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Quality of Life of Caregivers of Pediatric Patients with Cancer at Kenyatta National Hospital, Kenya

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Abstract

Background: Family caregivers of children diagnosed with cancer play a critical supportive role in the care of these patients. The quality-of-life (QoL) challenges experienced by these caregivers have been shown to adversely affect their care for these children. The QoL of caregivers of children with cancer at Kenyatta National Hospital (KNH) and the experienced caregiving burden were unclear. Consequently, we assessed the QoL of caregivers of pediatric patients with cancer at KNH in Kenya and its relationship with their caregiving burden.

Methods: An analytical cross-sectional study was conducted among family caregivers of pediatric patients with cancer at KNH, selected using a stratified random sampling technique. The study tools were the Zarit Caregiver Burden Interview (ZBI) and the Caregiver Quality of Life Index-Cancer (CQOLC). The data were analyzed descriptively and presented as percentages, frequencies, mean, and standard deviation, while the association between the caregivers' QoL and their caregiving burden level was evaluated using both bivariable and multivariable logistic regression analysis at a 95% confidence interval. Data analysis was performed using SPSS version 25.0. Appropriate ethical principles were observed.

Results: A total of 123 caregivers of children with cancer participated in the study. The majority (90.2%, n = 111) of the caregivers had a poor quality of life. Regarding their caregiving burden level, 50 (40.7%) experienced moderate-to-severe burden, while 69 (56.1%) experienced severe burden. Higher caregiving burden was associated with higher odds of poor QoL among caregivers (aOR = 7.902; 95% CI: 2.659-36.075; p = 0.002).

Conclusion: Caregivers of pediatric patients with cancer at KNH experienced considerable caregiving burden and a poor QoL, and the two positively correlated.

Recommendations: The study calls on the hospital management to support caregivers of children with cancer in the hospital psychologically, emotionally, socially, and materially for them to have a better QoL and to help ease the associated caregiving burden they bear.

Keywords: *Childhood cancer, pediatric patients, caregivers, caregiving burden, quality of life.*

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1. Introduction

The global burden of childhood cancer is on the rise, averaging a 1% increase every year since 1975 [1]. Childhood cancer is the 9th leading cause of mortality in children worldwide, the second after accidents or unintentional injuries in high-income countries (HICs) and the 14th in low- and middle-income countries (LMICs) [2]. Recent statistics from the World Health Organization (WHO) indicate that an estimated 400,000 children are diagnosed with cancer each year, most of whom live in LMICs, with leukemias, brain and central nervous system cancers, lymphomas and solid tumours such as Wilms tumours being the most common types. Regrettably, only about 20-30% of children with cancer will survive in LMICs compared to 80% or more in HICs [2].

While the total burden of childhood cancer in Kenya is unclear, potentially due to gaps in documentation of all cases at the national and sub-national levels, it is, however, observed that only 10- 20 percent of children with cancer in Kenya survive, in contrast to developed countries where up to 80 percent survive [3]. Avoidable deaths from childhood cancers in LMICs result from lack of or delayed diagnosis, misdiagnosis, obstacles to accessing care, abandonment of treatment, death from treatment toxicity/side effects, and relapse [4]. In all settings, worldwide, childhood cancers are acknowledged as exerting substantial physical, emotional, psychological, and financial burden on patients, families, communities, and health systems [5].

Family caregivers, and more so parents, are the main source of emotional and social support for children diagnosed with cancer, and are responsible for how well the children cope with the disease. Their involvement is particularly critical to ensuring treatment compliance and continuity of care [6]. Childhood cancer diagnosis and treatment exert significant physical, psychological, and social impact on their immediate families and often affect every aspect of family life [7]. Indeed, the uncertainty of relapse, the possibility of serious infection, and the adverse effects of cancer treatment negatively affect the health and well-being of both the patients and their caregivers [8]. Therefore, the QoL of family caregivers must be given due consideration for the good of their health and for the well-being of affected children [9].

