

Canadian Oncology Nursing Journal

Revue canadienne de soins infirmiers en oncologie

Volume 32, Issue 4 • Fall 2022
eISSN: 2368-8076



Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

Factors effecting quality of life for family caregivers of cancer patients in Kenya

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ABSTRACT

Background: Characteristics, including age, educational level, economics, and geographical setting during care provision significantly affect quality of life (QoL) among cancer patient caregivers in high-income countries. Investigation in middle/low income countries is limited.

Objective: To explore the factors associated with QoL among family caregivers (FCG's) of cancer patients in Kenya.

Methodology: This was a correlational study conducted at the largest teaching and referral hospital in Kenya. The study enrolled 164 family caregivers of cancer patients. The QoL (Family Version) was used to measure Quality of Life. Data collection was done using interviewer-administered questionnaires. A student *t*-test and Pearson chi-square were used to determine the association between personal, social, and disease characteristics and family caregiver quality of life.

Results: The average mean score of family caregiver QoL was 55.8 (SD±10.12) percent, which is lower than in other countries.

Conclusion: There was a significant association between family caregiver quality of life (QoL) and level of education, relationship to the patient, caregivers' ability to carry out normal activities, and caregiver knowledge of the stage of cancer.

Keywords: family caregiver, quality of life, cancer, Kenya

INTRODUCTION

Low and Middle-Income Countries (LMICs) account for 70% of cancer cases. The International Agency for Research on Cancer estimates that there were 18.1 million new cancer cases and 9.6 million cancer deaths in 2018 (Bray et al., 2018). Cancer ranks as the 3rd leading cause of mortality in Kenya, accounting for 7% of overall mortality. Cancer patients face challenges that also affect their care providers. The Family Caregivers (FCG) quality of life (QoL) scale can be used for measuring the effect (Lambert et al., 2013). Characteristics, including

age, education, economics, and geographic setting of FCG at the time of diagnosis affect their acceptance of the diagnosis and patient support (Choi et al., 2016). Consequently, efforts that lessen the burden experienced by FCG are important in enabling them to provide optimum, effective support to cancer patients (Pinkert et al., 2013).

FCGs monitor and manage symptoms and side effects of treatment, give drugs, manage assistive medical equipment and help with daily chores (Wang et al., 2020; Coumoundouros et al., 2019). Their role changes with the patient's condition and treatment strategies. However, caring for cancer patients is an additional role that may lower FCG's QoL due to disruption in their routines (Wang et al., 2020). Studies have documented factors associated with poor QoL of FCGs. For example, female FCGs of cancer patients account for a significant percentage of the general population with depression and lowered QoL (Lkhoyaali et al., 2015; Nguyen, 2015; Kilic & Oz, 2019; Thirumoorthy et al., 2016).

Other studies associate greater caregiving burden for family caregivers in advanced age due to their reduced physical state and social and financial resources compared to younger caregivers (Lkhoyaali et al., 2015; Yoon et al., 2018). Spouses are essential primary caregivers that support their patients emotionally and physically (Nguyen, 2015). By spending most of their time caring for their patients, spouses might fail to meet their own needs, leading to decreased health status. An inverse relationship exists between caregiving and FCG's QoL, as the more hours taken providing care to the patient, the lower the reported caregiver QoL (Jeong et al., 2020; Thirumoorthy et al., 2016; Sugiyama et al., 2018). The level of knowledge in caring for cancer patients and efficient pain management are the crucial determinants of FCGs' QoL ((Kizza & Muliira, 2020). Education level also contributes to significant differences in QoL constructs due to financial and social opportunities, better communication skills and stress management techniques in FCGs with higher education (Kilic & Oz, 2019; Oh, 2017; Rha et al., 2015a).

Loss or decreased family income reduces caregiver QoL, as unemployed caregivers have low QoL compared to employed or retired caregivers ((Nguyen, 2015). Positive healthcare provider communication improves FCGs QoL by enhancing their understanding of the disease (Oh, 2017). Healthcare providers have a role in raising the need for FCG assistance in managing their health, provision of opportunities for caregiver respite and social support (Yoon et al., 2018; Kilic & Oz, 2019). Despite the reports of reduced QoL for FCGs, caregiving may result in personal satisfaction, personality enhancement, meaningful life, and a greater appreciation (Lkhoyaali et al., 2015).

