

DETERMINANTS OF QUALITY OF LIFE AMONG PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN A COUNTY TEACHING AND REFERRAL HOSPITAL, KENYA.

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Abstract

Introduction: Primary caregivers of children with cerebral palsy (CP) face various challenges physical, social, psychosocial, and environmental that affect their quality of life (QOL). The study aimed to identify factors influencing caregivers' well-being for children with cerebral palsy at Kisii Teaching and Referral Hospital.

Methodology: A cross-sectional correlational study was undertaken, applied consecutive sampling and utilized the WHOQOL-BRIEF instrument to evaluate quality of life of ninety-six caregivers who participated in the study. Descriptive and inferential methods were adopted in analysing data.

Findings: The mean age of caregivers was 34.9 (SD 13.2), the majority being women, 88.5%, and married caregivers were 76%. Fifty one percent of children were aged between 2-5 years, males being prominent, 57.3% and 60.4% had moderate CP. Thirty-six caregivers had a high quality of life. Significant factors that influence QOL were marital status ($P = 0.005$), monthly household income ($P=0.006$), financial assistance ($P=0.002$), the severity of the disease ($P=0.001$), and additional medical condition ($P=0.005$).

Conclusion: The study established that caregivers who received financial assistance and caregiving support improved QOL ($P<0.001$) and ($P=0.020$) respectively, and caregivers of children able to walk independently ($P=0.003$).

Key words: *Cerebral palsy, primary caregivers, quality of life, WHOQOL-BRIEF.*

INTRODUCTION

Cerebral palsy is a lasting movement disorder caused by early brain injury that doesn't worsen over time. The injury targets the cerebral cortex brain's outer motor layer disrupting muscle control and impairing movement and posture for life. The brain can be injured before, during or after birth, and the damage is irreversible. (Khanna *et al.*, 2018; Mwinbam *et al.*, 2023; Zh Chia *et al.*,

2022). Its prevalence is 1.6 per 1000 births in wealthy nations and 2.9–3.4 in lower-income regions. (Declerck *et al.*, 2023a; Olusanya *et al.*, 2022). (CONFIRM). The primary caregiver offers full-time support to a child with cerebral palsy (Pandit *et al.*, 2020a) . In Kenya, 3% of children with cerebral palsy depend fully on caregiver aid (Sauce, 2021). Caring a child with cerebral palsy strains



caregivers and impacts their overall quality of life (Namanja & Phiri, 2022). (Namanja & Phiri, 2022). Quality of life reflects how individuals view their life status within cultural and personal value systems, shaped by goals and expectations. It involves four key areas: physical health, psychological state and environment aspects. (Vu *et al.*, 2022).

Cerebral palsy children fully depend on caregivers, who face intense emotional stress (Mwinbam *et al.*, 2023). Their limitations demand constant attention, causing stress that affects caregivers' physical and social health (Michael *et al.*, 2019a). Liu found caregiving strain affects physical, mental, social, and environmental aspects, influenced by child's disability and caregiver depression (Liu *et al.*, 2023). India Vadivelan noted that primary caregivers experienced financial burden because they lacked time to engage in employment opportunities, they experienced physical pain because of carrying cerebral palsy most of the time, the condition of the child made them feel guilty, they lacked information about cerebral palsy and treatment options, some reported spouse abused them and never get any financial support from them and at community level, they were isolated and discriminated they were never involved in social events (Vadivelan *et al.*, 2020a).

