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Evaluate the Quality of Life of Caregivers with Pediatric Neurological Disorder in Karachi (Cross-Sectional Study)

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ABSTRACT

Paediatric neurological disorder is defined as delays in the nervous system development in children can result from genetic disorders, injuries, infections, low oxygen levels, and neurotoxins. These disorders in children affect their physical, cognitive, memory, motor, and speech functions. The dysfunction can lead to complicated ongoing problems. Therefore, physicians, parents, and caregivers must understand these issues to manage them effectively. The purpose of this research was to assess the quality of life (QoL) of caregivers for children with neurological disorder. Across-sectional study will be conducted to evaluate the QoL of caregivers of children aged 1 to 10 years old who have this neurological disorder, using a Qol questionnaire's. This study to explore the quality of life experienced by caregivers of individuals with paediatric neurological disorders and to examine how this affects their lives. The Cross-sectional study carried out 377 children with neurological disorders and their caregivers to assess the quality of life of those responsible for the children's daily care. Data was collected from caregivers of children with down syndrome, delayed milestone, epilepsy, and cerebral palsy in various tertiary hospitals and rehabilitation centres in Karachi, using a standardized Quality of Life (QoL) questionnaire, to assess caregivers' quality of life and the impact of paediatric neurological disorders on their lives. The data was evaluated and analysed using the most recent SPSS version 26. Most caregivers had poor to moderate HRQoL (56% poor, 39.8% moderate). Cerebral palsy and epilepsy were the most common conditions. SF-30 results showed mild–moderate physical limitations and moderate emotional and social difficulties (Cronbach's α = 0.751). Child age, caregiver marital status, and caregiver–child relationship significantly affected HRQoL, while other demographic and clinical factors showed no significant association. The study found that caregivers of children with neurological disorders in Karachi experience significant physical, emotional, and social burden, leading to poor quality of life—especially among mothers. Marital status and the caregiver–child relationship significantly affect caregiver well-being. The findings emphasize the need for better family support systems, improved rehabilitation and education services, and further research to develop effective family-centered interventions.

Keywords: *Paediatric neurological disorder, paediatric neurological disabilities, QOL, Quality of life of caregiver*

INTRODUCTION

Neurological disorders among the paediatric population account for a significant portion of the global burden of disease. Previously, the burden of these disorders was found to be high in developing countries, such as geographical regions South Asia and sub-Saharan Africa. The burden of neurological disorders in these regions continues to skyrocket because of the high prevalence of prematurity. Given previous findings of high incidence, there is high (DALYs), meaning, the conditions are likely to contribute significantly to the GBD. However, the conditions have not gained much in previous GBD reports due to a lack of global data on neurological conditions. By 2030, the WHO estimates that 12% of global mortality will be due to GBDs attributable to neurological disorders. Over the interval of 1990-2015, the burden of disability-adjusted life years DALYs attributable to most conditions improved and there was a relative increase in years lived with disability. Nevertheless, the burden of DALYs due to neurological disorders remains high in developing countries. [1]

Any dysfunction in the nervous system leads to neurological disorders. Delays in the development of the nervous system in children can be the result of genetic disorders, injuries, infections, hypoxia, and neurotoxins. The disorders in children are shown in the form of an impact on the physical, cognitive, memory, motor, and speech functions. The dysfunction can lead to complex chronic problems, and the physician, parents, and caregivers would need to understand these problems holistically for effective management. [2]

Quality of life is described as a totality, encompassing perception, emotion, and thinking processes based on an individual's assessment of his or her own existence. It is an expression of individual well-being and includes satisfaction in all aspects of life, such as physical and mental health, the environment, and social area Research highlights the significance of gender, with findings indicating that females tend to have a lower quality of life. While some studies show that males achieve higher scores in physical health, others also report superior scores for men in psychological well-being. It is found that, within families of children with disabilities, fathers reported higher quality of life across all domains compared to mothers. Similarly, it has been observed that mothers generally experience a lower quality of life than fathers. [3]

As a result, children with neurological disorder often need comprehensive care and rehabilitation throughout their lives, which creates significant psychological, physical, and financial strains for their families. Parents, who serve as the main caregivers for children with disabilities, shoulder a significant caregiving responsibility. They must assist with the children’s everyday activities while also monitoring their evolving health conditions, which ultimately impacts the caregivers’ way of life and can lead to a decrease in their overall quality of life. Caregiver burden is characterized as a complex reaction to the physical, emotional, psychological, and financial challenges stemming from the caregiving role. [4]

Children diagnosed with neurological disorders frequently encounter mobility impediments that augment their dependence on caregivers for locomotion and personal hygiene. This reliance constrains their engagement in quotidian activities and detrimentally influences their overall quality of life. In the context of Pakistan, a lower middle-income nation, the availability of consistent, interdisciplinary rehabilitation services is severely constrained. Consequently, therapeutic interventions are often inconsistent, and the primary burden of care—particularly in terms of mobility assistance—rests predominantly upon caregivers, primarily mothers. The management of a child’s chronic health requirements, coupled with daily obligations, can prove to be immensely burdensome. The responsibility of caring for children with multiple disabilities, in the absence of sufficient support, imposes a substantial strain on caregivers, adversely affecting both their physical and psychological well-being. Empirical research consistently indicates that mothers of children with disabilities are at a heightened risk of experiencing psychological distress, particularly depression, in comparison to mothers of children without disabilities. Caregivers of children with disabilities frequently grapple with social exclusion, stemming from their diminished capacity to participate in community engagements. This social isolation may precipitate stigma and create tension within their familial and social networks. In addition to psychological tribulations, caregivers often endure physical challenges, including sleep deprivation, bodily discomfort, and elevated blood pressure. A significant concern emerges when these cumulative strains commence to substantially compromise the caregivers' overall quality of life. [5]

The idea of family burden was initially presented by Grad and Sainsbury, and it refers to the negative impacts that individuals with disabilities impose on their families in cognitive, physical, emotional, social, and economic aspects. This burden encompasses the challenges and hardships faced by all family members due to having a sick or suffering relative. A child with a disability may struggle to perform self-care activities independently and may require assistance from their caregivers. Parents can assist with self-care tasks such as bathing, toileting, eating, dressing, ensuring safety, and managing medication. This can lead to a significant physical strain on parents, particularly those who also have to handle other household responsibilities and may not get enough rest. The social strain arises when families with a child who has a disability face barrier to participating in social situations or when parents find themselves isolated from the community. Quality of life encompasses an individual's overall well-being, incorporating both the continuity of this well-being and their emotional responses, whether positive or negative, as well as experiences that foster a sense of fulfilment. All aspects of a person's life, including physical, mental, environmental, and social factors, influence their quality of life. [6]

The population of children with disabilities is varied and includes those with genetic disorders, brain or spinal cord injuries, nutritional deficiencies, and infections that result in prolonged cognitive, mobility, visual, auditory, and behavioural challenges. Additionally, it encompasses those exposed to environmental toxins and children who face anxiety or depression due to stressful experiences. A child's disability can negatively affect the physical and mental health of their parents, potentially leading to a reduced overall quality of life (QoL). The World Health Organization describes QoL as "an individual's assessment of their situation in life within the context of their cultural values and the environment they live in, in relation to their goals, standards, concerns, and expectations." The ongoing difficulties of parenting a child with a long-term disability can be overwhelming, resulting in physical, emotional, and financial challenges. Consequently, children often become more dependent on their parents, introducing new challenges in providing care for a child with a chronic condition. Furthermore, caregivers face different functional limitations that require extra effort and tailored attention, especially when compared to children of the same age and gender. Moreover, the emotional strain and concerns parents may have for the future, along with the social stigma surrounding children with developmental delays, can adversely affect caregivers' quality of life. Research comparing the QoL of mothers with disabled children to those without found that mothers of disabled children generally reported a significantly lower QoL. In addition, mothers of children with disabilities voiced concerns that arose during the COVID-19 lockdown, such as a decline in their children's health and limited access to essential medical supplies. Another 2020 study found that two-thirds of caregivers of children with attention-deficit/hyperactivity disorder (ADHD) reported poor QoL, with the psychological dimension having the most significant adverse effect, while the environmental aspect had the least impact. One study highlighted the difficulties caregivers face when managing the various stresses of caring for their chronically ill children due to insufficient resources and facilities available for their needs. Considering cultural expectations in Eastern countries, women are typically responsible for managing household duties and supporting all family members who reside in the home, which often includes grandparents. As a result, mothers bear the primary responsibility for ensuring their child adheres to treatment, attends medical appointments, and meets dietary needs. In addition to tending to their ill child, mothers must also care for other family members daily. Therefore, it is vital to examine how having a child with a disability affects caregivers' QoL; their well-being must be taken into account alongside that of their children According to the Convention on the Rights of Persons with Disabilities (CRPD), children with disabilities "are those who have long-term physical, mental, intellectual, or sensory impairments that, in interaction with various obstacles, may impede their full and effective participation in society on an equal footing. [7]