Several recent studies done across the globe have demonstrated that family caregivers of children with cancer have low QoL. For instance, in studies in Turkey [7, 10], in Indonesia [11], in Brazil [12], in Iran [13], and in Saudi Arabia [14], family caregivers of children diagnosed with cancer were reported to have a low QoL. Among the commonly cited physical health problems experienced by these caregivers are fatigue, lack of time to rest, sleep problems, weight loss, and loss of appetite. Further, feelings of guilt, anxiety, depression, despair, regret, fear/worry, and poor concentration are commonly cited psychological problems, while lack of social support, disruption of personal relations, disrupted sex life, and financial difficulties are commonly cited social problems [6, 9, 15].

Further, evidence from various empirical studies indicates that caregivers experiencing QoL-related challenges occasioned by childhood cancer diagnosis are more unlikely to effectively meet a number of treatment-related tasks such as properly administering medications at home, adhering to scheduled medical appointments, and having an increased risk of treatment abandonment [12, 15, 16]. They are also less likely to offer adequate psychological, emotional, and social support to their sick children and struggle to maintain robust communication and

relationships with the affected child and their medical care team [7]. Indeed, poor QoL among these caregivers is concerning as it's known to lead to poor or inefficient caregiving practices that eventually negatively impact the care outcomes of these children [10, 12].

Studies on QoL among caregivers of children diagnosed with pediatric cancer in the sub-Saharan Africa context, Kenya included, are limited, hence why we conducted this study.

2. Methodology

Study Design: An analytical cross-sectional study design was adopted.

Study Area: We conducted the study in the pediatric oncology wards at Kenyatta National Hospital. Kenyatta National Hospital (KNH) is Kenya's largest public teaching and referral hospital. Located on Hospital Road, off Ngong Road, it has a bed capacity of over 2,000 beds and is served by over 6,000 medical and non-medical staff. It offers specialized, often advanced, healthcare services to patients in its various units mainly on a referral basis, with the patients coming from across the country and beyond. It also facilitates medical training and research among students and supports national healthcare planning. It has several pediatric cancer wards on its third floor that serve pediatric patients with various cancers. We chose KNH as the study area as it is a leading centre of care for pediatric patients with cancer in the country and beyond.

Study Population: A total of 180 family caregivers of pediatric patients with cancer at Kenyatta National Hospital constituted the study population.

Sample Size: In total, 123 caregivers of pediatric patients with cancer at KNH were sampled. Cochran's Modified Formula for Finite Populations was applied in determining the sample size as follows: $nf = n / (1 + n/N)$, explained as nf = appropriate size of sample for populations < 10,000; n = appropriate size of sample when populations ≥ 10,000 (which equals 384) and N = estimated population size (in our case, it was = 180). Hence, $nf = 384 / (1 + 384 / 180)$. Consequently, nf = 123. The adopted formula was considered appropriate because it improved the accuracy and efficiency of the estimated sample size.

Sampling procedure: A stratified random sampling technique was adopted to recruit study participants. For this, the caregivers were first stratified by their child's cancer type, as recorded in the pediatric oncology ward registers. The number of participants selected from each stratum was then determined in proportion to the size of the corresponding cancer category in the study population. Subsequently, eligible caregivers within each stratum were assigned unique identification numbers and selected using simple random sampling until the required sample size for each stratum was attained. Stratification in sample selection was helpful in ensuring that the study insights came from caregivers of children with diverse kinds of childhood cancer and not just from those caring for children with a single type.

Inclusion and Exclusion Criteria: All caregivers of children undergoing cancer treatment at KNH who were admitted, available during the study, and consented to participate were included in the study. However, caregivers of pediatric patients who learned of their children's cancer diagnosis during the study's data collection period, as they would not have had the sought-after experience beforehand; those not involved in the caregiving role on a regular basis; and those who failed to consent were excluded from the study.