Most (70–80%) cancer patients in Kenya are diagnosed at an advanced stage of disease due to factors such as lack of knowledge, access /availability of cancer treatment facilities, and use of alternative therapies (e.g., traditional medicine)

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DOI: 10.5737/23688076324542

among others. In Kenya, families are essential in caring for cancer patients who do not require hospitalization (Ministry of Health, 2017). Despite this, the impact of caregiving on FCGs QoL has not been evaluated before in Kenya. Further, most studies on factors associated with the QoL of cancer patients and their FCGs have been conducted in high income countries (Thirumoorthy et al., 2016; Jeong et al., 2020; Lkhoyaali et al., 2015; Kilic & Oz, 2019) increasing the need for understanding association between personal, social, disease characteristics, and FCG's quality of life in the Kenyan context.

MATERIALS AND METHODS

Study objective

The study was designed to explore the factors associated with QoL among family care givers (FCG's) of cancer patients in Kenya.

Study design and setting

The study adopted a descriptive correlational design. It was conducted in a cancer care centre in Kenya's largest teaching and referral hospital. The Cancer Care Centre is the only government-funded hospital providing comprehensive cancer treatment, including surgery, radiotherapy, and chemotherapy at a subsidized rate.

Recruitment / data collection process

FCGs were recruited using simple random sampling from a sample frame of caregivers accompanying patients attending their appointments in the hospital from Monday to Thursday in March 2021. Family caregivers who met the inclusion criteria were approached and sensitized about the study during morning health education. Those who agreed to participate picked a piece of folded paper from a box. The papers were marked YES or NO. This was to guarantee that each caregiver had an equal chance of participating in the study. To avoid an FCG participating twice, a red sticker was placed on the patient's file for those FCG who picked yes and completed the questionnaire. For those who picked NO their files were marked with a yellow sticker to avoid their participation in the future. FCGs who consented were informed about the risks, benefit and purpose of the procedure and confidentiality was reassured. The exercise was conducted in a private room, which was arranged prior to the start of the exercise. FCGs were given option of withdrawing from the study at any time in the process. The patient file was marked with yellow sticker if FCG withdrew from the study.

Sample size

The target population was 240 caregivers. The cancer centre receives 60 new cancer patients in a week. Using Cochran's formula, a sample size of 149 caregivers was required with an additional 15 FCGs (10%) to cater for withdrawals. Therefore, the required sample size was 164 FCGs.

Inclusion criteria

Adult FCGs (18 years old & above) who were literate in Kiswahili or English languages, who provided unpaid care to an adult cancer patient for at least one month, and who were related to the patient by blood or kinship were eligible to participate in the study.

Data collection tools

Information on caregiver demographic characteristics (e.g., age, sex, marital status, education level, and monthly income), patient disease characteristics (disease- and treatment-related information), and social factors were collected using structured interviewer administered questionnaires. Caregiver's QoL was measured using the Quality of Life (Family Version) (Ferrell & Grant, 2012) with physical, psychological, social, and spiritual domains comprising 37 items. The scoring is based on a scale of 0=worst outcome to 10=best outcome. Several items (item numbers 1–4, 6, 13–20, 22, 24–29 and 33) have reverse anchors and these scores were reversed. For example, if a subject circled "3" on such an item, (10–3=7), thus a score of 7 was recorded. The test-retest reliability was $r = 0.89$ and internal consistency was $\alpha r = 0.69$. Factor analysis confirmed the four QOL domains as subscales for the instrument.

Data analysis

Descriptive statistics, including mean, standard deviation, frequencies, and percentages were used to describe the personal, social, and disease characteristics of the caregivers and their cancer patients. T-test, ANOVA, and Pearson's correlations were used to identify potential associates of QoL. Associations identified through bivariate analyses were included for multiple linear regression analyses to describe the association between caregivers' characteristics, disease characteristics and QoL. Statistical software IBM SPSS Statistics 25.0 was used to analyze the data.

