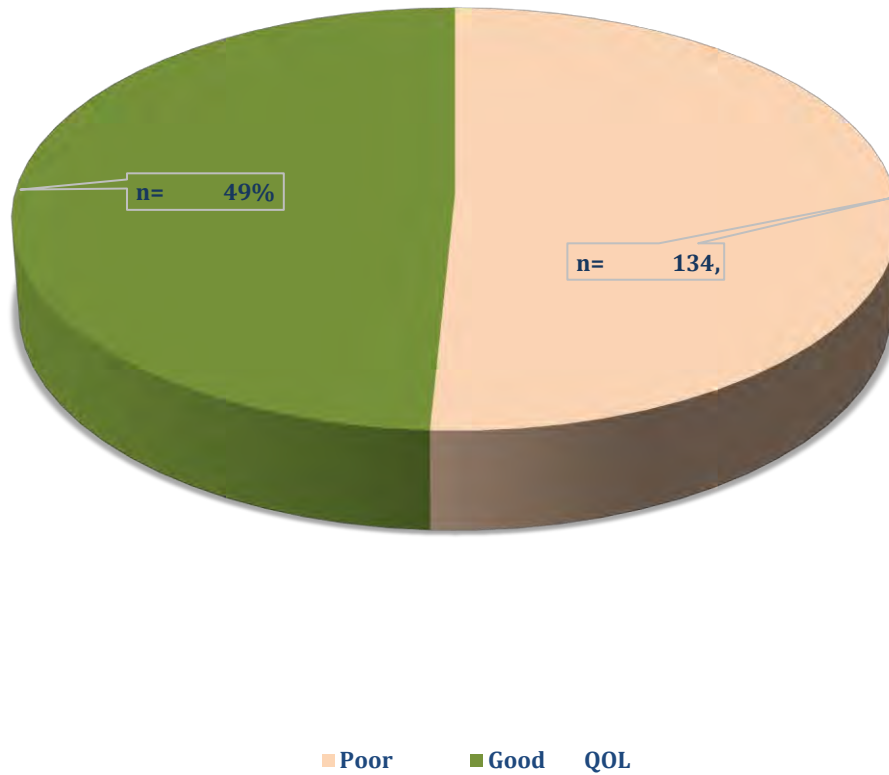


Figure 15: Overall calculated QOL of the mothers of visually impaired children
Findings of the study revealed that, mothers with poor QOL were slightly more in number as compared to those with good QOL (n=134, 51% vs n= 130, 49%) as shown in figure 15.

4.4. Association of Sociodemographic of the Children with Physical Health of the mothers:

Association of physical health of the mothers with socio-demographic characteristics of the visually impaired children was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. It was noted that physical health of the mothers was significantly affected by the age of the child (p value= 0.042), cause of impairment (p value= 0.028) and duration of impairment (p value= 0.002). results revealed that 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 4.

Table 4: Association of Physical Health of mothers with Sociodemographic characters of children

Sr. No.	Sociodemographic characters of children	Physical health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Gender			0.099 (1)	0.753
	Male	74 (51)	70 (49)		
	Female	64 (53)	56 (47)		
2	Age			8.18 (3)	0.042
	5-8 years	53 (46)	62 (54)		
	9-11 years	44 (67)	22 (33)		
	12-14 years	14 (44)	18 (56)		

	15-17 years	27 (52)	24 (48)		
3	Cause of visual impairment			4.80 (1)	0.028
	Congenital	68 (46)	79 (54)		
	Non-Congenital	70 (60)	47 (40)		
4	Type of visual impairment			1.87 (4)	0.759
	Cataract	34 (56)	27 (44)		
	Glaucoma	7 (64)	4 (36)		
	Refractive errors	49 (54)	42 (46)		
	Blind	14 (48)	15 (52)		
	Others	34 (47)	38 (53)		
5	Level of visual impairment			1.30 (3)	0.728
	Mild	97 (53)	85 (47)		
	Moderate	24 (49)	25 (51)		
	Severe	3 (75)	1 (25)		
	Total blind	14 (48)	15 (52)		
6	Duration of visual impairment			14.81 (3)	0.002
	Less than 1 year	33 (58)	24 (42)		
	1-3 years	38 (68)	18 (32)		
	4-5 years	36 (55)	30 (45)		
	More than 5 years	31 (37)	54 (63)		

4.5. Association of Sociodemographic of the mothers with their Physical Health:

Association of physical health of the mothers with socio-demographic characteristics of the mothers themselves was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. Results of the Chi square test revealed that physical health of the mothers was significantly associated with duration of caregiving (p value= 0.031). It was revealed by the findings that mothers who had long duration of caregiving to the visually impaired child reported relatively good physical health (duration 4-5 years and more than 5 years) as compared to those with less duration of caregiving. Results are given in table

5.