Children with cerebral palsy need long-term care, which can be emotionally, financially and physically taxing. Caregivers play a great role in implementing treatment and management plans of care. Studies have shown that cerebral palsy children have special needs because of self-care limitations. It's exhausting and stressful, hence causing physical and psychological problems to primary caregivers. Sadness and chronic sorrow may continue to be evident in primary

caregivers for several years after disclosure of the diagnosis.(Ogunlana *et al.*, 2019). This study aims to deepen understanding of how care-giving affects the well-being of those primarily responsible for children with cerebral palsy, the research addresses a gap in knowledge specific to sub-Saharan contexts, where care-giving challenges differ from those in wealthier nations due to cultural, economic, and infrastructural disparities. No studies at KTRH have examined caregiver life quality in cerebral palsy. Assessing child and caregiver factors is key to improving well-being. The objective of the study was to establish life quality determinants among primary caregivers of children living with cerebral palsy in Kisii Teaching and Referral Hospital, Kisii County, Kenya. The specific objectives were to assess primary caregivers of children living with cerebral palsy's perception on their quality of life, to determine primary caregivers variables that impact quality of life across primary caregivers of children living with cerebral palsy and to evaluate child-related variables that impacts the quality of life of primary caregivers of children living with cerebral palsy.

METHODS

A cross-sectional correlational design was adopted to analyze links between caregiver and child traits and life quality, with data gathered once. Primary caregivers above 18 who gave consent were enrolled in the study. Those caregivers who were excluded from the study were those with psychological issues and who declined to consent. Permission for the research was granted by Kisii Teaching and Referral Hospital Institutional scientific and Ethical Review Committee (ISERC). A consecutive non-probability method was used to select 96 accessible caregiver



representatives, Selection was done sequentially during data collection, based on their accessibility and availability, until the required sample size was attained. Primary caregivers provided self-report using the WHOQOL BREF questionnaire, a standardized English and Kiswahili version, administered by the researcher.

In section A, the primary caregiver filled in their demographic data and of the child. Section B involved primary caregivers completed the WHOQOL-BREF tool, consisting of 26 items. The initial part of this section assessed Items 1 and 2 independently. Item 1 gauged general life quality, while Item 2 focused on overall health perception. Items 3 through 26 were grouped into four distinct domains. Scores were derived from a positively scaled Likert range of 1 (dissatisfied) to 5 (satisfied). Overall scores were derived by adding all four domain values and dividing the total by 24, then converting to percentages. Scores near 100 indicated high life quality; those below 60% signified low well-being, as observed in a Nepalese study (Pandit et al., 2020a). A pre-test of research instruments was done at Nyamira County Referral Hospital, Nyamira to assess how well the objectives aligned with the study's purpose and the validity of WHOQOL-BREF.

Descriptive and inferential methods were adopted in analysing data. Categorical variables and continuous variables were examined by univariate analysis using frequency, mean, and percentage in describing the variables. In bivariate analysis, Fischer's exact and Pearson's chi-square inferential statistics were employed. They assessed how caregiver life quality, the dependent variable, was affected by primary caregiver and child characteristics independent variables. The

odds ratio of logistic regression was also used, in the end to assess a high quality of life. Significant variables were all subjected to multivariate analysis. P value of 0.005 was chosen as statistical significance to attain reliable evidence.

FINDINGS

Primary caregivers and children characteristics

All 96 enrolled participants filled the questionnaires issued; all were completed and analyzed. Findings indicated a mean age of 34.9 years (± 13.2 SD), with 45.8% below 30. Most of the caregivers were predominantly female, 85, (88.5%). Majority of the caregivers were parents 73(76%) and 73(76%) were married. 58(60.4%) had secondary level education. Almost half of the households were low-income households, 46(47.9%). Moreover, 62.5% of caregivers spent over 12 hours daily providing care. All 96 children needed help with basic tasks like bathing, feeding, and dressing. Majority of children, 49(51%), were aged between 2-5 years. Gender, male children were 55(57.3%), 58(60.4%) had moderate disease. The predominant type of cerebral palsy was spastic, affecting 58 (60.4%) children, while dyskinetic was 17(17.7%). A significant number of children, 82 (85.4%), had additional medical conditions. Regarding to mobility, most children walk with an assistive device 64(66.7%).