Ethical considerations

Approval and clearance were obtained from the University Ethical Committee, the National Commission for Science, Technology and Innovation and the Hospital Ethics/Research Committee (Study registration certificate number Cancer Treatment Centre /104/2021). Eligible participants were informed of the study objectives and signed informed consent prior to participation. Confidentiality was assured.

RESULTS

Patient, family caregiver and disease characteristics

The patients had an average age of 55.4 (SD±14) years, 61% ($n = 100$) were female, 43.9% ($n = 72$) had primary level education, and 72.6% ($n = 119$) were married. In assessing the cancer staging, 47% ($n = 77$) of the patients were in stage 3, 26.2% ($n = 43$) were in stage 2 and 20.1% ($n = 33$) were in stage 4. More than three-quarters (84.8%, $n = 139$) of the patients could not carry out their normal daily activities, and 93.9% ($n = 154$) had health insurance cover.

The FCG average age was 37.7 (SD±9.6) years, 45.1% ($n = 74$) had high school as their highest level of education, 70.1% ($n = 115$) were married, and 52.4% ($n = 86$) lived in urban areas. The family caregiver average quality of life mean score was 55.8 (SD ± 10.12). The average scores of specific QoL components were physical 30.88 ± 10.32, psychological 80.4 ± 23, social 57.62 ± 10.4, and spiritual 37.49 ± 6.84 (Table 1).

Table 1

Demographic results for personal and social characteristics of FCG

Family caregiver factors	Mean ±SD	Frequency (n)	Percentage (%)
Personal characteristics			
Age			
Mean (SD)	37.7 ±9.62		
Level of education			
Primary school		36	22
High school		74	45.1
College		43	26.2
Graduate/professional degree		11	6.7
Relationship with patient			
Daughter		47	28.7
Son		25	15.2
Brother		16	9.8
Mother		35	21.3
Father		41	25
Suffering from any major disease/disability			
Yes		140	85.4
No			
Social characteristics			
Marital status			
Single		45	27.4
Married		115	70.1
Divorced		4	2.4
Residence			
Rural		76	46.3
Urban		86	52.4
Both		2	1.2
Employment status			
Employed		54	32.9
Self employed		66	40.2
Not employed		44	26.8
Occupation			
Farmer/Worker/Domestic		39	23.8
Civil servant		6	3.7
Private sector		26	15.9
Self-employed/business		93	56.7
Household monthly income			
Below 91 US dollars		65	39.6
91 US dollars to 273 US dollars		79	48.2
Above 273 US dollars		20	12.2
Ability to carry out daily activities			
Yes		135	82.3
No		29	17.7
Rating of general health			
Excellent		10	5.9
Very good		82	50
Good		56	34.1
Fair		13	10
	Mean	Standard Deviation	
Family caregiver QoL			
Physical	30.88	10.324	
Psychological	80.4	23.005	
Social	57.62	10.413	
Spiritual	37.49	6.837	
Total QoL scores	55.78	10.122	

Almost all of the FCG (97.6%, $n = 160$) knew the type of cancer, and 73.2% ($n = 120$) knew the stage of the cancer for their patients. Majority 62.8% ($n = 103$) of FCG who were aware of the likely complications of the disease (Table 2).

Association between FCG’s personal, social and knowledge on disease characteristics and FCG’s QoL

No significant relationship was determined between age and family caregiver QoL ($p > 0.05$). There was a significant difference in family caregiver QoL based on level of education ($F = 2.235, p = 0.009$), relationship to the patient ($F = 2.284, p = 0.006$), the ability of the caregiver to carry out everyday activities ($t = 5.541, p < 0.0001$), their own general health rating ($F = 4.225, p = 0.007$) and receiving support in the provision of care to the patient ($t = -3.079, p = 0.002$) (see Table 3). Findings also show a significant difference in FCG QoL based on caregiver knowledge on the cancer stage ($t = -2.039, p = 0.045$) and the stage of cancer ($F = 2.609, p = 0.003$) (see Table 4).

