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Quality of life outcomes of head and neck cancer survivors and their family caregivers at the Korle Bu Teaching Hospital

Selina O BOADU [1,3], Benjamin ABAIDOO [2*], Kenneth K BAIDOO [1], Emmanuel D KITCHER[1], Joel YARNEY [4], Mary-Ann DADZIE [4]

[1] Ear, Nose and Throat Unit, Korle Bu Teaching Hospital; [2] Ophthalmology Unit, Department of Surgery, University of Ghana Medical School, Accra, Ghana; [3] Psychiatry Department, Korle Bu Teaching Hospital; [4] National Radiotherapy, Oncology and Nuclear Medicine Centre

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Abstract

Background: A steady increase in the number of patients diagnosed with head and neck cancer (HNC) has necessitated the need for further studies on the quality-of-life (QOL) outcomes of these patients and their caregivers.

Objective: The study evaluated the QOL of HNC survivors and their family caregivers in a sub-Saharan African tertiary health facility.

Methods: This was a descriptive cross-sectional study at the Ear, Nose and Throat (ENT) Department and the National Radiotherapy, Oncology and Nuclear Medicine Centre at the Korle Bu Teaching Hospital. After consenting to be part of the study, the demographic characteristics of participants were recorded on a data collection form, and their QOL outcomes were evaluated using the World Health Organisation Quality of Life (WHO-QOL) questionnaires. An independent sample t-test was used to analyse the differences in mean score values in QOL. Logistic regression analysis was used to examine factors associated with the overall QOL of patients with HNC. Odds ratios and 95% confidence intervals were calculated. P-values less than 0.05 were considered statistically significant.

Results: A total of 160 patients with HNC and 160 family caregivers participated in this study. The mean ages of the patients and caregivers were 45.1 (SD 15.9) years and 36.2 (SD 13.1) years, respectively. Both HNC patients and their caregivers had a good QOL overall. However, HNC patients had a better QOL compared with their family caregivers (72.12 (SD 19.30) vs. 62.70 (SD 16.6), p = 0.001) in each domain and the overall QOL, except satisfaction with health. A total of 74.4% (n = 119) of patients with HNC had a QOL outcome. Education and the type of treatment received were associated with a good quality of life.

Conclusion: Both HNC patients and their caregivers have a good QOL. However, patients with HNC had a better QOL compared with their family caregivers.

Keywords: Head and neck cancers, psychological well-being, quality of life, family caregivers

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INTRODUCTION

Head and neck cancer (HNC) includes a group of neoplasms affecting the paranasal sinuses, nasal and oral cavities, pharynx and larynx. It is among the ten most common cancers globally, with 540,000 new cases and 271,000 deaths annually worldwide [1]. Patients with HNC usually present with an advanced disease in middle adulthood at the time of diagnosis [2]. These patients may experience social and psychological issues that present with disfigurement, inability to return to work, resistance to eating in public, and stigma associated with having a disease that is increasingly transmitted through sexual practices [3,4,5]. Overall, these negative outcomes have a detrimental effect on their quality of life (QOL).

Cancer experience is not only a stressful event for patients but also for their caregivers, who are often the primary

* *Corresponding author*
Email: babaidoo@ug.edu.gh

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source of support and care for patients with HNC. A study has shown that these patients and their caregivers experience severe psychiatric symptoms, which are consistent with a diagnosis of post-traumatic stress disorder [6]. Caregivers experienced cancer-related distress equal to or even more severe than the HNC patients themselves [7]. Unpublished information at the ENT Unit at the Korle-Bu Teaching Hospital (KBTH) reveals a steady increase in the number of HNC cases. This increase may subsequently have a toll on the QOL of these patients and their caregivers. Hence, this study sought to explore the QOL outcomes of HNC survivors and their caregivers, provide insights into the magnitude of HNCs at the KBTH, and further determine the extent of the burden of care on family caregivers. The outcomes of this study will enable the implementation of appropriate interventions to enable caregivers and patients to cope with adverse quality of life.