Table 5: Association of Sociodemographic characters of mothers with their Physical Health

Sr. No.	Sociodemographic characters of children	Physical Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Marital status			1.83 (2)	0.399
	Married	116 (53)	102 (47)		
	Divorced	9 (39)	14 (61)		
	Widow	13 (56)	10 (44)		
2	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)		
3	Residences			0.617 (1)	0.432
	Urban	68 (55)	56 (45)		
	Rural	70 (50)	70 (50)		
4	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)		
5	Occupation of mothers			7.72 (3)	0.052
	Housewife	87 (53)	77 (47)		
	Day laborer	30 (56)	24 (44)		
	Govt. employee	16 (39)	25 (61)		
	Others	5 (100)	0 (0)		
6	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)		
7	Family type			0.860 (1)	0.354
	Nuclear	67 (55)	54 (45)		
	Joint	71 (49)	72 (51)		
8	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)		
9	Number of disable children			3.61 (2)	0.164
	1-2	118 (51)	112 (49)		
	More than 2	20 (63)	12 (73)		

	None	0 (0)	2 (100)		
10	Duration of caregiving			8.88 (3)	0.031
	Less than 1 year	38 (59)	26 (41)		
	1-3 years	30 (67)	15 (33)		
	4-5 years	21 (40)	31 (60)		
	More than 5 years	49 (48)	54 (52)		

4.6. Association of Sociodemographic of the Children with Psychological health of Mothers:

Association of psychological health of the mothers with socio-demographic characteristics of the visually impaired children was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. It was noted that psychological health of the mothers was significantly influenced by the age of the child (p value= 0.0008). Findings suggest that mothers whose children were above 12 years reported relatively good psychological health as compared to those whose children were of young age group. Detailed results are provided in table 6.

Table 6: Association of Psychological Health of mothers with Sociodemographic characters of children

Sr. No.	Sociodemographic characters of children	Psychological Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Gender			0.183 (1)	0.669
	Male	77 (53)	67 (47)		
	Female	61 (51)	59 (49)		
2	Age				

	5-8 years	65 (46)	50 (54)	8.18 (3)	0.0008
	9-11 years	42 (64)	24 (36)		
	12-14 years	11 (34)	21 (66)		
	15-17 years	20 (39)	31 (61)		
3	Cause of visual impairment			1.44 (1)	0.230
	Congenital	72 (49)	75 (51)		
	Non-Congenital	66 (56)	51 (44)		
4	Type of visual impairment			2.12 (4)	0.714
	Cataract	32 (53)	29 (47)		
	Glaucoma	7 (64)	4 (36)		
	Refractive errors	51 (56)	40 (44)		
	Blind	13 (45)	16 (55)		
	Others	35 (49)	37 (51)		
5	Level of visual impairment			1.63 (3)	0.653
	Mild	95 (52)	87 (48)		
	Moderate	27 (55)	22 (45)		
	Severe	3 (75)	1 (25)		
	Total blind	13 (45)	16 (55)		
6	Duration of visual impairment			7.28 (3)	0.063
	Less than 1 year	34 (60)	23 (40)		
	1-3 years	29 (52)	27 (48)		
	4-5 years	40 (61)	26 (39)		
	More than 5 years	35 (41)	50 (59)		

4.7. Association of Sociodemographic of the mothers with their

Psychological Health:

Association of psychological health of the mothers with their socio-demographic characteristics was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. Results of the Chi square test revealed that psychological health of mothers, who were widow, was relatively poor as compared to those who were married or divorced (p value= 0.005). Similarly, mothers who were married to a distant relative reported a relatively good psychological health as compared to those who were married out of the family or to their first cousin (p value= 0.033). Likewise, mothers living in rural

areas reported poor psychological health as compared to those who were living in urban areas (p value= 0.015). Moreover, mothers who were illiterate reported poor psychological health as compared to those with higher education (p value= 0.0001). Furthermore, it was reported that mothers who were government employees reported good psychological health as compared to those who were house wives or day laborers (p value= 0.0001). Similarly, mothers with low monthly income presented poor psychological health as compared to those with high monthly income (p value= 0.0001). All these factors were significantly related with psychological health of mothers. Detailed results are given in table 7.

Table 7: Association of Sociodemographic characters of mothers with their Psychological Health

Sr. No.	Sociodemographic characters of children	Psychological Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Marital status			10.65 (2)	0.005
	Married	115 (53)	103 (47)		
	Divorced	6 (26)	17 (74)		
	Widow	17 (74)	6 (26)		
2	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)		
3	Residences			5.87 (1)	0.015
	Urban	55 (44)	69 (56)		
	Rural	83 (59)	57 (41)		
4	Education of mothers			2.34 (4)	0.0001
	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)		
5	Occupation of mothers			2.01 (3)	0.0001
	Housewife	90 (55)	74 (45)		
	Day laborer	36 (67)	18 (43)		
	Govt. employee	9 (22)	32 (78)		
	Others	3 (60)	2 (40)		
6	Monthly income				
	Less than 20,000	29 (78)	8 (22)		