Table 2

Family caregiver knowledge on patient’s disease characteristics

Family caregiver knowledge	Frequency (n)	Percentage (%)
Knowledge of type of cancer patient is suffering from		
Yes	160	97.6
No	4	2.4
Knowledge of the patient cancer stage		
Yes	120	73.2
No	44	26.8
Patient stage of cancer		
Stage 1	11	6.7
Stage 2	43	26.2
Stage 3	77	47
Stage 4	33	20.1
Knowledge of likely related complications		
Yes	103	62.8
No	61	37.2
Extent caregivers are affected by the patient disease		
Extremely	73	44.7
Moderately	86	52.4
A little bit	5	2.9

Table 3*Association between personal characteristics, social characteristics, and family caregiver quality of life*

Personal Characteristics	Mean	n	df	Pearson (r)	t statistic	F-statistic	p-value
Age	37.7	164		0.145			0.064
Highest level of education							
Primary school	58.63	36	3			2.235	0.009
High school	55.04	74					
College	53.72	43					
Graduate/professional degree	59.56	11					
Relationship to patient							
Daughter	52.5	47	4			2.284	0.006
Son	59.15	25					
Brother	58.31	16					
Mother	55.91	35					
Father	56.4	41					
Family caregiver suffering from any major illness							
Yes	57.94	24	1		0.247		0.806
No	55.41	140					
Social characteristics							
Marital status							
Single	56.04	45	2			0.958	0.385
Married	55.45	115					
Divorced	62.5	4					
Residence							
Rural	55.62	76	2			0.625	0.537
Urban	56.1	86					
Both	48.11	2					
Employment status							
Employed	56.58	54	2			1.488	0.229
Self employed	54.16	66					
Not employed	57.25	44					
Occupation							
Farmer/Worker/Domestic	53.91	39	4			0.731	0.572
Civil servant	55.41	6					
Private sector	57.75	26					
Self-employed/business	55.96	93					
Monthly income							
Below Ksh.10,000	54.81	65	2			0.554	0.576
10,001 to 30,000	56.23	79					
Above 30,000	57.15	20					
Ability to carry out normal activities							
Yes	57.65	135	1		5.541		p<0.0001
No	47.09	29					
General health rating							
Excellent	55.17	9	3			4.225	0.007
Very Good	57.81	80					
Good	55.06	57					
Fair	48.63	17					
Receive support in provision of care to the patient							
Yes	53.96	103	1		-3.079		0.002
No	58.87	61					

Table 4

Analysis of variance comparing disease characteristics and family caregiver QoL

Disease characteristics	Mean	N	Df	t statistic	F-statistic	P-value
Knowledge the type of cancer your patient is suffering from						
Yes	55.76	160	1	-0.167		0.867
No	56.62	4				
Knowledge of the stage of the cancer disease						
Yes	54.9	120	1	-2.039		0.045
No	58.32	43				
Stage of cancer						
Stage 1	52.65	11	3		2.609	0.003
Stage 2	54.1	43				
Stage 3	55.02	77				
Stage 4	62.46	33				
Knowledge of the likely complications of this type of cancer						
Yes	55.95	118	1	0.247		0.806
No	55.5	44				
Extent of the effect of the disease on caregiver						
Extremely	54.51	74	1		1.329	0.268
Moderately	55.94	76				
A little bit	61.51	5				

3.3. Predictors of QoL of FCG of cancer patients

The model summary developed through the stepwise multiple regression analysis found that the final model explains 45.2% of family caregiver QoL. Analysis of variance showed that the model was significant and, thus, was appropriate in predicting family caregiver QoL ($p < 0.05$). Findings show significant predictors of QoL for FCG were the ability to carry out their everyday activities, caregiver rating on their own general health, number of hours spent per day on caregiving, and receiving support in care provision. Findings also show that FCG level of education, residence, relationship to the patient, marital status, having a significant ailment themselves, and awareness on the patient's stage of cancer were not significant in predicting the FCGs QoL (see Table 5).