MATERIALS AND METHODS

This was a comparative cross-sectional study conducted at the Ear, Nose and Throat (ENT) Unit and the Oncology Centre at the KBTH from July 2022 to November 2022. On average, 210 patients are diagnosed with HNC yearly at the KBTH and ultimately undergo any of the treatment modalities, which include surgery, radiotherapy or a combination of surgery and radiotherapy. The study included adult HNC patients and their caregivers aged between 18 and 88 years who were receiving care at the ENT Unit and the Oncology Centre at the KBTH.

HNC patients and their family caregivers with psychological disorders, as well as those unaccompanied HNC participants, were excluded. The proportion of HNC patients who suffer some degree of depression (15% to 50%) at any given point across the disease trajectory from a previous study was used [8]. For this comparative cross-sectional study, the minimum sample size required for the study was derived from the formula [9];

$$N = (Z\alpha+Z\beta)(Z\alpha+Z\beta)*(p1(1-p1)+p2(1-p2)) / (p1-p2)(p1-p2),$$

Where N is the sample size required for both groups.

p1 is the prevalence of HNC patients who suffer some degree of depression [8].

p2 is the proportion of morbidity of depression in caregivers of HNC patients, which has been found to range from 9.0% to 57.0% [10].

$\alpha = 0.05$ the level of significance = 1.96, β = the power of the test, i.e. 80 % power = 0.2.

Using p1 = 16%, p2 = 26%. From the above formula, a total of 248 persons from the two groups were required to be recruited into the study. After accounting for attrition (20%), the sample size was determined as (120/100) x 257 ≈ 308 participants. Therefore, a minimum of 154 HNC patients and 154 caregivers were required for the study. However, a total of 160 participants were recruited for each group in order to increase the power of the test.

A register of patients attending the HNC clinic was used as the sampling frame. A simple random sampling technique was used in the selection of participants. Identification numbers (IDs) of HNC patients who had been booked to be seen were entered in Microsoft Excel 2015 worksheets. A random number generator command (RAND function) in Excel 2015 was given for the randomisation of the IDs of participants. The first five (5) ID numbers that appeared on the spreadsheet for the list of random numbers were selected and invited to participate in the study. This was done weekly until the number of participants to be recruited was obtained. Recruitment was done with the help of the nurses at ENT, and two trained Research Assistants. Each patient was paired with a caregiver. The pairing was done at the preference of the patient and guided by the principal researcher (PR). In this regard, the PR guided patients with more than one caregiver in choosing a primary or close caregiver for the study.

Potential participants who met the criteria for inclusion were approached at the Outpatient Department of the study sites for consent after the purpose of the study had been explained to them. Those who consented were selected and given a questionnaire to complete at an agreed time and venue. Demographic characteristics of the participants recorded include gender, age, educational background, and employment status of HNC survivors and their caregivers. Age was categorised as follows: 18 - 40 years young adult, 40 - 59 years middle-aged adult, and ≥ 60 years old adults) [11]. The Medical history included the site of cancer diagnosis (oral cavity, oropharynx, hypopharynx, and larynx), type of treatment (surgery, radiotherapy, chemotherapy, and combination), and duration of treatment. The World Health Organisation Quality of Life (WHO-QOL) tool was used to assess the quality of life of HNC survivors and their caregivers. The tool was validated by the WHOQOL Group [12] and achieved a Cronbach alpha for the four domains: physical health 0.8, psychological health 0.76, social relationship 0.66 and environmental well-being 0.80 for reliability analysis.

The (WHO-QOL) is a 26-item Likert-type scale, of which 24 items are divided into four domains assessing physical health, psychological health, social relationships, and environmental well-being, and the remaining two questions examine self-perceived QOL and satisfaction with health. Each domain is represented by several questions formulated for a Likert response scale, with intensity (nothing - extremely), capacity (nothing - completely), frequency (never - always) and assessment scales (very dissatisfied - very satisfied; very bad - very good), all of them consisting of five levels (one to five). The domain scores are scaled positively; higher scores denote a higher quality of life. Three items were compulsorily reversed before scoring: items 3, 4 and 26. The transformed score for each domain was derived from the summation of raw scores. The overall

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scores for the QOL outcome were calculated by averaging the sum of all the other domain elements. The total score varied from 0 to 100%, with a mean score of 60% representing the cut-off point for a good quality of life outcome [13].