	21,000-50,000	77 (60)	51 (40)	3.10 (3)	0.0001
	51,000-100,000	13 (25)	38 (75)		
	More than 100,000	19 (40)	29 (60)		
7	Family type			1.10 (1)	0.29
	Nuclear	59 (49)	62 (51)		
	Joint	79 (55)	64 (45)		
8	Total number of children			2.79 (2)	0.47
	1-3	67 (48)	73 (52)		
	4-5	51 (59)	35 (41)		
	More than 5	20 (53)	18 (47)		
9	Number of disable children			2.39 (2)	0.302
	1-2	120 (52)	110 (48)		
	More than 2	18 (56)	14 (43)		
	None	0 (0)	2 (100)		
10	Duration of caregiving			6.08 (3)	0.108
	Less than 1 year	42 (66)	22 (34)		
	1-3 years	21 (46)	24 (54)		
	4-5 years	25 (48)	27 (52)		
	More than 5 years	50 (48)	53 (52)		

4.8. Association of Sociodemographic of the Children with Environmental Health of Mothers:

Association of environmental health of the mothers with socio-demographic characteristics of the visually impaired children was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were

considered statistically significant. Results of the Chi square test revealed that mothers whose children were 15-17 years of age presented relatively poor environmental health as compared to mothers of other children (p value= 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 value= 0.0001). Likewise, mothers whose child was visually impaired for more than 5 years, reported relatively good environmental health as compared to others (p value= 0.002).

Detailed results are presented in table 8.

Table 8: Association of Environmental Health of mothers with Sociodemographic characters of children

Sr. No.	Sociodemographic characters of children	Environmental Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Gender			0.693 (1)	0.406
	Male	77 (53)	67 (47)		
	Female	58 (48)	62 (52)		
2	Age			10.65 (3)	0.014
	5-8 years	57 (49)	58 (51)		
	9-11 years	44 (67)	22 (63)		
	12-14 years	15 (47)	17 (53)		
	15-17 years	19 (37)	32 (63)		
3	Cause of visual impairment			14.13 (1)	0.0001
	Congenital	60 (41)	87 (59)		
	Non-Congenital	75 (64)	42 (36)		
4	Type of visual impairment			6.55 (4)	0.161
	Cataract	29 (48)	32 (52)		
	Glaucoma	5 (45)	6 (55)		
	Refractive errors	47 (52)	44 (48)		
	Blind	10 (35)	19 (65)		
	Others	44 (61)	28 (39)		
5	Level of visual impairment			6.04 (3)	0.110
	Mild	101 (55)	81 (45)		
	Moderate	23 (47)	26 (53)		
	Severe	1 (25)	3 (75)		
	Total blind	10 (35)	19 (65)		
6	Duration of visual impairment				

	Less than 1 year	38 (67)	19 (33)	1.50 (3)	0.002
	1-3 years	34 (61)	22 (39)		
	4-5 years	32 (49)	34 (51)		
	More than 5 years	31 (37)	54 (63)		

4.9. Association of Sociodemographic of the mothers with their Environmental Health:

Association of environmental health of the mothers with their socio-demographic characteristics was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. It was noted that environmental health of the mothers who were widow was poor as compared to those who were married or divorced (p value= 0.005). Similarly, mothers living in urban areas reported good environmental health as compared to those living in rural areas (p value= 0.0001). Likewise, mothers with no education reported poor environmental health as compared to those who received some formal education (p value= 0.0001). Furthermore, mothers who were government employees reported good environmental health as compared to those who were housewives or day laborers (p value= 0.0001). Likewise, mothers whose monthly income was poor also reported poor environmental health as compared to those who were higher in social ladder (p value= 0.0001). similarly, mothers living in joint family system reported poor environmental health as compared to those who were living in nuclear family (p value= 0.007). Furthermore, mothers with more than 5 children reported good environmental health as compared to those who had less number of children (p value= 0.026). It was also observed that mothers who were giving care to visually impaired child for longer time

reported relatively good environmental health as compared to those with less duration of caregiving (p value= 0.012). Detailed results are given in table 9.

Table 9: Association of Environmental Health of mothers with their Sociodemographic characters

Sr. No.	Sociodemographic characters of children	Environmental Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Marital status			10.75 (2)	0.005
	Married	110 (51)	108 (49)		
	Divorced	7 (30)	16 (70)		
	Widow	18 (78)	5 (22)		
2	Husband			0.08 (2)	0.960
	First/ Second cousin	73 (51)	71 (49)		
	Distant relative	27 (53)	24 (47)		
	Out of family	35 (51)	34 (49)		
3	Residences			1.63 (1)	0.0001
	Urban	47 (38)	77 (62)		
	Rural	88 (63)	52 (37)		
4	Education of mothers			5.34 (4)	0.0001
	Illiterate	51 (75)	17 (25)		
	Primary	26 (59)	18 (41)		
	Secondary	37 (64)	21 (36)		
	Diploma	12 (33)	24 (67)		
	Graduation	9 (16)	49 (84)		
5	Occupation of mothers			2.63 (3)	0.0001
	Housewife	86 (52)	78 (48)		
	Day laborer	39 (67)	15 (43)		
	Govt. employee	8 (20)	33 (80)		
	Others	2 (40)	3 (60)		
6	Monthly income			1.11 (3)	0.0001
	Less than 20,000	33 (89)	4 (11)		
	21,000-50,000	92 (72)	36 (28)		
	51,000-100,000	8 (16)	43 (84)		
	More than 100,000	2 (4)	46 (96)		
7	Family type			7.22 (1)	0.007
	Nuclear	51 (42)	62 (58)		
	Joint	84 (59)	59 (41)		
8	Total number of children			7.26 (2)	0.026
	1-3	68 (49)	72 (51)		
	4-5	53 (62)	33 (38)		
	More than 5	14 (37)	24 (63)		
9	Number of disable children				
	1-2	120 (52)	110 (48)		