As parents gradually learn to accept their children, they may experience societal pressure, particularly when their children display unpredictable behaviors in public, such as outbursts. To avoid these uncomfortable situations, some parents choose to limit their social interactions. This leads to a reduction in their social circles. Additionally, some parents may withdraw from their relatives and friends, concerned that they won't fully understand the needs of their children. Furthermore, parents may feel anxious about their children's futures, especially as they age and parents are no longer able to manage their care. The research indicated a significant relationship between the psychological health quality of life domain and the functional performance of the children.[8]

In households where there are children with disabilities, it is typically the mother who assumes the responsibility of caring for the child, managing their special education and rehabilitation, which leads to a heavy load of caregiving. Because mothers take on this caregiving role, they often find it difficult to dedicate enough time to other family members and may experience social isolation from their own community.[9]

Caring for children with neurological and developmental impairments places a significant psychological, physical, and social load on families, especially primary caregivers. Existing research suggests that caregivers of epileptic children experience high levels of despair, anxiety, and sleep problems, resulting in major impairments in mental health and family function. Similarly, caregivers for children with developmental delays report significantly lower quality of life in the physical, psychological, social, and environmental areas. Research on Down syndrome reveals significant decreases in caregivers' health-related quality of life and family functioning, with lower family functioning ratings indicating a severe burden. These deficits are closely linked to difficulties in daily tasks and greater parental stress, underscoring the significant psychosocial pressure that families face when caring for children with trisomy 21. Collectively, these data highlight the significant epidemiological and psychosocial impact of caregiving, emphasizing the importance of tailored support and family-focused treatments. [10,11,12,13]

Children with neurological impairments and medical complexity frequently need long-term, intense care due to chronic physical, cognitive, and neurological limitations. These continuing health needs increase medical reliance and caregiving duties, resulting in persistent psychological stress, emotional anguish, weariness, and a lower quality of life for caregivers, as well as a detrimental impact on overall family functioning. [14,15,16,17]

Pediatric neurological and developmental problems, such as cerebral palsy, global developmental delay, and epilepsy, are frequently severe and chronic, causing major motor, cognitive, and functional deficits in children. These illnesses necessitate constant medical, therapeutic, and assistive care, imposing a significant burden on caregivers. Greater clinical severity, delayed milestones, and poorly controlled seizures are consistently associated with lower caregiver quality of life, increased stress, and anxiety. Caregivers also have daily tasks like treatment management, medication adherence, and dealing with societal stigma. Early developmental delays, such as those experienced during the COVID-19 epidemic, enhance the caregiver's psychological burden. Overall, the intricacy and chronicity of these illnesses underscore their significant influence on caregiver well-being and the importance of focused support. [18,19,20,21,22,23]

Early clinical and environmental variables, such as prematurity, low birth weight, and insufficient caregiver understanding, can all contribute to developmental delays in infants. Chronic neurological diseases such as epilepsy impose additional cognitive, emotional, and care demands, greatly increasing caregiver stress and lowering quality of life. [23,24]

METHODOLOGY

Study Design:

This study will be observational cross-sectional study.

Sample Technique:

It will be a non-probability convenience sampling technique.

Outcome Measure

The study used the SF-30 questionnaire to assess caregivers' health-related quality of life (HRQoL), finding that 56.0% had poor HRQoL, 39.8% had moderate HRQoL, and only 1.3% reported good quality of life. HRQoL was not substantially correlated with gender, education, occupation, the existence of another affected child, or the type of neurological condition, but it was strongly correlated with caregiver age, marital status, and caregiver-child connection.

Data Analysis:

The Data will be analyzed using software packages, including descriptive statistics (means, frequencies and percentages) to describe the demographics of study participants and levels of knowledge regarding Quality of life . SPSS will also assist in inferential statistical analyses which can include tests such as chi-square tests or t-tests to check for significant difference in knowledge levels between various groups of participants.

Ethical Considerations:

Ethical approval for this study was obtained from the institutional review board of the respective universities involved. All participants were clearly informed about the purpose, procedures, and voluntary nature of the research before data collection. Participation was completely voluntary, and students were given the option to withdraw at any point without any consequences. Written informed consent was obtained from each participant, and anonymity and confidentiality of the data were strictly maintained. The data collected was stored securely and used solely for academic research purposes. The study involved no physical or psychological risk to the participants and did not interfere with their academic or personal activities. There were no conflicts of interest declared by the researchers.

Reliability:

Reliability of a questionnaire as a survey instrument ensures the accuracy of measures by assessing its internal consistency. There are different methods available to evaluate the internal consistency of the questionnaire

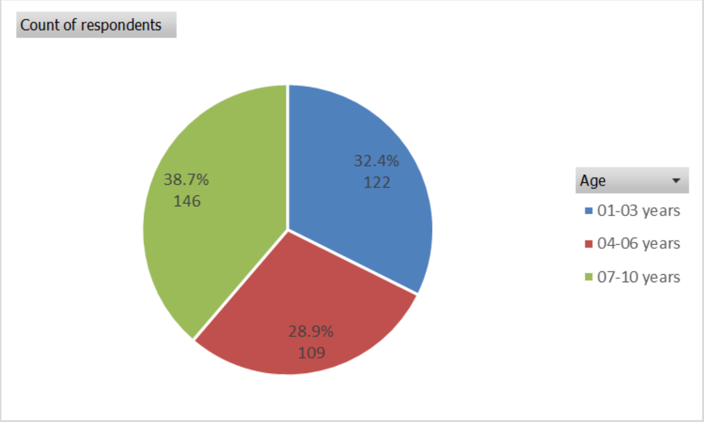
RESULT

Introduction

This chapter discusses the results of statistical applications on dependent variables, independent variables, and their mutual relations. It reviews two aspects of data analysis i.e. (i) Data dissection and its visualization aiming to provide research glimpse briefly to general audience and (ii) Statistical descriptions including descriptive statistics, correlation & chi-square analysis, and diagnostic analysis.

This chapter of results & discussion contains nine sections; First section is introduction which discusses the objective of chapter. The second section is data visualization of all data sets. Third Section is descriptive statistical details of dependent variables with independent variables. The fourth section is correlation matrix of data which stated and discussed the inter-relation of variables. Fifth Section contains chi-square analysis which compares the actual and expected results leading to accept or reject null hypothesis. Sixth section is the discussion of diagnostic Analysis which attempted to ascertain that either all verification checks be maintained during that statistical tools' application or not. It includes reliability test, normality test, multicollinearity and homogeneity test and test. Reliability test aims to identify the internal consistency of questionnaires, normality test aiming to find the symmetry or normality of responses. And homogeneity test aiming to vet that all chosen samples have had familiar characteristics. Moreover, multicollinearity aims to identify the situation in which two or more explanatory variables in a model are highly linearly related. The seventh section is summary which discusses the decision acceptance and rejection of hypothesis and overall chapter briefly along with results of this research.

Chart 1: Age-wise status of respondents: Showing break-up of population w.r.t. age-wise of respondents:



The age-wise distribution of respondents showed that out of a total of 377 participants, the largest proportion belonged to the 07–10 years age bracket, comprising 146 respondents (38.7%). This was followed by the 01–03 years age group with 122 respondents (32.4%), while the 04–06 years age bracket included 109 respondents (28.9%). Overall, the sample was well distributed across the three age categories, with a slightly higher representation of children aged 7–10 years, indicating that this age group formed the largest segment of the study population.