DISCUSSION

Caregivers in this study had a slightly lower QoL 55.8 (± 10.12) compared with caregiver QoL in other African countries like Uganda (70.20 \pm 20.13) and Ethiopia (82.23 \pm 16.2) (Kizza & Muliira, 2020; Yihedego et al., 2020a). The differences in the QoL scores could be attributed to sociodemographic factors such as age (37.7 years), level of education (high school education=45.1%) and differences in healthcare systems. Most cancer patients in Kenya access services in public hospitals since the hospital provides care at a subsidised rate. However, patients experience delays in treatment due to the high number of patients awaiting the same services. Studies

conducted in developed countries (e.g., Singapore, UK, USA, and Canada) have reported high FCG QoL in domains including emotional reactivity, social support, physical concerns, and self-needs (Lim et al., 2017). The vulnerability of FCGs to poor QoL can be linked to socio-demographic factors and health-care systems in their countries.

FCG's level of education and QoL

This study showed statistically significant difference in family caregiver QoL in relation to the level of education, which is similar to previous studies done in Uganda, Turkey, India and China (Kizza & Muliira, 2020; Kilic & Oz, 2019; Thirumorthy et al., 2016; Yu et al., 2017). The significance may be attributed to caregiver educational background, which determines efficiency and quality of care provided to cancer patients and the FCGs' QoL. Caregivers with higher education may have higher income, as well as enhanced access to, and comprehension of, cancer disease information and resources for patient care. Healthcare providers should involve FCGs in psychological issues and cancer management irrespective of their educational status to improve their QoL (Rha et al., 2015b).

Type of relationship and FCG QoL

This study showed significant difference in FCGs QoL in respect to the relationship to the patient, which is similar to previous studies (Nguyen, 2015; Kilic & Oz, 2019; Qiuping et al., 2018), but contrary to Kajiwara et al. (2019) and Rasouli, (2020). The similarity could be attributed to the

Table 5*Predictors of Family caregiver quality of life*

	Coefficients		t	P-value	95%CI	
	B	Std. Error			Lower Bound	Upper Bound
(Constant)	48.734	14.448	3.373	0.001	20.146	77.322
Family caregiver age	0.100	0.107	0.935	0.351	-0.112	0.313
Family Caregiver highest level of education	-0.527	1.206	-0.437	0.663	-2.912	1.859
Marital status	0.	1.317	0.046	0.964	-2.547	2.667
Residence	-0.527	1.644	-0.320	0.749	-3.781	2.727
Source of livelihood	-0.146	1.407	-0.104	0.917	-2.930	2.637
Relationship with patient	-0.113	0.575	-0.196	0.845	-1.251	1.025
Occupation	1.211	0.756	1.601	0.112	-0.286	2.708
Approximate monthly income	0.917	1.420	0.645	0.520	-1.894	3.727
Suffering from major disease	-0.090	2.580	-0.035	0.972	-5.195	5.016
Ability to carry out personal tasks with ease	8.052	2.325	-3.463	0.001	-12.653	-3.451
Rating on general health	2.489	1.156	-2.154	0.033	-4.775	-0.202
Number of hours spend per day on caregiving	-0.179	0.100	-1.789	0.007	-0.377	0.019
Knowledge on patient type of cancer	13.003	10.356	1.256	0.212	-7.488	33.494
Knowledge of patient cancer stage	1.669	2.005	0.832	0.407	-2.298	5.635
Stage of cancer	-0.436	0.986	-0.442	0.659	-2.387	1.515
Receive support in provision of care	3.076	1.742	1.766	0.008	-0.370	6.523

effect of culture on the caregiving role. For example, most African cultures place the responsibility of caring for a sick family member in the hands of the immediate relatives and more so the young to take care of elderly parents. Caregiver experiences also vary across cultures and so affect their QoL. Understanding the impact of FCG relationships with cancer patients should be considered in practice to guide adoption of interventions that improve FCGs QoL.

FCG's self-rating in general health and QoL

This study showed significant difference in QoL of FCG based on self-rating of general health, findings that correlate with those of Jeong et al. (2020). The perceived positive self-health rating may be attributed to the age difference. Younger caregivers are likely to rate themselves higher compared to older caregivers because of their optimal functional capacity compared to the elderly. Positive self-health rating may be correlated to personal confidence in executing care-giving roles, which moderate FCGs-perceived QoL.