	More than 2	15 (47)	17 (53)	2.39 (2)	0.302
	None	0 (0)	2 (100)		
10	Duration of caregiving			11.04 (3)	0.012
	Less than 1 year	40 (63)	24 (37)		
	1-3 years	29 (64)	16 (36)		
	4-5 years	22 (42)	30 (58)		
	More than 5 years	44 (43)	59 (57)		

4.10. Association of Sociodemographic of the Children with Social health of Mothers:

Association of social health of the mothers with socio-demographic characteristics of the visually impaired children was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. Results of the Chi square test revealed that mothers whose children were in 9-11 years of age range, reported relatively poor social health as compared to others (p value= 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 value= 0.0001). 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 impairment (p value= 0.0001). Similarly, it was also found that mothers whose child had visual impairment for long duration reported good social health as compared to those whose child had less duration of visual impairment (p value= 0.039). Detail about results is given in table 10.

Table 10: Association of Social Health of mothers with Sociodemographic characters of children

		Social Health of mothers		
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Sr. No.	Sociodemographic characters of children	Poor n (%)	Good n (%)	X ² (df)	P value
1	Gender			0.487 (1)	0.485
	Male	73 (51)	71 (49)		
	Female	66 (55)	54 (45)		
2	Age			9.25 (3)	0.026
	5-8 years	58 (51)	57 (49)		
	9-11 years	41 (62)	25 (38)		
	12-14 years	10 (31)	22 (69)		
	15-17 years	30 (57)	21 (43)		
3	Cause of visual impairment			14.13 (1)	0.0001
	Congenital	71 (41)	76 (59)		
	Non-Congenital	75 (64)	42 (36)		
4	Type of visual impairment			2.94 (4)	0.0001
	Cataract	22 (36)	39 (63)		
	Glaucoma	9 (82)	2 (18)		
	Refractive errors	65 (71)	26 (29)		
	Blind	9 (31)	20 (69)		
	Others	34 (47)	38 (53)		
5	Level of visual impairment			7.63 (3)	0.054
	Mild	103 (57)	79 (43)		
	Moderate	24 (49)	25 (51)		
	Severe	3 (75)	1 (25)		
	Total blind	9 (31)	20 (69)		
6	Duration of visual impairment			8.34 (3)	0.039
	Less than 1 year	28 (49)	29 (51)		
	1-3 years	30 (54)	26 (46)		
	4-5 years	44 (67)	22 (33)		
	More than 5 years	37 (44)	48 (56)		

4.11. Association of Sociodemographics of the Mothers with their Social Health:

Association of social health of the mothers with their socio-demographic characteristics was determined using Pearson Chi Square Test of Independence after confirming the assumptions of the test. All p-values below 0.05 were considered statistically significant. Results of the Chi square test revealed that mothers who were widow reported poor social health as compared to married or divorced (p value= 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 to their first cousin (p value= 0.047). It was found that mothers with high education level reported poor social health as compared to those with low education level (p value= 0.028). Likewise, it was also found that mothers who were living in nuclear family reported poor social health as compared to those living in joint family (p value= 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 greater number of children (p value=0.003). details of result are provided in table 11.

Table 11: Association of Social Health of mothers with their Sociodemographic characters

Sr. No.	Sociodemographic characters of children	Environmental Health of mothers		X ² (df)	P value
		Poor n (%)	Good n (%)		
1	Marital status			1.50 (2)	0.001
	Married	103 (47)	115 (53)		
	Divorced	17 (74)	6 (26)		
	Widow	19 (82)	4 (17)		
2	Husband			6.13 (2)	0.047
	First/ Second cousin	68 (47)	76 (53)		
	Distant relative	26 (51)	25 (49)		
	Out of family	45 (65)	24 (35)		
3	Residences			1.35 (1)	0.244
	Urban	70 (57)	54 (43)		
	Rural	69 (49)	71 (51)		
4	Education of mothers			10.86 (4)	0.028
	Illiterate	41 (60)	27 (40)		
	Primary	22 (50)	22 (50)		
	Secondary	27 (47)	31 (53)		
	Diploma	12 (33)	24 (67)		
	Graduation	37 (64)	21 (36)		
5	Occupation of mothers			0.889 (3)	0.828
	Housewife	83 (51)	81 (49)		
	Day laborer	31 (57)	23 (43)		
	Govt. employee	22 (54)	19 (46)		
	Others	3 (60)	2 (40)		
6	Monthly income				
	Less than 20,000	24 (65)	13 (35)		

	21,000-50,000	66 (52)	62 (48)	2.68 (3)	0.444
	51,000-100,000	25 (49)	26 (51)		
	More than 100,000	24 (50)	24 (50)		