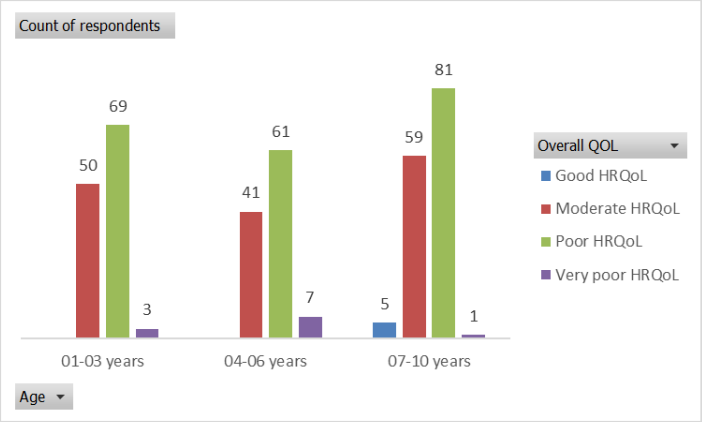
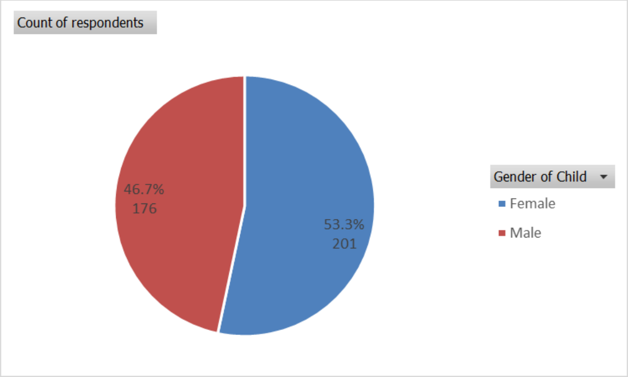


Figure 1 Distribution Of Health-Related Quality Of Life (HRQoL) Across Age Groups

The distribution of health-related quality of life (HRQoL) across age groups indicates that most caregivers experienced moderate to poor HRQoL. In the 01–03 years age group, 50 caregivers (41.0%) reported moderate HRQoL, 69 caregivers (56.6%) reported poor HRQoL, and 3 caregivers (2.5%) experienced very poor HRQoL. For the 04–06 years group, 41 caregivers (37.6%) had moderate HRQoL, 61 caregivers (55.9%) had poor HRQoL, and 7 caregivers (6.4%) were categorized as very poor. Among caregivers aged 07–10 years, the largest proportion fell into the poor HRQoL category, with 81 caregivers (55.5%), followed by 59 caregivers (40.4%) in the moderate HRQoL category, and 5 caregivers (3.4%) in the good HRQoL category; only 1 child (0.7%) reported very poor HRQoL. Overall, the findings suggest that poor HRQoL was most prevalent across all age groups, with moderate HRQoL also common, while good or very poor HRQoL was relatively rare.

Chart 2: Gender status-wise population: Showing break-up of population w.r.t. gender of respondents:



Out of a total of 377 respondents, 201 children were female, representing 53.3% of the sample, while 176 children were male, accounting for 46.7%. This indicates a slightly higher proportion of female children compared to male children in the study population, though the distribution between the two genders was relatively balanced.

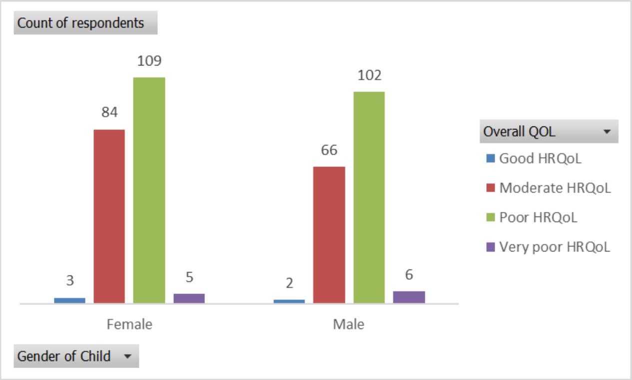
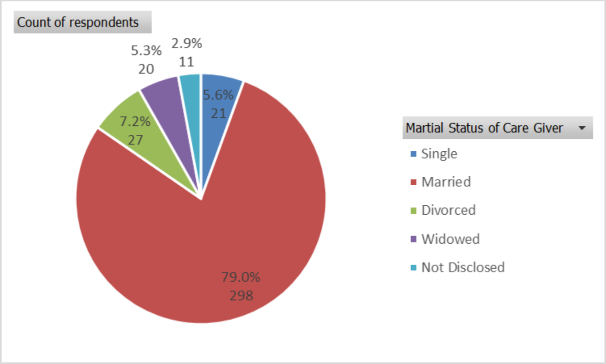


Figure 2 Distribution Of Health-Related Quality Of Life (HRQoL) Across Caregiver Marital Status

The distribution of health-related quality of life (HRQoL) among caregivers by gender shows that the majority experienced moderate to poor HRQoL. Among female caregivers (n = 201), 84 (41.8%) reported moderate HRQoL, 109 (54.2%) reported poor HRQoL, 5 (2.5%) experienced very poor HRQoL, and only 3 (1.5%) had good HRQoL. Similarly, among male caregivers (n = 176), 66 (37.5%) had moderate HRQoL, 102 (58.0%) reported poor HRQoL, 6 (3.4%) experienced very poor HRQoL, and 2 (1.1%) had good HRQoL. Overall, the data suggest that poor HRQoL was slightly more prevalent among male caregivers, while moderate HRQoL was slightly higher among females, and very few caregivers of either gender reported good HRQoL.

Chart 3: Marital status-wise population: Showing break-up of population w.r.t. marital status of respondents:



Out of the 377 caregivers, the majority were married, with 298 respondents (79.0%), indicating that most children were cared for within married households. A smaller proportion of caregivers were divorced (27; 7.2%) or single (21; 5.6%), while 20 caregivers (5.3%) were widowed. Additionally, 11 respondents (2.9%) did not disclose their marital status. Overall, the distribution shows a strong predominance of married caregivers, with other marital categories representing relatively smaller proportions of the study population. females, and very few caregivers of either gender reported good HRQoL.

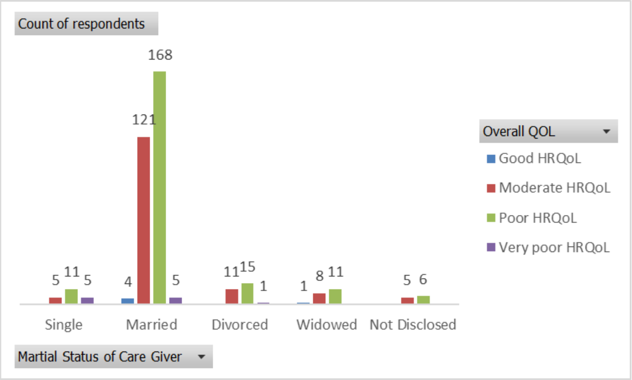
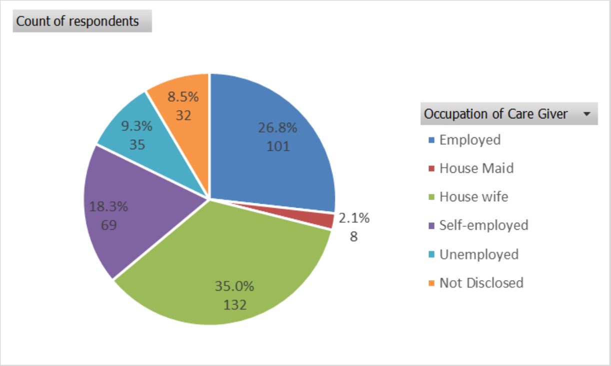


Figure 3 Distribution Of Health-Related Quality Of Life (Hrqol) Across Caregiver Marital Status

The distribution of health-related quality of life (HRQoL) across caregiver marital status shows that the majority of caregivers experienced moderate to poor HRQoL, regardless of the caregiver's marital status. Among single caregivers (n = 21), 5 (23.8%) had moderate HRQoL, 11 (52.4%) had poor HRQoL, and 5 (23.8%) reported very poor HRQoL. Married caregivers (n = 298), 121 (40.6%) reported moderate HRQoL, 168 (56.4%) poor HRQoL, 5 (1.7%) very poor HRQoL, and 4 (1.3%) good HRQoL. Divorced caregivers (n = 27) had 11 (40.7%) moderate HRQoL, 15 (55.6%) poor HRQoL, and 1 (3.7%) very poor HRQoL. Widowed caregivers (n = 20), 8 (40.0%) reported moderate HRQoL, 11 (55.0%) poor HRQoL, and 1 (5.0%) good HRQoL. For the not disclosed group (n = 11), 5 (45.5%) had moderate HRQoL and 6 (54.5%) poor HRQoL. Overall, the findings indicate that poor HRQoL was consistently the most common outcome across all marital status categories, with moderate HRQoL also prevalent, and good or very poor HRQoL relatively rare.

Chart 4: Occupation-wise population: Showing break-up of population w.r.t. Occupation of respondents:



Among the 377 caregivers, the largest group comprised housewives, with 132 respondents (35.0%), indicating that over one-third of caregivers were not engaged in paid employment. This was followed by employed caregivers, who accounted for 101 respondents (26.8%). Self-employed caregivers constituted 69 respondents (18.3%), while unemployed caregivers represented 35 respondents (9.3%) of the sample. A smaller proportion were reported as house maids, with 8 respondents (2.1%). Additionally, 32 caregivers (8.5%) did not disclose their occupation. Overall, the findings show that the majority of caregivers were either housewives or engaged in some form of employment, reflecting diverse occupational backgrounds within the study population.