Data Analysis

Data obtained was entered into a Microsoft Access database and transferred into IBM SPSS version 25 for analysis. Descriptive data were presented as means and standard deviations, and categorical data were presented as counts and percentages. The quality of life of patients with HNC and their caregivers was measured using the World Health Organisation QOL questionnaire in the domain of physical health, psychological health, social relationships, and environmental well-being. Scores in these domains were presented as percentages. Raw scores were converted to transformed scores using SPSS syntax, which directly converted the raw score into transformed domain scores for each domain on a scale from 0 to 100 to enable comparisons between domains with unequal numbers of items. An independent sample t-test was used to analyse the significant difference in mean score values of the health-related quality of life scores for patients with HNC and their family caregivers. Logistic regression analysis was conducted to analyse the association between socio-demographic data and clinical factors and the overall quality of life of the patients with HNC. Odds ratios and 95% confidence interval were calculated. P-values less than 0.05 were considered statistically significant.

Table 1. Demographic characteristics of head and neck cancer patients and family caregivers

Characteristic	HNC patients (N=160) N (%)	Family caregivers (N=160) N (%)
Age group :		
18-40	67(41.9)	108(67.5)
40-59	59(36.9)	43(26.9)
≥ 60	34(21.3)	9(5.6)
Sex :		
Male	116(72.5)	73(45.6)
Female	44(27.5)	87(54.4)
Religion		
Christian	139(86.9)	141(89.2)
Islam	21(13.1)	19(10.8)
Education :		
Primary School	29 (58.0)	6(3.8)
Junior High School	41(25.6)	46(28.7)
Senior High School	39 (24.4)	36(22.5)
Tertiary	61 (38.1)	72(45.0)
Employment status :		
Employed	128(80.0)	125(78.1)
Unemployed	32(20.0)	35(21.9)

Mean age patients = 45.1±15.9; min = 18.0; max = 88.0. Mean age caregivers = 36.2±13.1; min = 18.0; max = 80.0

RESULTS

A total of 160 patients with HNC and 160 family caregivers participated in this study. The mean age of the patients was 45.1 ± 15.9 years, with minimum and maximum ages of 18 years and 88 years. The mean age of the caregivers was 36.2 ± 13.1 years, with minimum and maximum ages of 18 years and 80 years, respectively. Most (67.5 %, n = 108) family caregivers were aged 18 - 40 years, and the majority of patients and caregivers were male (72.5%) and female (54.4%), respectively. Christians constituted the majority among both patients and caregivers, with 86.9% (n = 139) and 89.2% (n = 141), respectively. The primary level of education among patients was comparatively higher than among caregivers (58% vs 3.8%). A large proportion of both patients (80.0%, n = 128) and caregivers (78.1%, n = 125) were employed, and more than half of the caregivers (n = 93, 58.1%) were children of the patients (Table 1).

Clinical characteristics of patients with HNC

For participants who had records for the duration of treatment, the mean duration of treatment for the patients with HNC was 9.0 ± 3.8 months, with the minimum and maximum duration of treatment being 1 month and 108 months, respectively. The majority (81.2%, n = 95) had a duration of treatment less than 12 months. Among the patients with HNC, the cancer location was as follows: larynx (25.6%, n = 41), oropharynx (11.4%, n = 18),