7	Family type			6.48 (1)	0.011
	Nuclear	74 (61)	47 (39)		
	Joint	65 (45)	78 (55)		
8	Total number of children			1.14 (2)	0.003
	1-3	60 (43)	80 (57)		
	4-5	55 (64)	31 (36)		
	More than 5	24 (63)	14 (37)		
9	Number of disable children			5.74 (2)	0.056
	1-2	115 (50)	115 (50)		
	More than 2	22 (69)	10 (31)		
	None	2 (100)	0 (0)		
10	Duration of caregiving			0.624 (3)	0.891
	Less than 1 year	35 (55)	29 (45)		
	1-3 years	22 (49)	23 (51)		
	4-5 years	29 (56)	23 (44)		
	More than 5 years	53 (52)	50 (48)		

CHAPTER V: DISCUSSION

In the present study QOL of the mothers of visually impaired children was assessed along with finding the factors that affect their QOL. Moreover, association of QOL of the mothers of the visually impaired children with socio-demographic characteristics was also determined. QOL was determined using WHOQOL-BREF which helped to assess their QOL with regard to four different dimensions namely physical health, psychological health, environment and social interaction.

Results of the study showed that 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 majority of the mothers demonstrated low quality of life. Current study findings 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 disable children were significantly lower (Awaji et al., 2021). Likewise, another study revealed that parents of children with serious health issues experience heightened levels of anxiety and depression. Moreover, mothers of children born with congenital anomalies face an elevated risk of cardiovascular disease and mortality compared to parents of healthy children (Cohn et al., 2020). This can be explained by the fact that parents, especially mothers, of children with some abnormality experience high levels of anxiety and stress due to health, education and life achievements of their children. This could eventually lead to their poor physical health and decreased social interactions as well.

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 (n=134, 51% vs n=130, 49%). Previous studies also confirm the current findings regarding QOL of mothers. A study conducted in Saudi Arabia in 2021 revealed mothers of disable children experience lower quality of life as compared to those who had normal children (Awaji et al., 2021).

The study's findings demonstrated 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 (p-value = 0.042). Mothers with children aged 9-11 years (n=44, 67%) showed a 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 (p-value = 0.0008). A significant majority of mothers with children in the 9-11-year age group (n=42, 64%) reported experiencing a 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 (p-value = 0.026). Mostly, the mothers having children from age group of 9-11 years (n=41, 62%) were facing poor social health as compared to others group. In addition, the environmental health of mothers was also significantly connected to the ages of their children (p-value = 0.014). 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 Hongjuan et al. in 2017 in China also found that quality of life of mothers of visually impaired children is significantly affected by the age of the child with respect to all four domains of QOL; physical health, psychological health, social health and environmental health (Hongjuan

Yu et al., 2017). On contrary, a study that was conducted by Ikeu et al. in 2022 showed that child's age does not have a significant association with the parents' QoL (Ikeu et al., 2022). The current results could be attributed to the fact that young children require more attention of their mother especially if the child is visually impaired. The time period between 9-11 years of age is a period of transition in the life cycle of the child from childhood to teenage. Their physical, social, psychological and emotional requirements undergo changes that also significantly affect the QOL of their mothers.

It was also noted that physical health, environmental health and social health of mothers was significantly associated with cause of visual impairment of their children (p -value=0.028), (p -value=0.0001) and (p -value=0.0001) but not with psychological health. These results are similar to the previous literature. Behnaz and Mohammad conducted research in 2016 in Iran. Results of their study showed that there was a significant difference in QOL of mothers with respect to different causes of disability of children. Mothers of congenitally disable children reported comparatively good score of QOL as compared to those whose child developed disability later in life (Behnaz & Mohammad, 2016). This fact can be explained on the basis that those children who are congenitally impaired, their mothers gradually develop coping mechanisms and adjusted to the circumstances. While those mothers whose children develop visual impairment later in life lack considerable adjustment in the changed circumstances and are unable to cope with the social and psychological trauma that a visually impaired child put on them.

The present study also revealed that the specific types of visual impairment were notably linked to the social health of mothers (p -value = 0.0001). Particularly, mothers with children diagnosed with Glaucoma tended to experience a lower quality of life. These

findings are associated with the previous ones. Al Qureshi et al. carried out research in 2017 in Saudi Arab. The aim of study was to evaluate the quality of life (QoL) measures of mothers of children with glaucoma. Findings of the study showed poor QoL with mother caregivers (P-value=0.031) (Al Qurashi et al., 2017). Another research conducted by Amy et al., in 2022. The aim of the study was to describe the caregiver burden and QoL of caregivers of pediatric glaucoma patients. Results of the study indicated significantly higher burden and poor QoL in caregivers (Amy et al., 2022). This could be due to the fact of children with glaucoma might experience physical challenges in terms of mobility, hand eye coordination, and motor skills due to their visual limitations. Due to this reason regular visits of children to eye specialists and medical interventions can increase the workload for mothers, leading to various social, physical and psychological challenges.