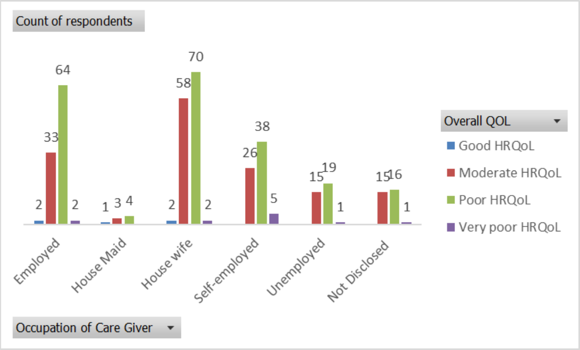
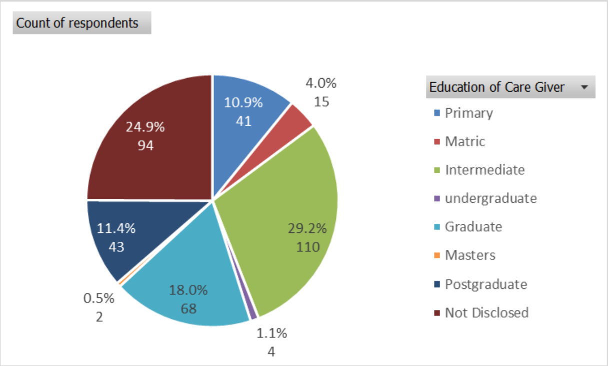


Figure 4 The Distribution Of Health-Related Quality Of Life (HRQoL) Across Caregiver Occupation

The distribution of health-related quality of life (HRQoL) across caregiver occupation shows that most caregivers experienced moderate to poor HRQoL, regardless of the caregiver's employment status. Among employed caregivers (n = 101), 33 (32.7%) had moderate HRQoL, 64 (63.4%) poor HRQoL, 2 (2.0%) very poor HRQoL, and 2 (2.0%) good HRQoL. House maid caregivers (n = 8) reported 3 (37.5%) moderate HRQoL and 4 (50.0%) poor HRQoL. For housewives (n = 132), 58 (43.9%) had moderate HRQoL, 70 (53.0%) poor HRQoL, and 2 (1.5%) very poor HRQoL, while 2 (1.5%) had good HRQoL. Self-employed caregivers (n = 69) showed 26 (37.7%) moderate HRQoL, 38 (55.1%) poor HRQoL, and 5 (7.2%) very poor HRQoL. Among unemployed caregivers (n = 35), 15 (42.9%) had moderate HRQoL, 19 (54.3%) poor HRQoL, and 1 (2.9%) very poor HRQoL. In the not disclosed group (n = 32), 15 (46.9%) had moderate HRQoL, 16 (50.0%) poor HRQoL, and 1 (3.1%) very poor HRQoL. Overall, the findings indicate that poor HRQoL was the most prevalent outcome across all occupational categories, with moderate HRQoL also common, while good or very poor HRQoL remained relatively rare.

Chart 5: Education-wise population: Showing break-up of population w.r.t. education-wise of respondents:



Out of the 377 caregivers, the largest proportion had an intermediate level of education, with 110 respondents (29.2%). This was followed by caregivers who were graduates, comprising 68 respondents (18.0%), and those with postgraduate education, accounting for 43 respondents (11.4%). Caregivers with primary education included 41 respondents (10.9%), while matric-level education was reported by 15 respondents (4.0%). A very small proportion had completed undergraduate education (4 respondents; 1.1%) or master's education (2 respondents; 0.5%). Additionally, 94 caregivers (24.9%) did not disclose their educational status. Overarll, the educational profile indicates a wide range of educational attainment among caregivers, with a substantial proportion having at least intermediate or higher education.

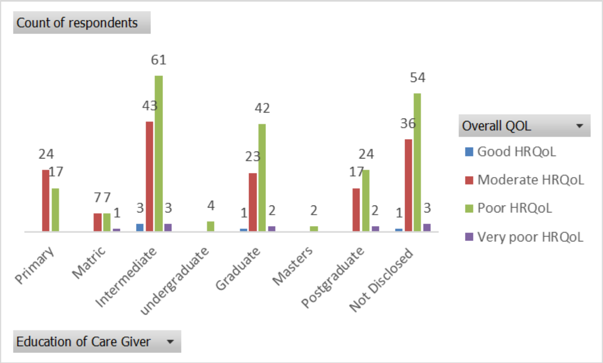
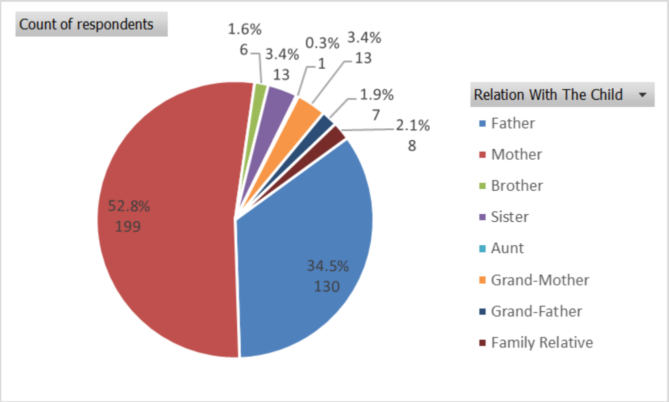


Figure 5 The Distribution Of Health-Related Quality Of Life (HRQoL) Across Caregiver Education Levels

The distribution of health-related quality of life (HRQoL) across caregiver education levels shows that the majority of caregivers experienced moderate to poor HRQoL, regardless of the caregiver's educational attainment. Caregivers had primary education (n = 41), 24 (58.5%) had moderate HRQoL and 17 (41.5%) had poor HRQoL. For matric-educated caregivers (n = 15), 7 (46.7%) reported moderate HRQoL, 7 (46.7%) poor HRQoL, and 1 (6.6%) very poor HRQoL. Caregivers having intermediate education (n = 110) showed 43 (39.1%) moderate HRQoL, 61 (55.5%) poor HRQoL, 3 (2.7%) very poor HRQoL, and 3 (2.7%) good HRQoL. In the undergraduate group (n = 4), all caregivers fell in poor HRQoL. Among graduate caregivers (n = 68), 23 (33.8%) had moderate HRQoL, 42 (61.8%) poor HRQoL, and 2 (2.9%) very poor HRQoL, with 1 (1.5%) reporting good HRQoL. Caregivers with master's education (n = 2) had caregivers exclusively in the moderate HRQoL category, while the postgraduate group (n = 43) included 17 (39.5%) moderate HRQoL, 24 (55.8%) poor HRQoL, and 2 (4.7%) very poor HRQoL. Among caregivers who did not disclose their education (n = 94), 36 (38.3%) had moderate HRQoL, 54 (57.5%) poor HRQoL, and 3 (3.2%) very poor HRQoL, with 1 (1.1%) reporting good HRQoL. Overall, poor HRQoL was consistently the most prevalent outcome across all education levels, with moderate HRQoL also common, and good or very poor HRQoL occurring relatively rarely.

Chart 6: Relation-wise population: Showing break-up of population w.r.t. relation-wise of respondents:



Out of the 377 respondents, the majority of caregivers were mothers, accounting for 199 respondents (52.8%), followed by fathers with 130 respondents (34.5%). Smaller proportions of caregivers were sisters (13; 3.4%) and grandmothers (13; 3.4%). Grandfathers constituted 7 respondents (1.9%), while brothers accounted for 6 respondents (1.6%). Very few caregivers were family relatives (8; 2.1%) or aunts (1; 0.3%). Overall, the findings indicate that caregiving responsibilities were predominantly undertaken by parents, particularly mothers, with extended family members playing a comparatively minor role.