Table 2. Clinical characteristics of head and neck cancer patients

Characteristics	Number (N)	Percentage (%)
Duration of treatment (months)		
< 12	95	81.2
12 - 36	17	14.5
36 - 60	4	3.4
>= 60	1	0.9
Site of cancer :		
Oral cavity	7	4.4
Oropharynx	18	11.4
Hypopharynx	17	10.6
Larynx	41	25.6
Duration of diagnosis		
< 1 years	74	46.3
1 - 3 years	63	39.4
3 - 5 years	14	8.8
> 5 years	9	5.6
Type of treatment :		
Surgery	41	25.6
Radiotherapy	21	13.1
Chemotherapy	49	30.6
Combination	49	30.6

Mean duration of treatment = 9.0 ± 3.8 months Minimum duration of treatment = 1 month, maximum = 108 months.Note that records available for duration of treatment and site of cancer were analysed out of the 160 patients.

hypopharynx (10.6%, n = 17) and oral cavity (4.4%, n = 7) were also reported as cancer sites. About half of the patients (46.3%, n = 74) were diagnosed less than 12 months prior to the study. Approximately 30.6% (n = 49) of the patients were treated with chemotherapy in combination with either radiotherapy or surgery (Table 2).

Table 3. Health-related quality of life scores for head and neck cancer patients and family caregivers

QoL Domain	Mean values		Difference	P-value
	HNC patients Mean±SD	Caregivers Mean±SD		
Physical health	76.4±17.7	64.7±14.2	11.8	0.001*
Psychological health	66.4±21.6	61.6±17.7	4.7	0.037*
Social relationship	69.7±21.4	62.9±19.4	6.7	0.005*
Environmental wellbeing	78.1±18.3	65.3±14.6	12.7	0.001*
Self-perceived QoL	76.4±23.8	67.7±23.5	8.7	0.001*
Satisfaction with health	66.9±29.5	70.3±24.7	-3.4	0.267
Overall	72.12± 19.30	62.70 ±16.6	9.4	0.001*

Table 4. Association between demographic and clinical characteristics and overall HRQOL of for head and neck cancer patients

Factor	OR	Confidence	Interval	P-value
Age		Lower	Upper	
18-40	Reference			
40-59	1.90	0.60	6.20	0.290
>=60	0.40	0.10	1.90	0.250
Male	Reference			
Female	0.70	0.20	0.20	0.20
Education				
Primary	Reference			
JHS	0.10	0.02	7.05	0.036*
SHS	0.11	0.02	25.16	0.017*
Tertiary	0.16	0.03	28.47	0.041*
Employment:				
Employed	Reference			
Unemployed	3.20	0.80	12.70	0.096
When diagnosed:				
<1 year	Reference			
1-3 years	1.44	0.29	7.05	0.655
3-5 years	1.98	0.16	25.16	0.599
>5 years	3.36	0.40	28.47	0.267
Type of treatment				
Surgery	Reference			
Radiotherapy	0.04	0.02	0.65	0.025*
Chemotherapy	0.43	0.12	1.57	0.200
Combination	0.09	0.01	0.59	0.013*
Treatment duration				
<12 months	Reference			
12-36 months	2.60	0.53	12.85	0.241
36-60 months	0.00	0.00	-	0.999
> 60 months	0.00	0.00	-	1.000
*Statistically significant association.				

Health-related quality of life scores for patients with HNC and family caregivers

In an independent t-test analysis, with an exception from the domain "satisfaction with health", there was a significant difference in mean score for QOL between the patients and the caregivers in all the other domains (physical health, psychological health, social relationship, environmental well-being, and self-perceived quality of life) with the HNC patient having a better QOL compared with their caregiver ($p < 0.05$) in each domain. The HNC patients had a better overall health-related quality of life (HRQOL) compared with the caregivers ($p > 0.05$). Although there was a significant difference between patients with HNC and family caregivers in terms of the overall QOL outcome ($p = 0.001$), both had a good overall HRQOL (Table 3).

Association between demographic and clinical characteristics and overall HRQOL of head and neck cancer patients and family caregivers

A total of 119 (74.4%) patients with HNC had a good quality of life outcome. From the logistic regression analysis, education and type of treatment received (radiotherapy and a combination of other therapies) were associated with good quality of life outcomes among HNC patients. (Table 4).