Research Instruments: The data collection instruments were the Zarit Caregiver Burden Interview (ZBI) scale, used to assess caregivers' caregiving burden, and the Caregiver Quality of Life Index-Cancer (CQOLC) scale, used to assess their QoL. The Zarit Caregiver Burden

Interview (ZBI) scale was created by Zarit et al. in 1980. It is an instrument comprising 22 items, scored on a Likert-type scale with 5 response options: never (0 points), rarely (1 point), sometimes (2 points), quite often (3 points), and almost always (4 points). Its total score ranges from 0 to 88, and the aggregate scores are assessed as follows: 0-20: no to mild burden; 21-40: mild to moderate burden; 41-60: moderate to severe burden; and ≥ 61: severe burden. Hence, higher scores indicate greater caregiver burden [17]. Developed by Michael A. Weitzner, the Caregiver Quality of Life Index-Cancer (CQOLC) is a self-administered instrument designed to evaluate the QoL of caregivers of patients with cancer. The CQOLC consists of 35 items that have a five-point Likert format that ranges from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) to 4 (very much). Ten items relate to *burden*, seven to *disruptiveness*, seven to *positive adaptation*, three to *financial concerns,* and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, management of patient's pain, and family interest in caregiving) [18]. Individual CQOLC factor scores are obtained by summing the responses to the items that load on that particular factor, while the total CQOLC score is obtained by summing scores for all 35 items. Not all 35 items load onto a factor; items 2, 4, 13, 15, 23, 30, and 32 do not load on any factor, but are included in the total CQOLC score. The CQOLC scale total score ranges from 0 to 140. Overall, an aggregate score of 92 was used as the cutoff, with scores < 92 indicating poor/impaired QoL and scores≥ 92 indicating good/unimpaired QoL, as categorized in Gan's study [18]. The CQOLC scale has been shown to be both valid and reliable, with internal consistency (Cronbach's alpha) values of 0.89, 0.83, 0.73, and 0.81 for the four subscales, and 0.90 for the total CQOLC score [19]. This tool was chosen because it is specifically tailored to assess the QoL of family caregivers of patients with cancer, with an emphasis on the impact of caregiving on QoL.

Validity and Reliability: To this end, we pretested the study questionnaire with 12 family caregivers of pediatric patients with cancer at the Moi Teaching and Referral Hospital. Validity was ensured through subject matter expert scrutiny of the questionnaire items by the supervising faculty members. We evaluated the reliability of the questionnaire using Cronbach's Alpha. The questionnaire yielded a Cronbach's alpha of 0.874, exceeding the acceptable threshold of 0.7, and was therefore deemed reliable.

Data Collection Procedure: Upon receiving the study's ethical approval from the relevant ethical committees, we sought permission to collect data from the appropriate authorities at KNH. Thereafter, the researcher approached the family caregivers of children being treated for cancer at KNH during their rest hours. During the initial brief encounters, the researcher introduced herself, briefed potential respondents on the study, its aims, and the inclusion criteria, and requested their participation. Caregivers who met the inclusion criteria and consented to participate were asked to meet the researcher at the Patient's Private Office within the pediatric cancer wards to complete the study questionnaire. The questionnaire was interviewer-administered and took 30-45 minutes to complete.

Data Analysis and Presentation: We analyzed the data using SPSS version 25. The data were analyzed descriptively and presented as frequencies and percentages, as well as the mean and standard deviation. Additionally, the association between caregivers' demographic attributes and their caregiving burden level and their QoL was assessed using bivariable and multivariable logistic regression analyses at 95% confidence intervals, with results shown in the tables.

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3. Results

In total, 123 caregivers of children with cancer took part in the study.

3.1 Socio-Demographic Characteristics of the Caregivers

The majority (77.2%, n = 95) of the caregivers were female and were aged 20 - 49 years (95.9%, n = 118). Most had either Secondary (39.8%, n = 49) or Primary education (30.1%, n = 37) and were married (66.7%, n = 82). Further, most were unemployed (69.9%, n = 86). For most, the average monthly household income was below Kshs. 10,000 (73.2%, n = 90). Table 1 illustrates the findings.