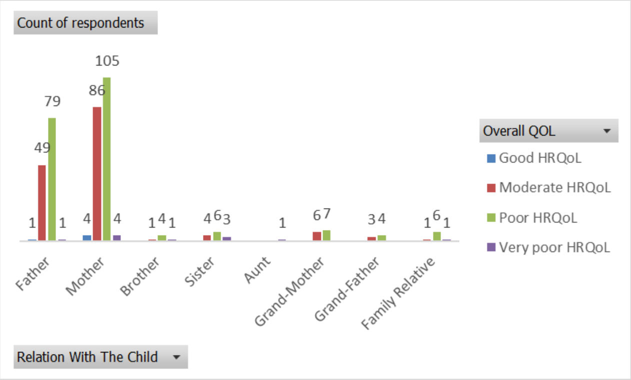
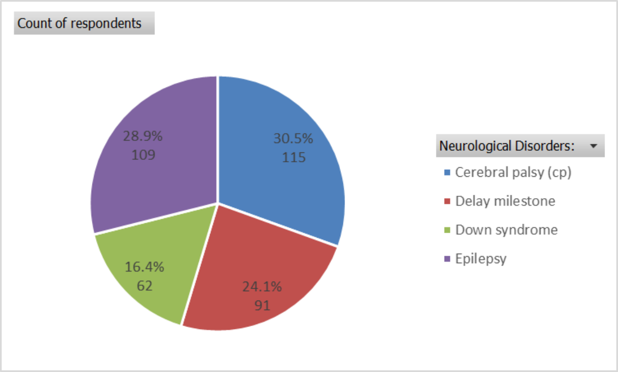


Figure 6 Distribution Of Health-Related Quality Of Life (HRQoL) Across Caregiver–Child Relationships

The distribution of health-related quality of life (HRQoL) across caregiver–child relationships shows that most caregivers experienced moderate to poor HRQoL, regardless of who the primary caregiver was. Among caregivers-fathers (n = 130), 49 (37.7%) had moderate HRQoL, 79 (60.8%) poor HRQoL, and 1 (0.8%) very poor HRQoL, with only 1 (0.8%) reporting good HRQoL. Caregivers-mothers (n = 199) showed a similar pattern, with 86 (43.2%) moderate HRQoL, 105 (52.8%) poor HRQoL, 4 (2.0%) very poor HRQoL, and 4 (2.0%) good HRQoL. Among brother caregivers (n = 6) had 1 (16.7%) moderate HRQoL, 4 (66.7%) poor HRQoL, and 1 (16.7%) very poor HRQoL, while sister caregivers (n = 13) had 4 (30.8%) moderate HRQoL, 6 (46.2%) poor HRQoL, and 3 (23.0%) very poor HRQoL. For extended family members, grandmothers (n = 13) had 6 (46.2%) moderate HRQoL and 7 (53.8%) poor HRQoL, grandfathers (n = 7) had 3 (42.9%) moderate HRQoL and 4 (57.1%) poor HRQoL, and the single aunt caregiver reported very poor HRQoL for the child. Family relatives (n = 8) had 1 (12.5%) moderate HRQoL, 6 (75.0%) poor HRQoL, and 1 (12.5%) very poor HRQoL. Overall, poor HRQoL was the most prevalent outcome across all caregiver relationships, with moderate HRQoL also common, and very few caregivers experiencing good HRQoL.

Chart 7: Neurological Disorders-wise population: Showing break-up of population w.r.t. Neurological Disorders-wise of respondents:



Among the 377 children in the study, the distribution of neurological disorders was as follows: the most common condition was cerebral palsy (CP), reported in 115 children (30.5%), followed closely by epilepsy in 109 children (28.9%). Delay in developmental milestones was observed in 91 children (24.1%), while Down syndrome affected 62 children (16.4%). These results indicate that cerebral palsy and epilepsy were the most prevalent neurological disorders in the study population, together accounting for nearly 60% of all cases

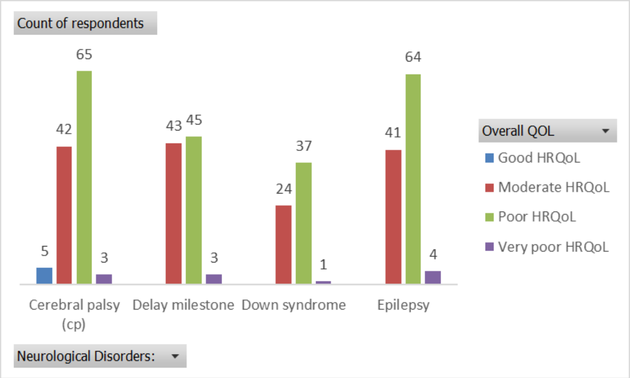


Figure 7 :Distribution Of Health-Related Quality Of Life (HRQoL) Among Caregivers Varied According To The Type Of Neurological Disorder

The distribution of health-related quality of life (HRQoL) among caregivers varied according to the type of neurological disorder. Child with cerebral palsy (n = 115) mostly experienced poor HRQoL, with 65 (56.5%) reporting poor, 42 (36.5%) moderate, 5 (4.3%) good, and 3 (2.6%) very poor HRQoL. Among cahild with delayed milestones (n = 91), 45 (49.5%) had poor HRQoL, 43 (47.3%) moderate, and 3 (3.2%) very poor, with no caregiver reporting good HRQoL. For child with Down syndrome (n = 62), poor HRQoL was again most common (37; 59.7%), followed by moderate (24; 38.7%) and very poor HRQoL (1; 1.6%), with none reporting good HRQoL. Among child with epilepsy (n = 109), 64 (58.7%) reported poor HRQoL, 41 (37.6%) moderate, and 4 (3.7%) very poor, with no caregiver in the good HRQoL category. Overall, these results indicate that poor HRQoL was the predominant outcome across all types of neurological disorders, while moderate HRQoL was also common, and good or very poor HRQoL was relatively rare.

Descriptive Statistics

Table 1: Descriptive Analysis of demographics Scale:

Elements	N	Min.	Max.	Mean	SD	Variance
Age	377	1	3	2.06	0.84	0.71

Gender	377	1	2	1.53	0.50	0.25
Marital status	377	1	5	2.23	0.78	0.61
Occupation	377	1	6	3.17	1.65	2.72
Education	377	1	8	4.84	2.50	6.27
Relation	377	1	8	2.21	1.62	2.61
Another Child With Similar Disorder In Family.	377	0	1	0.01	0.07	0.01
Neurological Disorders	377	1	4	2.44	1.20	1.44

Among the 377 children in the study, the distribution of neurological disorders was as follows: the most common condition was cerebral palsy (CP), reported in 115 children (30.5%), followed closely by epilepsy in 109 children (28.9%). Delay in developmental milestones was observed in 91 children (24.1%), while Down syndrome affected 62 children (16.4%). These results indicate that cerebral palsy and epilepsy were the most prevalent neurological disorders in the study population, together accounting for nearly 60% of all cases.

Table 2: Descriptive Analysis of SF-30 Scale:

Elements	N	Min.	Max.	Mean	SD	Variance
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase?	377	1	5	2.40	1.45	2.11
Do you have any trouble taking a long walk?	377	1	5	2.30	1.41	1.99
Do you have any trouble taking a short walk outside of the house?	377	1	5	1.89	1.21	1.47
Do you have to stay in a bed or a chair most of the day?	377	1	5	1.93	1.27	1.61
Do you need help with eating, dressing, washing yourself or using the toilet?	377	1	5	2.54	1.48	2.20
Were you limited in doing either your work or other daily activities?	377	1	5	2.68	1.45	2.10
Were you limited in pursuing your hobbies or other leisure time activities?	377	1	5	2.69	1.49	2.22
Were you short of breath?	377	1	5	2.62	1.50	2.24
Have you had pain?	377	1	5	2.69	1.47	2.16
Did you need to rest?	377	1	5	2.72	1.51	2.28
Have you had trouble sleeping?	377	1	5	2.62	1.47	2.17
Have you felt weak?	377	1	5	2.66	1.48	2.18
Have you lacked an appetite?	377	1	5	1.97	1.25	1.55
Have you felt nauseated?	377	1	5	1.85	1.20	1.45
Have you vomited?	377	1	5	1.50	1.00	1.01