Table 1: Characteristics of caregivers of children with cerebral palsy (n =96)

	Frequency	Per cent
Age (Mean, SD)	34.9±13.2	
<30 years	44	*45.8
30 - 49 years	31	32.3
50 years and above	21	21.9
Gender		
Male	11	11.5
Female	85	*88.5
Relationship to the child		
Parent	73	*76.0
Grandparent	23	24.0
Marital status		
Single	23	24.0
Married	73	*76.0
Highest level of education		
No formal education	22	22.9
Primary	16	16.7
Secondary	58	*60.4
Employment status		
Employed	4	4.2
Self-employed	33	34.4
Unemployed	59	*61.5
Monthly household income		
Less than or equal to Ksh 10,000	46	*47.9
Ksh 10,001 - 20,000	25	26.0
Ksh.,20,001 - 50,000	22	22.9
>Ksh.50,000	3	3.1
Receive financial assistance for caregiving.		
Yes	8	8.3
No	88	*91.7
Have insurance cover		
Yes	23	24.0
No	73	*76.0
Duration of caregiving		
Less than or equal to 1 year	27	28.1
1 - 3 years	56	*58.3
4 - 6 years	9	9.4
>6 years	4	4.2
Hours of caregiving		
4 - 8 hours	4	4.2
8 - 12 hours	32	33.3
>12 hours	60	*62.5
Child requires assistance with daily activities (e.g., feeding, dressing, bathing)		
Yes	96	*100.0
Receive additional caregiving support from family		
Yes	66	*68.8
No	30	31.3
Number of siblings		
Less than or equal to 2	52	*54.2
More than 2	44	45.8



Table 2: Characteristics of children with cerebral palsy

	Frequency	%
Child age		
Less or equal to 1 year	41	42.7
2 - 5 years	49	*51.0
>5 years	6	6.3
Gender of the child		
Male	55	*57.3
Female	41	42.7
Severity of disease		
Mild	21	21.9
Moderate	58	*60.4
Severe	17	17.7
Type of cerebral palsy		
Spastic	58	*60.4
Dyskinetic	17	17.7
Ataxic	5	5.2
Mixed	16	16.7
Have additional medical conditions (e.g., epilepsy, intellectual disability, vision/hearing impairment)		
Yes	82	*85.4
No	14	14.6
Mobility		
Walks independently	7	7.3
Bedridden	25	26.0
Walks with assistive device	64	*66.7
Child have speech or communication difficulties		
Yes	86	*89.6
No	10	10.4

The Quality of Life among Primary Caregivers of Children with Cerebral Palsy

WHOQOL-BREF assessed caregiver life quality across four areas: physical, psychological, social, and environmental. Scores were added and expressed as percentages. Physical health scored highest at 60.7 ± 12.9 , followed by psychological health at 57.5 ± 13.7 , indicating moderate well-being. The social relationships domain scores 56.2 ± 16.3 , highlighting challenges in social interactions. The environment domain, with a score of 51.6 ± 13.7 . Overall, the total QoL score stands at 60.0 ± 16.0 as shown in Table 3.

Table 3: Quality of life components among primary caregivers of children with cerebral palsy

QoL components	Mean $\pm$ SD %
Physical	60.7 $\pm$ 12.9
Psychological	57.5 $\pm$ 13.7
Social	56.2 $\pm$ 16.3
Environment	51.6 $\pm$ 13.7
Total	60.0 $\pm$ 16.0

A study found 36 caregivers (37.5%) with high life quality and 62% had low life quality.

Pearson's and Fischer's tests showed marital status mattered ($p=0.005$); single caregivers had lower QoL (87%) than married ones (54.8%), implying marriage offers stronger support.



Table 4 : Cerebral palsy primary caregiver-related factors that influence their quality of life