DISCUSSION

This study sought to evaluate the quality of life (QOL) outcomes of HNC survivors and their caregivers in a sub-Saharan African tertiary health facility. In our study, most (72.5%, n = 116) of the HNC survivors were males aged 18-88 years, and more than half (54.4%, n = 87) of the caregivers were females. This is similar to the study by D'Souza et al. [14], which reported 54% of males within the age bracket of 40 to 64 years out of the 89 HNC survivors assessed. Similarly, Terrell et al. [15] reported a male preponderance (78%) within the age group 27 - 88 years out of 570 patients with HNC studied. This variation of HNC prevalence in sex could be explained by the fact that men are more likely to be engaged in significant risk factors for HNCs, such as tobacco smoking and alcohol consumption [16].

Again, Lo et al. [17] demonstrated that the treatment impact on all dimensions of QOL generally affected younger patients more as compared to older patients. Our result of female preponderance in family caregiving is also supported by Guerrriere et al. [18], who found in their study on family caregivers of HNC survivors that 70% of caregivers were females with a mean age of 59 years. Another study done among 200 cancer fighters and their caregivers in New Delhi revealed that most caregivers were females (55%) with a mean age of 40 years. Globally, the task of family caregiving is predominantly seen as a female occupation involving the provision of informal care for family members with chronic health complications and disabilities [19,20]. Even in situations where each gender

tends to share similar roles domestically, the task of family caregiving remains a feminine-dominated venture [21,22]. About 70 - 80% of caregivers were female and spent more than 50% of their time in caregiving compared to males [23,24]. In most societies and cultures, women are expected to adopt the role of a family caregiver by staying at home to perform house chores and care for kids, making them less likely to be employed away from home, while men are expected to work away from home [25,26]. Women's role in family caregiving is, therefore, directly premised on the sense of obligation to their families [27].

More than 70% of the patients with HNC in this study had a good QOL outcome. This result could be explained by the significant sacrifices and role of family caregivers in caring for their HNC patients and providing them with the needed social and psychological support for improving their health status, even at the expense of the caregivers. Our results also demonstrate that although HNC patients and their caregivers may have a good QOL, patients with HNC have a better QOL than their family caregivers. Both may experience some significant level of challenges associated with the cancer condition. This is consistent with a previous study by Hodges and Humphris [7], who indicated that caregivers experienced cancer-related distress equal to or even more severe than that of the patients. Furthermore, Verdonck-de Leeuw et al. [28] found clinical levels of psychological distress in one-fifth of caregivers and one-quarter of HNC patients. Similarly, Vickery et al. [29] showed that caregivers have more psychological disorders compared to patients with HNC. Caregivers have shown poor mental health (e.g., high levels of depression, anxiety symptoms, low QOL) compared to the general population or in comparison with HNC patients [7].

Our finding - that patients with HNC report better QOL than their caregivers is consistent with that of Richardson et al. [31], who also reported a better QOL among patients with HNC compared with their caregivers. This finding highlights the significant burden caregivers endure. Roing et al. [32] in their study explained this difference in QOL outcome between patients with HNC and their caregivers by indicating that lifestyle changes such as disrupted work-life balance and social isolation imposed on caregivers as a result of providing care negatively affect their QOL and significantly increase their stress level. Rigoni et al. [33] also indicated that caregivers had a compromised QOL, just as patients with HNC. The burden of caregiving primarily manifests as overwhelming responsibilities and substantial disruptions to daily routines. Our findings may suggest that caregivers of patients with HNC in Ghana may experience a burden similar to that reported in other contexts, contributing valuable insights to the literature on QOL among HNC survivors and their caregivers.