The present study also revealed that duration of visual impairment was significantly associated with physical, environmental and social health of mothers (p-value=0.002), (p value=0.002) and (p-value=0.039) respectively. Mothers whose children had experienced visual impairment for a duration of 1-3 years were predominantly associated with poorer physical health. Those with less than 1 year of exposure to visual impairment reported compromised environmental health, with 67% indicating this issue. Additionally, mothers with children who had been dealing with visual impairment for 4-5 years were in the majority in experiencing challenges related to their social health. Similarly, physical and environmental health of mothers was significantly associated with the duration of their caregiving to their visual impaired children (p-value=0.031) and (p-value=0.012) respectively. But it was not associated with psychological and social health. It was also noted that mothers who have been providing care for a duration of 1-3 years were more

prone to poor physical health when compared to other groups. These results are somehow similar with the previous literature. Zahra et al., conducted a study in 2015 in Iran. It was shown in their study that having a child with sensory impairment from their childhood is significantly related to a worse level of QOL of mothers (p -value=0.001) (Zahra et al., 2015). Shukir & Bokan also conducted research in 2018 in Iraq. This study aimed to assess the quality of life of mothers who have been dealing child with visual impairments for 1-2 years. The results of the study showed that mothers were feeling low self-esteem. Most of the mothers complained of psychosocial problems (Shukir & Bokan., 2018). This phenomenon might be attributed to the fact that mothers require social and family support in order to manage a visually impaired child. Caring for a visually impaired child might involve assisting with daily activities such as dressing, eating, and playing, which can impact a mother's daily routine and well-being. They also experience emotional challenges related to their child's development and the realization of their visual impairment at this age.

The results also showed that certain sociodemographic characters of mothers also affect their QOL. It was noted that marital status of mothers was significantly associated with their psychological, environmental and social health (p -value=0.005), (p -value=0.005) and (p -value=0.001) respectively. Most of the widow mothers were living with poor social life as compared to other groups. These results are similar with the previous studies. There is a paucity of literature in this regard. This could be due to fact that dealing with the loss of one's spouse while also caring for a visually impaired child can lead to heightened emotional stress and grief to a widow mother. Being a single mother to a visually impaired child can present unique parenting challenges that require additional effort and resources.

The results indicated a significant association between the psychological and social wellbeing of mothers who were married out of their family (p -value=0.003) and (p value=0.047) respectively. A notable majority of mothers who were married outside the immediate family were experiencing challenges in their social health, majority of cases, surpassing other groups in this regard. These findings are somehow similar with the previous studies. Klajdi carried out research in 2018. The findings of the study showed that mothers who were married outside their family, were facing lower QOL than those who are married in family (Klajdi et al., 2018). Another study that was conducted by Chakraborty et al. in 2019 showed that women whose children are visually impaired and they are not married in their immediate families facing poor QOL. Stress had a negative association with both mental and physical health quality of life of the mothers (Chakraborty et al., 2019). This may be due to the reason that managing relationships and interactions with a spouse from outside the immediate family can impact a mother's role in caregiving and decision-making for their visually impaired child. On the other hand, cultural differences and varying family dynamics can affect the support and involvement of the spouse in caring for the visually impaired child.

The results of the study showed that psychological and environmental health of mothers was significantly associated with their residence (p -value=0.015), (p -value=0.001) respectively. Most of the mothers were living with poor environmental health as compared to other groups. These results are somehow not similar with the previous literature. Youssef Althiabi carried out research in Saudi Arab in 2021. Results of the study showed that attitudes towards taking care of children with sensory impairment is related to their residence and it in turn, affected the health of mothers (Althiabi, 2021). This could be

attributed to the fact that rural areas have limited access to specialized healthcare and support services for visually impaired children. This can place an additional burden on mothers who need to travel long distances to access the necessary care. Limited public transportation in rural areas can make it difficult for mothers to transport their visually impaired children to medical appointments, therapy sessions, and other necessary activities. Likewise, rural communities are full of illiteracy, misconceptions, social taboos which can result in stigma and social exclusion for both the child and the mother. In most of the cases, mother is blamed for a visually impaired child.

Similarly, education of mothers was significantly associated with psychological, environmental and their social health (p-value=0.001), (p-value=0.001) and (p-value=0.028) respectively. Most of the illiterate mothers were facing poor QOL as compared to those who were at higher ladder in the educational level. These findings are also backed with the previous literature. Pau et al. carried out research in Spain in 2018.

Results of their study showed that education of the mothers of these children was positively effecting the health of mothers (Pau et al., 2018). This could be due to the reason that mothers with low education levels might have difficulty accessing accurate and up-to-date information about their child's visual impairment. This can lead to uncertainty and stress in managing their child's condition effectively. Moreover, lower education levels might be associated with limited job opportunities and lower income levels. An illiterate mother is not empowered enough to raise a visually impaired child effectively. It was noted that illiteracy among mothers and rural residency is closely related with certain myths and misconceptions related to visual impairment among child. These conditions significantly compromise the QOL of mothers.

In the present study it was also noticed that psychological and environmental health of mothers was significantly associated with their occupation (p -value=0.0001) and (p -value=0.0001) respectively. Mothers who were working as day laborer presented poor psychological and environmental health as compared to those who were housewives or doing governmental jobs. These results are somehow similar with the previous literature. Miyako et al. carried out research in 2016 in Japan. Results of the study showed that employment status of mothers of visually impaired children was significantly affecting their overall health (p -value=0.01) (Miyako Kimura, 2016). However, in their study they found that employed mothers face poor QOL as compared to housewives. The possible explanation to this contrasting result could be that women doing governmental employment were more empowered financially and also, they were educated. These women can understand the psychological and emotional needs of their visually impaired child more effectively as compared to those who were engaged in day labor or were housewives.