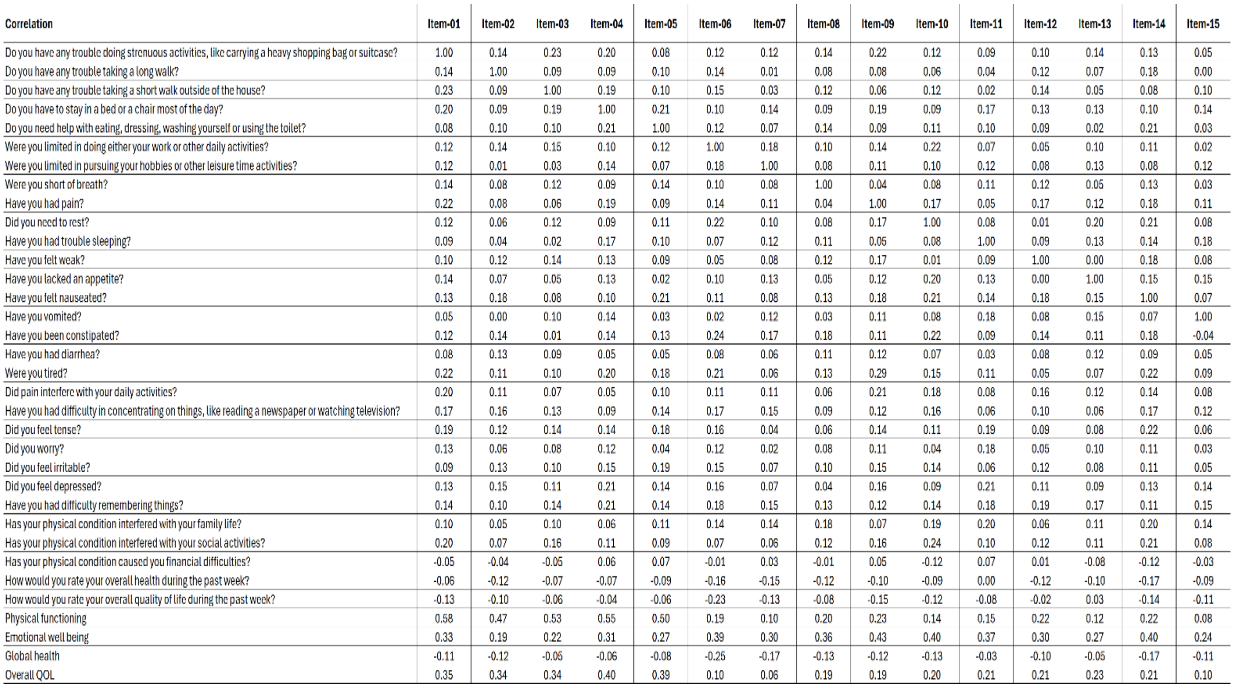
Have you been constipated?	377	1	5	1.89	1.23	1.52
Have you had diarrhea?	377	1	5	1.86	1.22	1.48
Were you tired?	377	1	5	2.68	1.49	2.21
Did pain interfere with your daily activities?	377	1	5	2.56	1.50	2.26
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	377	1	5	2.81	1.48	2.19
Did you feel tense?	377	1	5	2.79	1.49	2.23
Did you worry?	377	1	5	2.65	1.44	2.06
Did you feel irritable?	377	1	5	2.78	1.49	2.21
Did you feel depressed?	377	1	5	2.69	1.49	2.21
Have you had difficulty remembering things?	377	1	5	2.58	1.43	2.06
Has your physical condition interfered with your family life?	377	1	5	2.79	1.48	2.18
Has your physical condition interfered with your social activities?	377	1	5	2.63	1.43	2.06
Has your physical condition caused you financial difficulties?	377	1	5	2.40	0.68	0.46
How would you rate your overall health during the past week?	377	1	5	2.85	1.02	1.03
How would you rate your overall quality of life during the past week?	377	1	5	3.10	1.04	1.09

The analysis of HRQoL items among 377 respondents revealed varying levels of physical, emotional, and social challenges. For physical functioning, mean scores ranged from 1.50 to 2.72 on a 5-point scale, with the highest mean observed for “Did you need to rest?” (M = 2.72, SD = 1.51), indicating moderate difficulty, while the lowest was for “Have you vomited?” (M = 1.50, SD = 1.00), suggesting minimal occurrence. Activities such as carrying heavy items (M = 2.40, SD = 1.45) and taking long walks (M = 2.30, SD = 1.41) showed mild-to-moderate difficulty, whereas basic daily self-care needs scored slightly higher (M = 2.54, SD = 1.48). For symptoms and emotional well-being, items assessing fatigue, tension, worry, irritability, and difficulty concentrating showed mean scores between 2.58 and 2.81, with “difficulty concentrating” having the highest mean (M = 2.81, SD = 1.48) and “difficulty remembering” slightly lower (M = 2.58, SD = 1.43). Pain and shortness of breath were moderately reported (M ≈ 2.56–2.62), reflecting some interference with daily activities. Gastrointestinal symptoms such as lack of appetite, nausea, constipation, and diarrhea had lower means (M ≈ 1.85–1.97), while vomiting was least frequent (M = 1.50). Regarding overall health and quality of life, respondents reported mean scores of 2.85 (SD = 1.02) for overall health and 3.10 (SD = 1.04) for overall QOL, indicating a moderately positive perception despite challenges in physical and emotional domains. Variances ranged from 0.46 to 2.28, showing the highest variability in items related to rest and fatigue, and lower variability in financial difficulties (M = 2.40, SD = 0.68, Var = 0.46). Overall, the data suggest that respondents experienced moderate difficulties in physical functioning, fatigue, and emotional well-being, while basic symptoms like vomiting and nausea were less common, and perceived overall health and quality of life remained moderately positive.

Correlation Matrix

Correlation is a statistical technique that ascertains whether and how strongly set of variables are related. In this research, correlation coefficient computed from the sample data measures the strength and direction (positive or negative) of a linear relationship between dependent and independent variables. If the value of the correlation coefficient is significant among the variable (s), we would have to go to evaluate the level of parity between the actual and expected results through Chi-square.

Table 3: Correlation Analysis of SF-30 scale:



Correlation	Item-01	Item-02	Item-03	Item-04	Item-05	Item-06	Item-07	Item-08	Item-09	Item-10	Item-11	Item-12	Item-13	Item-14	Item-15
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase?	1.00	0.14	0.23	0.20	0.08	0.12	0.12	0.14	0.22	0.12	0.09	0.10	0.14	0.13	0.05
Do you have any trouble taking a long walk?	0.14	1.00	0.09	0.09	0.10	0.14	0.01	0.08	0.08	0.06	0.04	0.12	0.07	0.18	0.00
Do you have any trouble taking a short walk outside of the house?	0.23	0.09	1.00	0.19	0.10	0.15	0.03	0.12	0.06	0.12	0.02	0.14	0.05	0.08	0.10
Do you have to stay in a bed or a chair most of the day?	0.20	0.09	0.19	1.00	0.21	0.10	0.14	0.09	0.19	0.09	0.17	0.13	0.13	0.10	0.14
Do you need help with eating, dressing, washing yourself or using the toilet?	0.08	0.10	0.10	0.21	1.00	0.12	0.07	0.14	0.09	0.11	0.10	0.09	0.02	0.21	0.03
Were you limited in doing either your work or other daily activities?	0.12	0.14	0.15	0.10	0.12	1.00	0.18	0.10	0.14	0.22	0.07	0.05	0.10	0.11	0.02
Were you limited in pursuing your hobbies or other leisure time activities?	0.12	0.01	0.03	0.14	0.07	0.18	1.00	0.08	0.11	0.10	0.12	0.08	0.13	0.08	0.12
Were you short of breath?	0.14	0.08	0.12	0.09	0.14	0.10	0.08	1.00	0.04	0.08	0.11	0.12	0.05	0.13	0.03
Have you had pain?	0.22	0.08	0.06	0.19	0.09	0.14	0.11	0.04	1.00	0.17	0.05	0.17	0.12	0.18	0.11
Did you need to rest?	0.12	0.06	0.12	0.09	0.11	0.22	0.10	0.08	0.17	1.00	0.08	0.01	0.20	0.21	0.08
Have you had trouble sleeping?	0.09	0.04	0.02	0.17	0.10	0.07	0.12	0.11	0.05	0.08	1.00	0.09	0.13	0.14	0.18
Have you felt weak?	0.10	0.12	0.14	0.13	0.09	0.05	0.08	0.12	0.17	0.01	0.09	1.00	0.00	0.18	0.08
Have you lacked an appetite?	0.14	0.07	0.05	0.13	0.02	0.10	0.13	0.05	0.12	0.20	0.13	0.00	1.00	0.15	0.15
Have you felt nauseated?	0.13	0.18	0.08	0.10	0.21	0.11	0.08	0.13	0.18	0.21	0.14	0.18	0.15	1.00	0.07
Have you vomited?	0.05	0.00	0.10	0.14	0.03	0.02	0.12	0.03	0.11	0.08	0.18	0.08	0.15	0.07	1.00
Have you been constipated?	0.12	0.14	0.01	0.14	0.13	0.24	0.17	0.18	0.11	0.22	0.09	0.14	0.11	0.18	-0.04
Have you had diarrhea?	0.08	0.13	0.09	0.05	0.05	0.08	0.06	0.11	0.12	0.07	0.03	0.08	0.12	0.09	0.05
Were you tired?	0.22	0.11	0.10	0.20	0.18	0.21	0.06	0.13	0.29	0.15	0.11	0.05	0.07	0.22	0.09
Did pain interfere with your daily activities?	0.20	0.11	0.07	0.05	0.10	0.11	0.11	0.06	0.21	0.18	0.08	0.16	0.12	0.14	0.08
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	0.17	0.16	0.13	0.09	0.14	0.17	0.15	0.09	0.12	0.16	0.06	0.10	0.06	0.17	0.12
Did you feel tense?	0.19	0.12	0.14	0.14	0.18	0.16	0.04	0.06	0.14	0.11	0.19	0.09	0.08	0.22	0.06
Did you worry?	0.13	0.06	0.08	0.12	0.04	0.12	0.02	0.08	0.11	0.04	0.18	0.05	0.10	0.11	0.03
Did you feel irritable?	0.09	0.13	0.10	0.15	0.19	0.15	0.07	0.10	0.15	0.14	0.06	0.12	0.08	0.11	0.05
Did you feel depressed?	0.13	0.15	0.11	0.21	0.14	0.16	0.07	0.04	0.16	0.09	0.21	0.11	0.09	0.13	0.14
Have you had difficulty remembering things?	0.14	0.10	0.14	0.21	0.14	0.18	0.15	0.13	0.12	0.14	0.18	0.19	0.17	0.11	0.15
Has your physical condition interfered with your family life?	0.10	0.05	0.10	0.06	0.11	0.14	0.14	0.18	0.07	0.19	0.20	0.06	0.11	0.20	0.14
Has your physical condition interfered with your social activities?	0.20	0.07	0.16	0.11	0.09	0.07	0.06	0.12	0.16	0.24	0.10	0.12	0.11	0.21	0.08
Has your physical condition caused you financial difficulties?	-0.05	-0.04	-0.05	0.06	0.07	-0.01	0.03	-0.01	0.05	-0.12	0.07	0.01	-0.08	-0.12	-0.03
How would you rate your overall health during the past week?	-0.06	-0.12	-0.07	-0.07	-0.09	-0.16	-0.15	-0.12	-0.10	-0.09	0.00	-0.12	-0.10	-0.17	-0.09
How would you rate your overall quality of life during the past week?	-0.13	-0.10	-0.06	-0.04	-0.06	-0.23	-0.13	-0.08	-0.15	-0.12	-0.08	-0.02	0.03	-0.14	-0.11
Physical functioning	0.58	0.47	0.53	0.55	0.50	0.19	0.10	0.20	0.23	0.14	0.15	0.22	0.12	0.22	0.08
Emotional well being	0.33	0.19	0.22	0.31	0.27	0.39	0.30	0.36	0.43	0.40	0.37	0.30	0.27	0.40	0.24
Global health	-0.11	-0.12	-0.05	-0.06	-0.08	-0.25	-0.17	-0.13	-0.12	-0.13	-0.03	-0.10	-0.05	-0.17	-0.11
Overall QOL	0.35	0.34	0.34	0.40	0.39	0.10	0.06	0.19	0.19	0.20	0.21	0.21	0.23	0.21	0.10