Receiving support in care provision and FCG's QoL

This study found a significant effect of receiving social support on FCGs QoL, which is similar to results of other studies (Kizza & Muliira, 2020; Nguyen, 2015; Kilic & Oz, 2019;

Rasouli-, 2020). The positive effect of social support could be attributed to the lessening of disease burden and coping difficulty by FCGs. Healthcare providers should educate FCGs about the importance of seeking social support in caring cancer patients.

FCG's knowledge on the stage of cancer and QoL

This study showed significant effect of caregiver knowledge about the stage of cancer on the caregiver QoL. The effect could be attributed to the increase in stress level following the FCG being informed about cancer stage. It could also be attributed to the uncertainty about the health needs and changes of the cancer patients. The findings differ from other studies (Warapornmongkholkul et al., 2018) due to factors such as social support, self-efficacy, and patient characteristics. Facilitating FCGs adequate understanding about the stage of cancer and management is important for their psychological preparedness and QoL.

The study also showed no significant difference in FCG QoL based on the caregiver knowledge of the type of cancer the patient is suffering from or knowledge of possible complications of cancer. The results are similar to studies by Kilic and Oz (2019) and Maree et al. (2018). The studies

demonstrated that regardless of the type of cancer, cancer diagnosis alone brings multi-factorial stresses that reduces the FCG QoL. The lack of significant difference in this study could be attributed to FCGs knowledge about cancer care. Despite efforts to create awareness of cancer and its treatment, some families still do not know aspects related to cancer prevention and management. Increasing FCGs understanding about cancer may have a positive effect on their QoL. Increasing FCG knowledge about potential complications of cancer may increase their QoL through enhanced understanding of the needed patient care and its management (Yihedego et al., 2020).

FCG's area of residence and QoL

The study showed no significant difference in the caregiver QoL based on where the caregiver resides. The findings are similar to those by Kajiwara et al. (2019) and Kizza and Muliira (2020). The similarities in findings could be attributed to the effect of social support and development of effective coping strategies by FCGs. However, the findings differ from those by Thirumoorthy et al. (2016), Kilic and Oz (2019), and Yihedego et al. (2020). FCGs residing in urban areas may have had high QoL scores due to enhanced access to cancer care needed by their patients. Residing in rural areas was associated with challenges of traveling long distances to urban centres, delays in diagnosis, and limited access to oncology services, all of which can pose a burden on the FCGs, affecting their QoL. In Kenya, modern cancer treatment centres are built especially in urban areas, which increase difficulties in accessing cancer care, predisposing FCGs to low QoL. Adopting measures such as bringing cancer care services closer to cancer patients and their FCGs could improve their QoL.

FCG's age and QoL

There was no significant relationship between FGC's age and QoL. The results are similar to Kilic and Oz (2019) and Yihedego et al. (2020). The similarities could be attributed to the young age of FCGs in these studies where their individual body performance is high and can bear the stress

associated with care provision relatively well compared with older persons. The results differ from those of studies including Thirumoorthy et al. (2016), Araki (2019), Yu et al. (2017), and Nguyen (2015), where a correlation between FGC's age and caregiving burden was found. The difference is attributed to the measurement tools used. While QoL Scale-Family was used in our study, the above authors used tools such as Caregiver Quality of Life Index-Cancer (CQOLC) and World Health Organization QOL-BREF. Advancing age in FCGs in these studies predisposed them to poorer QoL scores.

Strengths and limitations

The study was conducted in a national teaching and referral hospital where the study participants came from all over the country representing different social and ethnic backgrounds. The tool used (QoL- Family version) effectively identifies caregivers at risk for timely interventional programs. However, the cross-sectional design was subject to bias since some of the questions touched on personal information.

CONCLUSION

The results showed a significant difference in FGC's QoL in relation to their level of education, relationship to the patient, general self-health rating, receiving support in the provision of care, and knowledge on the type and stage of the patient cancer. However, there was no significant difference based on FGC's age.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

ACKNOWLEDGEMENT

I would like to express my sincere Special thanks to the Ministry of State for Defense, the Republic of Kenya, for sponsoring and giving me a chance to pursue a Master of Oncology Nursing, the Chief Executive Officer of Kenyatta National Hospital and the Head of Department of the Cancer Treatment Centre for the use of the institution as my study setting, the staff of Cancer Treatment Centre for their support during data collection.

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