It was also observed that psychological and environmental health of mothers was significantly associated with their monthly income (p -value=0.0001) and (p -value=0.0001) respectively. Majority of the mothers having monthly income less than 20 thousand were facing lower environmental health as compared to others. In the current study, it was also observed that family type of mothers was significantly associated with their environmental and social health (p -value=0.007) and (p -value=0.011) respectively. These results are somehow similar with the previous literature. Stephania et al. carried out research in 2018 in Brazil. The findings of the study showed that mother's quality of life was significantly affected by financial restrictions and social interaction difficulties as financial constraints lead to poor QOL (Stephania et al., 2018). Another study was conducted by Elsa et al.

in 2018, showed that monthly family income was affecting overall QOL of parents of visually impaired children (p-value=0.05) (Elsa et al., 2018). This may be due to the reason that higher family income can provide mothers of visually impaired children with better access to medical care, therapies, assistive devices, and educational resources for their visually impaired child. Financial resources can provide mothers with the flexibility to make choices about their caregiving role and pursue personal goals.

In the current study it was also observed that total number of children of mothers was significantly associated with their environmental and social health (p-value=0.026) and (p-value=0.003) respectively. Majority of the mothers having 4-5 children were living with poor social health as compared to other ones. These findings are similar with the previous literature. Eliza et al. conducted research in 2015 to find out the association of mothers of sensory impaired child with their total number of children. Findings of the study revealed that QOL of sensory impaired children was significantly associated with total number of children (Eliza et al., 2015). This could be due to the reason that balancing the needs and demands of multiple children, each with their unique requirements, can impact a mother's ability to address every child's needs effectively. The number of children can influence a mother's ability to engage in social activities and personal pursuits outside of caregiving.

5.1. Strengths:

- Researcher had used a validated tool WHOQOL-BREF for assessment of QOL of visually impaired children which provided a comprehensive account of QOL with respect to multiple domains of health; physical, psychological, environmental and social.

- The researcher had included mothers of visually impaired children residing in urban as well as rural areas and distinguished a significant difference in QOL of women with respect to their area of residency.
- The study findings helped to fill the gap in the existing literature regarding QOL of visually impaired children in Pakistan.

5.2. Limitations:

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

5.3. Conclusion:

The study found that 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 age of child, congenital visual impairment in 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 labor, 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.

5.4. Recommendations:

Based on the current findings, following recommendations are put forward for the health authorities and future researchers.

- While addressing the issues of visually impaired children, it is an important task to incorporate psychological counselling of caregivers, especially mothers, in the hospital settings of both urban and rural areas. Train lady health workers so they counsel at door to door in the rural areas.
- Results of the study suggest that educational level has a positive impact on QOL of mothers of visually impaired children so it is necessary to focus on education of women. This also implies that mothers should be provided necessary information through authentic channels to cope with the challenges of a visually impaired child.
- The finding of the study suggest that rural area inhabitants presented lower level of QOL. This implies that proper health facilities and knowledge provision regarding visual impairment and its management should be provided in rural areas.
- Income level is also found to improve the QOL of mothers. So, it is suggested that Introduce health insurance policies for those families whose children are congenitally visually impaired and provide free of cost treatment throughout life.

- Arrange visual screening camps at both urban and rural areas so diagnose visual impairment among children at early stage and refer them at any tertiary care hospital. This may be helpful in reducing caregiver burden.

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Appendix A – Questionnaire

ASSESSMENT OF OOL IN MOTHERS OF VISUALLY IMPAIRED CHILDREN IN A TERTIARY CARE HOSPITAL, RAWALPINDI

SECTION A - SOCIODEMOGRAPHIC INFORMATION OF VISUALLY IMPAIRED CHILDREN

1. Children age (years)?
 - a) 5-8
 - b) 9-11
 - c) 12-14
 - d) 15-17
2. Child's gender?
 - a) Male
 - b) Female
3. Cause of visual impairment?
 - a) Congenital
 - b) Non congenital
4. Types of visual impairment?
 - a) Cataract
 - b) Glaucoma
 - c) Refractive errors
 - d) Blind
 - e) Others
5. Child's level of visual impairment?
 - a) Mild visual impairment (6/12 – 6/18)
 - b) Moderate visual impairment (6/18 – 6/60)
 - c) Severe visual impairment (6/60 – 3/60)
 - d) Totally blind (> 3/60)
6. Child's duration of visual impairment?
 - a) < 1 years