Table 1: Socio-demographic characteristics of the caregivers

Socio-demographic attributes		Frequency (n)	Percentage (%)
Gender	Male	28	22.8
	Female	95	77.2
	Total	**123**	**100.0**
Age	20 - 29 years	38	30.9
	30 - 39 years	61	49.6
	40 - 49 years	19	15.4
	50 years & above	5	4.1
	Total	**123**	**100.0**
Education level	Primary	37	30.1
	Secondary	49	39.8
	College	19	15.4
	University	15	12.2
	No formal education	3	2.4
	Total	**123**	**100.0**
Marital status	Single	25	20.3
	Married	82	66.7
	Separated/Divorced	11	8.9
	Widowed	5	4.1
	Total	**123**	**100.0**
Occupation	Employed	14	11.4
	In business	19	15.4
	Unemployed	86	69.9
	Other	4	3.3
	Total	**123**	**100.0**
Average monthly household income level	Below Kshs. 10,000	90	73.2
	Kshs. 10,000 - Kshs. 30,000	23	18.7
	Above Kshs. 30,000	10	8.1
	Total	**123**	**100.0**

Further, majority of the caregivers were parents of the sick child (87.8%, n = 108), they had cared for the sick child for 1 - 3 years (83.7%, n = 103) or for over 3 years (12.2%, n = 15) and had other children other than the sick child (86.2%, n = 106), as depicted in Table 2.

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Table 2: Additional socio-demographic attributes of the caregivers

Relation to the sick child	Parent	108	87.8
	Relative	13	10.6
	Sibling	2	1.6
	Total	**123**	**100.0**
Caregiving duration	Less than 1 year	5	4.1
	1 - 3 years	103	83.7
	Over 3 years	15	12.2
	Total	**123**	**100.0**
Number of other children	None	17	13.8
	1 - 2	38	30.9
	More than 2	68	55.3
	Total	**123**	**100.0**

3.2 Caregiving Burden Level among the Caregivers

The majority of respondents had a moderate-to-severe burden (40.7%, n = 50) or a severe burden (56.1%, n = 69), indicating that their caregiving role for these children was heavy. Results are depicted in Table 3.

Table 3: Level of caregiving burden among the respondents

Caregiver burden level		**Frequency (n)**	**Percentage (%)**
Total score range	***Description***		
0 - 20	No to mild burden	0	0.0
21 - 40	Mild to moderate burden	4	3.3
41 - 60	Moderate to severe burden	50	40.7
≥ 61	Severe burden	69	56.1
Total		**123**	**100.0**

3.3 Quality of Life of Caregivers of Pediatric Patients with Cancer

The majority (90.2%, n = 111) of caregivers of pediatric patients with cancer were assessed to have a poor quality of life, while 9.8% (n = 12) were assessed to have a good quality of life, as illustrated in Figure 1.

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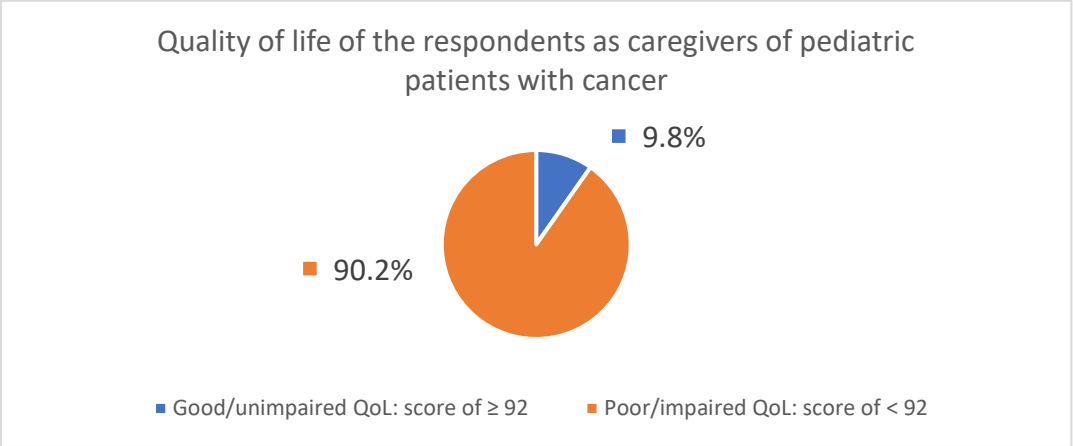