Correlation	Item-16	Item-17	Item-18	Item-19	Item-20	Item-21	Item-22	Item-23	Item-24	Item-25	Item-26	Item-27	Item-28	Item-29	Item-30
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase?	0.12	0.08	0.22	0.20	0.17	0.19	0.13	0.09	0.13	0.14	0.10	0.20	-0.05	-0.06	-0.13
Do you have any trouble taking a long walk?	0.14	0.13	0.11	0.11	0.16	0.12	0.06	0.13	0.15	0.10	0.05	0.07	-0.04	-0.12	-0.10
Do you have any trouble taking a short walk outside of the house?	0.01	0.09	0.10	0.07	0.13	0.14	0.08	0.10	0.11	0.14	0.10	0.16	-0.05	-0.07	-0.06
Do you have to stay in a bed or a chair most of the day?	0.14	0.05	0.20	0.05	0.09	0.14	0.12	0.15	0.21	0.21	0.06	0.11	0.06	-0.07	-0.04
Do you need help with eating, dressing, washing yourself or using the toilet?	0.13	0.05	0.18	0.10	0.14	0.18	0.04	0.19	0.14	0.14	0.11	0.09	0.07	-0.09	-0.06
Were you limited in doing either your work or other daily activities?	0.24	0.08	0.21	0.11	0.17	0.16	0.12	0.15	0.16	0.18	0.14	0.07	-0.01	-0.16	-0.23
Were you limited in pursuing your hobbies or other leisure time activities?	0.17	0.06	0.06	0.11	0.15	0.04	0.02	0.07	0.07	0.15	0.14	0.06	0.03	-0.15	-0.13
Were you short of breath?	0.18	0.11	0.13	0.06	0.09	0.06	0.08	0.10	0.04	0.13	0.18	0.12	-0.01	-0.12	-0.08
Have you had pain?	0.11	0.12	0.29	0.21	0.12	0.14	0.11	0.15	0.16	0.12	0.07	0.16	0.05	-0.10	-0.15
Did you need to rest?	0.22	0.07	0.15	0.18	0.16	0.11	0.04	0.14	0.09	0.14	0.19	0.24	-0.12	-0.09	-0.12
Have you had trouble sleeping?	0.09	0.03	0.11	0.08	0.06	0.19	0.18	0.06	0.21	0.18	0.20	0.10	0.07	0.00	-0.08
Have you felt weak?	0.14	0.08	0.05	0.16	0.10	0.09	0.05	0.12	0.11	0.19	0.06	0.12	0.01	-0.12	-0.02
Have you lacked an appetite?	0.11	0.12	0.07	0.12	0.06	0.08	0.10	0.08	0.09	0.17	0.11	0.11	-0.08	-0.10	0.03
Have you felt nauseated?	0.18	0.09	0.22	0.14	0.17	0.22	0.11	0.11	0.13	0.11	0.20	0.21	-0.12	-0.17	-0.14
Have you vomited?	-0.04	0.05	0.09	0.08	0.12	0.06	0.03	0.05	0.14	0.15	0.14	0.08	-0.03	-0.09	-0.11
Have you been constipated?	1.00	0.12	0.17	0.12	0.15	0.12	0.15	0.16	0.18	0.18	0.15	0.12	-0.14	-0.23	-0.07
Have you had diarrhea?	0.12	1.00	0.09	0.11	0.17	0.06	0.09	0.07	0.05	0.07	0.12	0.07	0.04	-0.13	-0.08
Were you tired?	0.17	0.09	1.00	0.14	0.15	0.17	0.10	0.18	0.18	0.17	0.11	0.15	-0.04	-0.10	-0.10
Did pain interfere with your daily activities?	0.12	0.11	0.14	1.00	0.10	0.13	0.07	0.13	0.10	0.09	0.13	0.19	-0.06	-0.13	-0.04
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	0.15	0.17	0.15	0.10	1.00	0.07	0.11	0.11	0.16	0.13	0.21	0.17	-0.10	-0.17	-0.10
Did you feel tense?	0.12	0.06	0.17	0.13	0.07	1.00	0.14	0.16	0.10	0.20	0.11	0.11	-0.06	-0.21	-0.08
Did you worry?	0.15	0.09	0.10	0.07	0.11	0.14	1.00	0.05	0.18	0.06	0.10	0.12	-0.06	-0.06	-0.02
Did you feel irritable?	0.16	0.07	0.18	0.13	0.11	0.16	0.05	1.00	0.12	0.14	0.05	0.12	-0.05	-0.14	-0.11
Did you feel depressed?	0.18	0.05	0.18	0.10	0.16	0.10	0.18	0.12	1.00	0.14	0.12	0.07	-0.02	-0.09	-0.08
Have you had difficulty remembering things?	0.18	0.07	0.17	0.09	0.13	0.20	0.06	0.14	0.14	1.00	0.14	0.20	0.07	-0.15	-0.14
Has your physical condition interfered with your family life?	0.15	0.12	0.11	0.13	0.21	0.11	0.10	0.05	0.12	0.14	1.00	0.12	-0.05	-0.10	-0.14
Has your physical condition interfered with your social activities?	0.12	0.07	0.15	0.19	0.17	0.11	0.12	0.12	0.07	0.20	0.12	1.00	-0.03	-0.09	-0.05
Has your physical condition caused you financial difficulties?	-0.14	0.04	-0.04	-0.06	-0.10	-0.06	-0.06	-0.05	-0.02	0.07	-0.05	-0.03	1.00	0.11	0.03
How would you rate your overall health during the past week?	-0.23	-0.13	-0.10	-0.13	-0.17	-0.21	-0.06	-0.14	-0.09	-0.15	-0.10	-0.09	0.11	1.00	0.18
How would you rate your overall quality of life during the past week?	-0.07	-0.08	-0.10	-0.04	-0.10	-0.08	-0.02	-0.11	-0.08	-0.14	-0.14	-0.05	0.03	0.18	1.00
Physical functioning	0.21	0.12	0.27	0.15	0.23	0.26	0.13	0.23	0.26	0.27	0.15	0.21	0.01	-0.15	-0.14
Emotional well being	0.38	0.24	0.42	0.42	0.37	0.31	0.32	0.30	0.37	0.40	0.41	0.39	-0.03	-0.22	-0.18
Global health	-0.20	-0.14	-0.10	-0.09	-0.15	-0.15	-0.05	-0.15	-0.08	-0.17	-0.13	-0.08	0.05	0.72	0.73
Overall QOL	0.11	0.15	0.31	0.22	0.20	0.19	0.17	0.22	0.24	0.20	0.17	0.26	0.05	0.21	0.31