	Total	Quality of life		Chi square	Df	P value
		Low n(%)	High n(%)			
Age				3.626	2	0.163
<30 years	44	23(52.3)	21(47.7)			
30 - 49 years	31	22(71.0)	9(29.0)			
50 years and above	21	15(71.4)	6(28.6)			
Gender				1.54	1	0.215
Male	11	5(45.5)	6(54.5)			
Female	85	55(64.7)	30(35.3)			
Relationship to the child				1.681	1	0.195
Parent	73	43(58.9)	30(41.1)			
Grandparent	23	17(73.9)	6(26.1)			
Marital status						*0.005
Single	23	20(87.0)	3(13.0)			
Married	73	40(54.8)	33(45.2)			
Education level				2.053	2	0.358
No formal education	22	16(72.7)	6(27.3)			
Primary	16	8(50.0)	8(50.0)			
Secondary	58	36(62.1)	22(37.9)			
Employment status						0.867
Employed	4	2(50.0)	2(50.0)			
Self employed	33	21(63.6)	12(36.4)			
Unemployed	59	37(62.7)	22(37.3)			
Monthly household income						*0.006
Less or equal to Ksh.10,000	46	35(76.1)	11(23.9)			
Ksh 10,001 - 20,000	25	11(44.0)	14(56.0)			
Ksh.,20,001 - 50,000	22	14(63.6)	8(36.4)			
>Ksh.50,000	3	0	3(100)			
Receive financial assistance for caregiving.						*0.002
Yes	8	1(12.5)	7(87.5)			
No	88	59(67.0)	29(33.0)			
Have insurance cover				7.048	1	*0.008
Yes	23	9(39.1)	14(60.9)			
No	73	51(69.9)	22(30.1)			
Duration as a caregiver						0.584
Less than or equal to 1 year	27	14(51.9)	13(48.1)			
1 - 3 years	56	37(66.1)	19(33.9)			
4 - 6 years	9	6(66.7)	3(33.3)			
>6 years	4	3(75.0)	1(25.0)			
Hours of caregiving daily						0.149
4 - 8 hours	4	1(25.0)	3(75.0)			
8 - 12 hours	32	18(56.3)	14(43.8)			
>12 hours	60	41(68.3)	19(31.7)			
Child requires assistance with daily activities						
Yes	96	60(62.5)	36(37.5)			
Receive additional caregiving support from family members?						*<0.001
Yes	66	33(50.0)	33(50.0)			
No	30	27(90.0)	3(10.0)			
Number of siblings				2.193	1	0.139
Less or equal to 2	52	29(55.8)	23(44.2)			
More than 2	44	31(70.5)	13(29.5)			



Monthly household income also significantly affects QoL ($p = 0.006$), as caregivers with lower incomes ($\leq$ Ksh. 10,000) have a higher percentage in the low

QoL category (76.1%) compared to those with higher incomes. The availability of financial assistance for care-giving was also significant ($P = 0.002$), with caregivers who

Table 5: Child-related factors that influence the quality of life among caregivers of children with cerebral palsy

	Total	Quality of life		Chi square	Df	P value
		Low n (%)	High n (%)			
Age of child				1.356	2	0.508
Less or equal to 1 year	41	26(63.4)	15(36.6)			
2 - 5 years	49	29(59.2)	20(40.8)			
>5 years	6	5(83.3)	1(16.7)			
Gender of child				1.025	1	0.311
Male	55	32(58.2)	23(41.8)			
Female	41	28(68.3)	13(31.7)			
Severity				14.03	2	*0.001
Mild	21	9(42.9)	12(57.1)			
Moderate	58	34(58.6)	24(41.4)			
Severe	17	17(100)	0			
Type					3	*0.032
Spastic	58	34(58.6)	24(41.4)			
Dyskinetic	17	9(52.9)	8(47.1)			
Ataxic	5	2(40.0)	3(60.0)			
Mixed	16	15(93.8)	1(6.3)			
Does the child have additional medical conditions?						*0.005
Yes	82	56(68.3)	26(31.7)			
No	14	4(28.6)	10(71.4)			
Mobility						*0.031
Walks independently	7	2(28.6)	5(71.4)			
Bedridden	25	20(80.0)	5(20.0)			
Walks with an assistive device	64	38(59.4)	26(40.6)			
Have speech or communication difficulties				2.411	1	0.120
Yes	86	56(65.1)	30(34.9)			
No	10	4(40.0)	6(60.0)			