Figure 1: Quality of life of caregivers of pediatric patients with cancer

The poor QoL among caregivers was demonstrated by a high burden (mean = 16.7), high disruptiveness (mean = 8.2), high financial concern (mean = 8.1), and low positive adaptation (mean = 8.8). In addition, factors such as disruption of sleep, dissatisfaction with sexual functioning, loss of day-to-day focus, and high mental strain (mean = 13.9) associated with the caregiving role also contributed to the caregivers' poor QoL, as outlined in Table 4.

Table 4: Mean values for the respective QoL domains (n = 123)

CQOLC domains	Items loaded	Total score range	Mean	Std. Dev. (SD)
Burden	1, 3, 5, 6, 7, 8, 9, 10	0 - 32	16.7	6.81
Disruptiveness	11, 12, 14, 16, 17	0 - 20	8.2	4.74
Positive adaptation	18, 19, 20, 21, 22, 24	0 - 24	8.8	5.05
Financial concerns	25, 26, 27	0 - 12	8.1	3.05
Additional factors	28, 29, 31, 33, 34, 35	0 - 24	13.9	3.44

* Loaded items denote the specific statements of the CQOLC component of the questionnaire used to compute the respective scores for the individual CQOLC domains.

3.4 Association of Caregiving Burden Related Factors with the Caregivers' Quality of Life

Multivariable logistic regression showed that, after adjusting for the caregivers' socio-demographic characteristics, caregivers who experienced moderate to severe or severe caregiving burden had 7.9 times higher odds of experiencing poor QoL compared to those who only experienced mild to moderate caregiving burden (aOR = 7.902; 95% CI: 2.659 - 36.075; p = 0.002). Similarly, caregivers with more than 2 other children had 4.4 times higher odds of experiencing poor QoL compared to those with 2 or less other children (aOR = 4.374; 95% CI: 1.751 - 19.86; p = 0.017). Additionally, caregivers whose households had monthly incomes of

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Kshs. 10,000 or more had lower odds of experiencing poor QoL compared to those whose households had monthly incomes of below Kshs. 10,000 (aOR = 0.074; 95% CI: 0.036 - 0.580; $p < 0.001$). This signified that severe caregiving burden was an independent predictor of poor QoL among caregivers of pediatric patients with cancer at KNH. Table 5 outlines the findings.

Table 5: Association of the level of caregiving burden with the caregivers' QoL

Variables	Variable categorization	Bivariable analysis		Multivariable analysis	
		Crude OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Gender	(male vs female)	0.247 [0.077, 0.793]	0.018*	1.729 [0.488, 4.173]	0.317
Age	(below 40 years vs ≥ 40 years & above)	0.440 [0.124, 1.552]	0.244	1.901 [0.569, 5.125]	0.253
Education level	(secondary or lower vs tertiary)	4.311 [1.205, 15.87]	0.031*	1.430 [0.678, 3.461]	0.391
Marital status	(married vs not married)	0.672 [0.216, 2.090]	0.365	1.677 [0.621, 3.834]	0.266
Occupation	(working vs not working)	0.177 [0.052, 0.605]	0.009*	2.182 [0.709, 5.188]	0.124
Monthly household income level	(< Kshs. 10,000 vs ≥ Kshs. 10,000)	0.092 [0.023, 0.361]	0.001*	0.074 [0.036, 0.580]	< 0.001*
Caregiving duration	(3 years or less vs over 3 years)	0.139 [0.041, 0.469]	0.001*	1.713 [0.728, 3.469]	0.176
Number of other children	(2 or less vs more than 2)	7.333 [1.47, 36.5]	0.007*	4.374 [1.751, 19.86]	0.017*
Caregiving burden level	(mild to moderate vs moderate to severe & severe)	36.667 [3.35, 401.5]	0.001*	7.902 [2.659, 36.075]	0.002*