Correlation	Physical functioning	Emotional well being	Global health	Overall QOL
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or suitcase?	0.58	0.33	-0.11	0.35
Do you have any trouble taking a long walk?	0.47	0.19	-0.12	0.34
Do you have any trouble taking a short walk outside of the house?	0.53	0.22	-0.05	0.34
Do you have to stay in a bed or a chair most of the day?	0.55	0.31	-0.06	0.40
Do you need help with eating, dressing, washing yourself or using the toilet?	0.50	0.27	-0.08	0.39
Were you limited in doing either your work or other daily activities?	0.19	0.39	-0.25	0.10
Were you limited in pursuing your hobbies or other leisure time activities?	0.10	0.30	-0.17	0.06
Were you short of breath?	0.20	0.36	-0.13	0.19
Have you had pain?	0.23	0.43	-0.12	0.19
Did you need to rest?	0.14	0.40	-0.13	0.20
Have you had trouble sleeping?	0.15	0.37	-0.03	0.21
Have you felt weak?	0.22	0.30	-0.10	0.21
Have you lacked an appetite?	0.12	0.27	-0.05	0.23
Have you felt nauseated?	0.22	0.40	-0.17	0.21
Have you vomited?	0.08	0.24	-0.11	0.10
Have you been constipated?	0.21	0.38	-0.20	0.11
Have you had diarrhea?	0.12	0.24	-0.14	0.15
Were you tired?	0.27	0.42	-0.10	0.31
Did pain interfere with your daily activities?	0.15	0.42	-0.09	0.22
Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	0.23	0.37	-0.15	0.20
Did you feel tense?	0.26	0.31	-0.15	0.19
Did you worry?	0.13	0.32	-0.05	0.17
Did you feel irritable?	0.23	0.30	-0.15	0.22
Did you feel depressed?	0.26	0.37	-0.08	0.24
Have you had difficulty remembering things?	0.27	0.40	-0.17	0.20
Has your physical condition interfered with your family life?	0.15	0.41	-0.13	0.17
Has your physical condition interfered with your social activities?	0.21	0.39	-0.08	0.26
Has your physical condition caused you financial difficulties?	0.01	-0.03	0.05	0.05
How would you rate your overall health during the past week?	-0.15	-0.22	0.72	0.21
How would you rate your overall quality of life during the past week?	-0.14	-0.18	0.73	0.31
Physical functioning	1.00	0.43	-0.15	0.60
Emotional well being	0.43	1.00	-0.22	0.47
Global health	-0.15	-0.22	1.00	0.34
Overall QOL	0.60	0.47	0.34	1.00

Annexed table of correlation analysis revealed generally weak to moderate inter-item associations, indicating minimal multicollinearity and suggesting that individual items captured related yet distinct dimensions of quality of life. Physical functioning demonstrated moderate to strong positive correlations with mobility- and independence-related items, including difficulty performing strenuous activities (r = 0.58), taking a long walk (r = 0.47), taking a short walk outside the home (r = 0.53), being confined to bed or a chair (r = 0.55), and requiring assistance with self-care activities (r = 0.50). Physical functioning was also moderately correlated with emotional well-being (r = 0.43) and showed a strong positive association with overall quality of life (r = 0.60). Emotional well-being exhibited moderate correlations with symptom-related items such as pain (r = 0.43), tiredness (r = 0.42), pain interference with daily activities (r = 0.42), depressive feelings (r = 0.37), and anxiety-related symptoms (r ≈ 0.31–0.32), indicating a close relationship between psychological distress and symptom burden. Global health showed strong positive correlations with self-rated overall health (r = 0.72) and overall quality of life (r = 0.73), while demonstrating weak to moderate negative correlations with symptom and functional limitation items. Overall quality of life was moderately associated with physical functioning (r = 0.60), emotional well-being (r = 0.47), and global health (r = 0.34), supporting the multidimensional nature of quality of life encompassing physical, emotional, and social domains.

STUDY LIMITATIONS

The methodology of this study presents several limitations that may impact the validity, reliability, and generalizability of the findings. First, the use of a cross-sectional design restricts the ability to establish causal relationships between caregiver characteristics and the quality of life of children with neurological disorders. Observations are limited to a single time point, which may not capture changes over time in either the child’s condition or the caregiver’s experiences. Second, the study employs a non-probability convenience sampling technique, selecting participants from specific hospitals and rehabilitation centers in Karachi. This approach introduces selection bias, as caregivers who attend these facilities may differ systematically from those who seek care elsewhere or have limited access to healthcare services, limiting the generalizability of the results to the broader population. Third, the inclusion criteria restrict the study to children aged 1–10 years with specific neurological disorders, such as cerebral palsy, epilepsy, Down syndrome, and delayed milestones, excluding other neurological conditions and age groups, thereby limiting applicability. Fourth, data were collected using self-reported questionnaires, which may be affected by response and recall biases, social desirability, or misinterpretation of questions. Fifth, the relatively short study duration of six months may not account for seasonal or situational variations in caregiving burden and children’s health status. Finally, while statistical analyses were planned, potential confounding variables such as socioeconomic status, access to rehabilitation services, and family support systems were not comprehensively controlled, which could influence the observed associations. Collectively, these limitations should be considered when interpreting the study findings and their implications for policy and practice in Karachi.

RECOMMENDATIONS FOR FUTURE RESEARCH

To address the limitations identified in this study, future research should consider adopting a longitudinal design, which would allow for tracking changes in the quality of life of children with neurological disorders and their caregivers over time, thereby providing insights into causal relationships and temporal trends. Employing a probability-based sampling method, such as stratified or cluster sampling, would improve representativeness and reduce selection bias, enabling results to be generalized more confidently to the broader population of caregivers in Karachi and similar settings. Expanding the inclusion criteria to encompass a wider range of neurological disorders and broader age groups would enhance the applicability of findings and provide a more comprehensive understanding of caregiver experiences across different conditions. Incorporating mixed-method approaches, such as combining quantitative questionnaires with qualitative interviews, could mitigate biases inherent in self-reported data and provide richer, more nuanced insights into caregiver challenges, coping strategies, and perceived quality of life. Extending the study duration and including multiple data collection points would help capture seasonal variations and situational fluctuations in caregiving burden. Additionally, controlling for potential confounding variables, such as socioeconomic status, family support, and access to healthcare and rehabilitation services, would strengthen the validity of statistical analyses. Finally, providing training for data collectors and using validated, culturally adapted instruments can enhance the reliability and accuracy of responses. Collectively, these methodological improvements would enable future studies to generate more robust, generalizable, and actionable evidence to inform interventions and policies for children with neurological disorders and their caregivers in Karachi.

CONCLUSION

In conclusion, this study highlights the considerable challenges faced by children with neurological disorders and their primary caregivers in Karachi. The findings indicate that the majority of caregivers of children experience moderate to poor health-related quality of life (HRQoL), with physical limitations and emotional difficulties being the most significant determinants. Caregiver characteristics, especially marital status and caregiver–child relationship, were shown to have a strong influence on HRQoL, underscoring the critical role of family and social support in managing pediatric neurological conditions. The predominance of mothers as primary caregivers reflects cultural norms and emphasizes the heightened physical, emotional, and social burden they bear. While the study provides valuable insights, methodological limitations—including the cross-sectional design, convenience sampling, self-reported measures, and limited inclusion criteria—restrict causal interpretations and generalizability. Nonetheless, the findings have practical implications for improving interventions, such as community-based support programs, accessible rehabilitation services, caregiver education, inclusive schooling, and advocacy for better resource allocation. Future research employing longitudinal and mixed-method approaches, broader sampling, and comprehensive control of confounding factors can build on these findings to generate more robust evidence. Overall, this study underscores the intertwined well-being of children with neurological disorders and their caregivers, highlighting the necessity of holistic, family-centered strategies to enhance quality of life and reduce caregiver burden in Karachi’s healthcare context.

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CONFLICT OF INTERST

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