Quality-of-life (QOL) outcome measures play a key role in analysing the perception of the effects of the disease on the daily activities of patients and caregivers. Quality-of-life (QOL) outcomes in patients are determined not only by the activity of the disease and its associated treatment but also by other factors that may influence the QOL outcome among patients. From our logistic regression analysis, education and the type of treatment received were associated with good QOL outcomes among HNC patients. Our finding that education is associated with good QOL outcome among patients with HNC [34] could be explained by the fact that HNC patients with low educational backgrounds may tend to be involved in unhealthy behaviours and lifestyles that may further deteriorate respective disease conditions. Additionally, such persons may have fewer resources to cope with the HNC disease, leading to reduced QOL.

A higher level of education may enable patients to understand the course of the disease and increase their desire to seek additional educational programs and interventions which are directed towards improving health outcomes. Additionally, our results indicate that the type of treatment for HNC had a significant impact on QOL. Parkar and Shah [34] also explained that the type of treatment received was associated with good QOL outcomes among patients with HNC. Patients undergoing treatments that balance cancer control with preservation of function and appearance may tend to report better QoL outcomes [35]. For example, treatments such as chemoradiotherapy and minimally invasive surgical techniques may help maintain speech, swallowing, and appearance, which are critical to social functioning and self-esteem [35]. Similarly, Kara et al. [36] reported that HNC survivors exhibit different QOL-related symptoms depending on combined treatment modalities and time post-treatment; hence, there is a need to understand the QOL differences based on treatment modalities when developing treatment plans for patients with HNC. According to Parkar and Shah [34], other factors associated with QOL may include age, female sex, duration of treatment, advanced tumour, and site of the tumour.

The limitation of the study can be attributed to its comparative cross-sectional nature, which does not establish a cause-and-effect relationship. Again, the study did not factor in the possibilities of other comorbidities of HNC survivors and their caregivers, which may account for or influence their QOL. Future studies should highlight the effects of comorbidities on HNC survivors and their caregivers. Furthermore, the data obtained from the questionnaire could not determine the difference between the well-being of the two groups (HNC survivors and their caregivers) in the long term. Future researchers may consider a prospective studies to evaluate the long-term QOL of HNC survivors and their family caregivers.

The present study suggests that the treatment, management and intervention protocol for head and neck cancer patients should not be limited to only survival but also to ensure their quality of life and that of the caregivers throughout the intervention and recovery process. These findings are helpful in designing a comprehensive care program in Ghana to address QOL issues for HNC survivors and their

caregivers. Quality of life (QOL) encompasses an individual's subjective perception of well-being and coping ability. Hence, there is a need for active support on the challenges of the caregiving burden. It is imperative to create a comprehensive cancer care program for patients and their caregivers at the time of diagnosis for sustainable health conditions and to improve their QOL.

Conclusion

This study has demonstrated that both HNC patients and their caregivers have a good quality of life. However, patients with HNC had a better QOL compared with their family caregivers. Screening for psychological or emotional issues and early referral to (psychological) support in the first line, if needed, may, therefore, ensure caregivers are able to be the important source of support for patients and, thus, avert the creation of "another or second patient". Moreover, knowledge of the risk factors or causes can be used to identify caregivers who may benefit from additional counselling and psychological support, such as caring for patients who are non-spousal or non-biologically related, as well as with comorbidity or severe tumour stage.

DECLARATIONS

Ethical consideration

Ethical approval for the study was obtained from the Institutional Review Board of the Korle Bu Teaching Hospital in Ghana with approval number KBTH-IRB/000173/2022. Permission to conduct the study was obtained from the study sites, and informed consent was obtained from all study participants before the commencement of the study.

Consent to publish

All authors agreed on the content of the final paper.

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None

Competing Interest

The authors declare no conflict of interest

Author contribution

SOB and KKB conceptualised and designed the study. SOB and BA performed data curation and analysis. Methodology development and investigation were carried out by SOB and BA. SOB managed project administration and resource provision. Software support was provided by BA. Supervision was provided by KKB, EDK, and JY. The manuscript was drafted by SOB and BA and reviewed for intellectual content by KKB, EDK, JY, and MAD. All authors read and approved the final version of the manuscript.

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Availability of data

Data is available upon request to the corresponding author

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