- b) 1-3 years
- c) 3-5 years
- d) > 5 years

**SECTION B - SOCIDEMOGRAPHIC INFORMATION OF
MOTHERS**

1. Mother's marital status?
 - a) Married
 - b) Divorced
 - c) Widow
2. Mother's husband?
 - a) First/second cousin
 - b) Distant relative
 - c) Outside the family
3. Mother's residence?
 - a) Urban
 - b) Rural
4. Mother's level of education?
 - a) Illiterate
 - b) Primary
 - c) Secondary
 - d) Diploma
 - e) Graduation
5. Mother's occupation?
 - a) Housewife
 - b) Day Laborer
 - c) Govt employee
 - d) Other
6. Monthly household income?
 - a) < 20,000
 - b) 20,000 - 50,000

c) 51,000-100,000

d) > 100,000

7. Family system?

a) Nuclear

b) Joint

8. Number of children in the family?

a) 1-3

b) 3-5

c) > 5

9. Number of disabled children in the family?

a) 1-2

b) > 2

c) None

10. Duration of caregiving?

a) < 1 years

b) 1-3 years

c) 3-5 years

d) > 5 years

SECTION C - ASSESSMENT OF QOL IN MOTHER

This assessment asks how you feel about your quality of life, health, and other areas of your life. Please keep in mind your standards, hopes, pleasures and concerns. We

ask that you think about your life in the last two weeks. Please read the question, assess your feelings, for the last two weeks.

		Very Poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Fairly Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last two week

		Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	Slightly	Moderately	Very	Extremely
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7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

		Not at all	Slightly	Somewhat	To a great extent	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information you need in your daily life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Not at all	Slightly	Moderately	Very	Extremely
15	How well are you able to get around physically?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the **last two weeks**.

		Very Dissatisfied	Fairly Dissatisfied	Neither satisfied nor Dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5

17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Infrequently	Sometimes	Frequently	Always
26	How often do you have negative feelings such as blue mood, despair, anxiety or depression?	1	2	3	4	5

Appendix B – Consent Form

I am Zil-e-Rubab, student of MSPH- Final Semester, Alshifa School of Public Health, Alshifa Eye Hospital, Rawalpindi. I am doing research on “Assessment of Quality of Life in Mothers of Visually Impaired Children in a Tertiary Care Hospital, Rawalpindi”.

PURPOSE OF THE RESEARCH

The purpose of this study is to assess the quality of life of mothers of visually impaired children.

PARTICIPATION

I do not anticipate that taking this study will contain any risk or inconvenience to you. Your participation is strictly voluntary and you may withdraw your participation at any time without penalty. I request you to answer the questions as honestly as possible. It will take no longer than 15 minutes to complete a questionnaire. All information collected will be used only for research purpose and will be kept highly confidential. Your identity and your responses will not be identifiable; all data will be stored anonymously. As this is solely a student project no incentive will be provided. Once study is completed, I would be happy to share the results with you if you desire.

Thank you for agreeing to participate in this study. Your feedback is important.

Consent

I have read and understand the information sheet and agree to take part in the study.

Signature _____ **Date** _____

Appendix C – IRB Letter



**AL-SHIFA SCHOOL OF PUBLIC HEALTH
PAKISTAN INSTITUTE OF OPHTHALMOLOGY
AL-SHIFA TRUST, RAWALPINDI**

MSPH-IRB/15-13
27th Mar, 2023

TO WHOM IT MAY CONCERN

This is to certify that **Zil-E-Rubab** D/O **Arif Ali** is a student of Master of Science in Public Health (MSPH) final semester at Al-Shifa School of Public Health, PIO, Al-Shifa Trust Rawalpindi. He/she has to conduct a research project as part of curriculum & compulsory requirement for the award of degree by the Quaid-i-Azam University, Islamabad. His/her research topic, which has already been approved by the Institutional Review Board (IRB), is “**Assessment of QOL in mothers of visually impaired children in a tertiary care hospital Rawalpindi**”.

Please provide his/her necessary help and support in completion of the research project. Thank you.

Sincerely,

Dr. Ayesha Babar Kawish
Head
Al-Shifa School of Public Health, PIO
Al-Shifa Trust, Rawalpindi

Appendix D - Budget

Budget item	Transport	Stationery and internet	Printing	Publishing
Pilot testing	500 Rs/-	6000 Rs/-	3000 Rs/-	-
Data collection	10,000 Rs/-	8,000 Rs/-	-	-
Thesis write-up	1,000 Rs/-	9,000 Rs/-	6,000 Rs/-	25,000 Rs/-
Total expenditure	12,500 Rs/-	23,000 Rs/-	9,000 Rs/-	25,000 Rs/-
Grand total	68,500 Rs/-			

Appendix E – Gantt Chart

Activities	April 2023	May 2023	June 2023	July 2023	August 2023	September 2023
Literature search						
Synopsis writing and IRB approval						
Pilot testing						
Data collection and entry						
Data analysis						
Write-up						
Thesis submission						

Appendix F – Reliability Analysis

Reliability Statistics

Cronbachs Alpha	N of Items
.885	7

Figure 17: Reliability of Physical Domain of WHOQOL -BREF

Reliability Statistics

Cronbachs Alpha	N of Items
.886	7

Figure 19: Reliability of Environmental Domain of WHOQOL-BREF

Reliability Statistics

Cronbachs Alpha	N of Items
.816	3

Figure 18: Reliability of Social Relations of WHOQOL-BREF

Reliability Statistics

Cronbachs Alpha	N of Items
.913	26

Figure 20: Reliability of WHOQOLBREF