* Statistically significant at 0.05 significance level

4. Discussion

4.1 Quality of Life of the Caregivers of Pediatric Patients with Cancer

The majority of the family caregivers caring for pediatric patients with cancer at KNH had a poor QoL, evidenced by a high burden, a high level of disruptiveness, a high level of financial concern, and low positive adaptation. It was also evidenced by inability to sleep well, dissatisfaction with their sexual performance, loss of daily alertness, and mental strain. The caregivers' poor QoL could be attributable to likely challenges experienced during their caring role, along with possibly the physical, psychological, emotional, and social toll that comes with taking care of a young one ailing from a critical illness such as cancer. Similarly, in a study conducted in Iran, a significant proportion of surveyed family members who cared for children who had cancer were reported to have a poor QoL [13]. A poor QoL among caregivers of children diagnosed with cancer was also evident in studies in India [20], Indonesia [11], Brazil [12] and Turkey [7, 10], with much of the poor QoL attributed to the physical, social, mental, financial/economic and spiritual strain associated with the caregiving role.

4.2 Caregiving Burden Level among Caregivers of Pediatric Patients with Cancer

Results demonstrated that the caregivers of pediatric patients with cancer at KNH suffered a heavy caregiving burden in relation to their caregiving role of the children, with the majority assessed as experiencing either a moderate to severe burden or a severe burden. This signified that caring for children with cancer was not an easy task, with the caregiving role exerting a heavy caregiving burden on the caregivers. Likewise, in a review of the QoL of caregivers of children diagnosed with cancer, the caregivers were found to experience a significant caregiving burden resulting from their responsibilities of caring for the children [21]. In studies done in India [22] and in Ethiopia [23], taking care of a child with cancer was found to exert a huge burden of care on family caregivers. This takes a huge toll on their life especially among those with inadequate support from their own families or from the health care system [10, 16].

Additionally, a statistically significant association was observed between caregivers' level of caregiving burden and their QoL, with moderate-to-severe or severe burden correlating with poor QoL. It was therefore evident that the caregivers of pediatric patients with cancer at KNH experienced a high burden attributable to the caregiving role, which impaired their QoL. It can therefore be deduced that the significant demands and responsibilities that come with caring for children with cancer exert a heavy toll on the caregivers, which in itself has an adverse effect on their QoL and hence the poor QoL. The heavy caregiving burden may stem from significant disruptions to caregivers' normal lives, as they must devote considerable personal time, resources, and emotions to care for the sick child, often over an extended period. Likewise, in studies conducted in Italy [6] and Malaysia [18], a notable proportion of the surveyed parents of children who had cancer were reported to experience a high caregiving burden, which contributed to a poor QoL. In Saudi Arabia, a significant proportion of caregivers of children with cancer experienced moderate to severe caregiving burden, which also impaired their QoL [24]. Likewise, in studies in Ethiopia [23], Iran [13], and China [25], most of the caregivers of children with cancer had a poor QoL, which was found to be strongly correlated with the significant caregiving burden that they experienced.

5. Conclusion

Caregivers of pediatric patients with cancer at KNH had a poor quality of life. The majority also bore an enormous caregiving burden, which was shown to correlate with their poor QoL.

6. Recommendations

Healthcare providers at KNH should offer ongoing psychosocial support to the caregivers of pediatric patients diagnosed with and being treated for cancer in the hospital and should encourage them to join relevant support groups to learn from shared experiences, for comfort, support, and a sense of belonging. Due emphasis, focus, and action on safeguarding the caregivers' QoL and general well-being is also needed from all relevant stakeholders. Other studies may investigate the self-care and support needs of caregivers of pediatrics being treated for cancer at KNH or examine the role of other players such as health care providers, counselors, community support groups and religious leaders in alleviating parents' burden of caring for pediatrics with cancer within the country.

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