Table 6: Multivariate analysis of determinants of high quality of life

	aOR(95%CI)	P value
Marital status		
Married	2.51(0.38, 16.45)	0.338
Single	Ref	
Household income		
Ksh.10,001 - 20,000	2.36(0.47, 11.92)	0.299
Ksh.,20,001 - 50,000	0.52(0.07, 4.09)	0.538
Less than Ksh.10,000	Ref	
Receive financial assistance		
Yes	24.76(6.84, 72.00)	*<0.001
No	Ref	
Presence of an insurance cover		
Yes	2.31(1.41, 12.91)	*0.048
No	Ref	
Receive additional caregiving support.		
Yes	15.32(1.54, 52.03)	*0.02
No	Ref	
Disease severity		
Mild	0.63(0.14, 2.89)	0.533
Moderate	Ref	
Type		
Dyskinetic	2.81(0.61, 12.93)	0.186
Ataxic	1.74(0.14, 21.80)	0.667
Mixed	0.78(0.05, 11.63)	0.859
Spastic	Ref	
Presence of other medical conditions		
Yes	0.28(0.05, 1.61)	0.154
No	Ref	
Mobility		
Bedridden	Ref	
Walks with assistive device	0.62(0.05, 8.35)	0.717
Walks independently	1.15(1.03, 9.24)	*0.036

receive support showing a higher proportion in the high QoL category (87.5%) compared to those who do not (33.0%). Additionally, having insurance cover $2(1) = 7.048$, $p = 0.008$ significantly impacts QoL, as caregivers with insurance show a higher proportion in the high QoL category (60.9%) compared to those without (30.1%). Finally, receiving additional care-giving support from

family members was statistically significant ($p < 0.001$). Pearson chi-square and Fisher's

test showed disease severity strongly linked to low caregiver QoL ($\chi^2=14.03$, $p=0.001$), with all severe CP cases falling in that category. CP type also mattered ($\chi^2=3.0$, $p=0.032$); mixed type had the highest low QoL rate (93.8%), followed by spastic (58.6%) and dyskinetic. QoL outcomes. Additional



medical conditions ($p = 0.005$) significantly influenced caregiver QOL, with caregivers of children who have additional conditions such as epilepsy or intellectual disabilities reporting a higher proportion in the low QOL category (68.3%) compared to those whose children do not have additional medical conditions (28.6%). Mobility ($P = 0.031$) is another significant factor, as caregivers of bedridden children had a higher proportion in the low QoL category (80.0%), while caregivers of children who walk with assistive devices (59.4%) or walk independently (28.6%).

Multivariate analysis of determinants of high quality of life

Significant variables were subjected to multivariate analysis as shown in the Table. Caregivers receiving financial aid were 24 times more likely to report better life quality (aOR 24.76, $p < 0.001$). Insurance also showed a positive link (aOR 2.31, $p = 0.08$), while extra caregiving support improved outcomes significantly (aOR 15.32, $p = 0.020$). Independent mobility in children raised caregiver QoL slightly (aOR 1.1, $p = 0.036$).

DISCUSSION

Managing cerebral palsy in children heavily relies on caregiver involvement. This has been identified to have a significant influence on the well-being of caregivers. This study found low QoL among CP caregivers, with only 37.5% reporting high scores with major impacts on psychological, social, and environmental aspects of caregivers' lives. The study also found that financial aid and insurance improved caregivers' life quality. Further the research observed that extra support in care-giving was shown to boost

caregiver well-being. Despite the challenges of attending children with cerebral palsy, such assistance remains key to improving their life quality. Additionally, research highlighted that caregivers of children with mild cerebral palsy reported better life quality, though the link wasn't strong in multivariate analysis. Lack of association could be attributed to smaller sample size utilized in the present study. Caregivers of mobile CP children showed better QoL than those caring for bedridden or device-dependent children.

The study outlines key factors shaping QoL for caregivers of children living with cerebral palsy. Slightly more than a third of caregivers (37.5%) reported a high QoL, with psychological, social, and environmental factors being the most negatively affected. These QoL elements overlap, showing caregivers endure emotional fatigue alongside isolation and environmental strain from constant care-giving demands. The study further highlights the importance of external resources in enhancing caregiver QoL. Financial assistance, insurance coverage, and additional support were identified as significant determinants that positively influenced caregivers' well-being. Financial assistance alleviates some of the monetary pressures that come with the costs of medical treatments, therapies, and assistive devices for children with CP. Insurance coverage also ensures access to necessary medical resources, further reducing the burden on caregivers. Additionally, the availability of additional care-giving support whether from family, friends, or healthcare professionals has a profound impact on reducing caregiver stress, improving their mental and physical health, and fostering a more balanced care-giving experience. key child-related factor influencing caregiver QoL was independent



walking. Those caring for mobile children reported higher well-being, likely due to reduced care demands and greater child autonomy.

A Brazilian study found caregivers of disabled children, including those with CP, faced more stress and poorer life quality than those with typically developing children (Barros et al., 2019). In regards to aspects majorly affected, a systemic review done in Saudia Arabia revealed that primary caregiver's physical, social and psychological were negatively affected.(Asiri et al., 2023). Financial assistance, insurance coverage, and additional support greatly impacted life quality of caregivers. In China, high care expenses led to financial pressure, adding to caregivers' burden. Financial pressure led to a high level of emotional stress and reduced life satisfaction, which negatively impacted quality of life.(Liu et al., 2025a). In Ethiopian, cross-sectional study showed that caregivers receiving emotional and financial help had improved health and better life quality. Caregivers who had access to social and professional support systems experienced lower levels of stress and were better able to cope with the challenges of care-giving. The study highlights how support in care-giving eases caregiver strain and boosts their life quality (Kassa et al., 2024). Mobile cerebral palsy children had reduced care demands from caregivers. In Japan, revealed that mothers of children with better mobility (GMFCS I–II, a mild form where children can walk reported less stress and higher life satisfaction than those caring for children who were non-ambulatory or bedridden. This outcome was further moderated by the availability of community and family support. (Moriwaki et al., 2022).

RECOMMENDATIONS

Financial aid and insurance improved caregiver's life quality, health agencies and governments ought to establish or broaden financial aid schemes tailored for caregivers of children with cerebral palsy. Provide subsidies or insurance coverage for assistive devices, physical therapy, and mobility training. Fund programs which focus on improving the mobility and independence of children with cerebral palsy, since caregivers of mobile CP children showed better QoL than those caring for bedridden or device-dependent children. Additionally, care-giving support whether from family, friends, or healthcare professionals has a profound impact on reducing caregiver stress, improving their mental and physical health. Health care workers to assist in formation of caregiver support groups within communities and offer education on CP care alongside counselling services. Further conduct a longitudinal study to offer deeper insight into how various factors impact caregivers' quality of life over time.

This cross-sectional study captured a single-time snapshot of caregiver life quality. A cause-and-effect link between the factors and quality of life cannot be established by the study. A longitudinal investigation would offer a more thorough comprehension. In addition, factors including distance, lack of transportation, and the severity of the child's health, caregivers who do not regularly attend the occupational clinic at Kisii Teaching and Referral Hospital may be overlooked in a hospital-based study, which could result in an underestimation or overestimation. A study on community-based participation and outreach will be taken into consideration.



Availability of additional care-giving support whether from family, friends, or healthcare professionals has a profound impact on reducing caregiver stress, improving their mental and physical health, and fostering a more balanced care-giving experience. Fund programs which focus on improving the mobility and independence of children with cerebral palsy. This could involve subsidies or insurance coverage for assistive devices, physical therapy, and mobility training. To obtain a deeper insight into how various

factors impact caregivers' quality of life longitudinal study to be conducted over time.

Health agencies and governments ought to establish or broaden financial aid schemes tailored for caregivers of children with cerebral palsy. Policies should encourage, fund programs which focus on improving the mobility and independence of children with cerebral palsy. This could involve subsidies or insurance coverage for assistive devices, physical therapy, and mobility training.

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