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# Supportive Care in Cancer

## Predictors of quality of life in head and neck cancer survivors up to 5 years after end of treatment: A cross-sectional survey --Manuscript Draft--

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<b>Abstract:</b>	<p><b>Purpose</b> This study aimed to assess quality of life (QoL) in head and neck cancer (HNC) survivors, and determine factors predictive of poor QoL in the first five years after the end of treatment.</p> <p><b>Methods</b> A cross-sectional survey, including the Quality of Life in Adult Cancer Survivors (QLACS) measure, was sent to HNC survivors in three Scottish health regions, with responses linked to routinely collected clinical data. Independent sample t-tests, ANOVAs, Pearson correlations and multiple hierarchical regressions were used to explore associations between and to determine the contribution made by demographic, lifestyle and clinical factors to predicting 'generic' and 'cancer-specific' quality of life.</p> <p><b>Results</b> 280 patients (65%) returned questionnaires. After adjustment, multivariate analysis showed that younger age, lower socio-economic status, unemployment and self-reported comorbidity independently contributed to poorer generic and cancer-specific quality of life. In addition to these factors, having had a feeding tube or a diagnosis of oral cavity cancer were independently predictive of poorer cancer-specific quality of life.</p> <p><b>Conclusions</b> Socio-economic factors and co-morbidity are important predictors of QoL in HNC survivors. These factors and the detrimental long-term effects of feeding tubes need</p>

	further attention in research and practice.
<b>Suggested Reviewers:</b>	<p data-bbox="579 184 1500 331">           Claire Foster, PhD            Professor of Psychosocial Oncology, University of Southampton            C.L.Foster@soton.ac.uk            Professor Foster is an expert in survivorship research and has experience of using the QLACS tool in research into quality of life in colorectal cancer survivors.         </p> <p data-bbox="579 348 1500 495">           Nicholas Hulbert-Williams, PhD            Professor of Behavioural Science, University of Chester            n.hulbertwilliams@chester.ac.uk            Professor Hulbert Williams is a Psychologist with expertise and an interest in survivorship and head and neck cancer.         </p> <p data-bbox="579 512 1500 653">           Maria Larsson, PhD            Associate Professor, Karlstads Universitet            Maria.Larsson@kau.se            Professor Larsson has published widely on the needs and experiences of head and neck cancer survivors         </p>

**Title:**

Predictors of quality of life in head and neck cancer survivors up to 5 years after end of  
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## **Abstract**

### **Purpose**

This study aimed to assess quality of life (QoL) in head and neck cancer (HNC) survivors, and determine factors predictive of poor QoL in the first five years after the end of treatment.

### **Methods**

A cross-sectional survey, including the Quality of Life in Adult Cancer Survivors (QLACS) measure, was sent to HNC survivors in three Scottish health regions, with responses linked to routinely collected clinical data. Independent sample t-tests, ANOVAs, Pearson correlations and multiple hierarchical regressions were used to explore associations between and to determine the contribution made by demographic, lifestyle and clinical factors to predicting 'generic' and 'cancer-specific' quality of life.

### **Results**

280 patients (65%) returned questionnaires. After adjustment, multivariate analysis showed that younger age, lower socio-economic status, unemployment and self-reported comorbidity independently contributed to poorer generic and cancer-specific quality of life. In addition to these factors, having had a feeding tube or a diagnosis of oral cavity cancer were independently predictive of poorer cancer-specific quality of life.

### **Conclusions**

Socio-economic factors and co-morbidity are important predictors of QoL in HNC survivors. These factors and the detrimental long-term effects of feeding tubes need further attention in research and practice.

## Introduction

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4 Head and neck cancer (HNC) is the sixth most common cancer worldwide and its incidence is  
5  
6 rising. In the UK alone a 51% increase in male oral and oropharyngeal squamous cell  
7  
8 carcinoma is mainly attributed to the rise in Human Papillomavirus (HPV) related cancers  
9  
10 [1]. In Scotland, incidence rates are particularly high [2]. Low socio-economic status (SES),  
11  
12 smoking, alcohol abuse, a lack of social support, and poor psychological health are all  
13  
14 strongly associated with increased incidence and poor prognosis [3, 4]. Patients with HNC  
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16 therefore represent a vulnerable group.  
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23 In 2008, more than 1.5 million people with HNC worldwide were still alive up to five years  
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25 after diagnosis [5]. In the UK, around 50% of people with oral cancer and 60% of people  
26  
27 with laryngeal cancer now survive for five years or more [6]. Patients with HPV-related  
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29 cancers respond more favourably to treatment, and the number living with HNC is likely to  
30  
31 increase significantly over the next 10-20 years [7]. The needs and concerns of survivors are  
32  
33 therefore of increasing relevance to the provision of long-term support.  
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39 The physical and psychosocial impact of HNC is considerable, as the consequences of  
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41 treatment can include severe pain, fatigue, anxiety, depression, dry mouth, speech,  
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43 swallowing and body image problems, among many others. Quality of life is fundamentally  
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45 important, as patients experience significant changes in the acute phase of treatment, and  
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47 many suffer longer term functional difficulties [8-10]. The negative psychosocial  
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49 consequences of HNC can be equally enduring [11]. Quality of life has also been shown to  
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51 predict survival in this patient group [12].  
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1 The factors which influence poor quality of life (QoL) outcomes in people with HNC become  
2 increasingly important as healthcare systems consider how best to utilise finite resources in  
3 the follow-up care of a growing number of survivors. The concept of risk stratification has  
4 attracted much attention in the context of survivorship care, as it provides a means of  
5 quantifying the probability of adverse outcomes in a patient group, and suggests which  
6 patients are likely to be at particular risk of poor outcomes, therefore enabling health care  
7 professionals to intervene appropriately [13]. Some predictors of poor QoL have been  
8 identified including feeding tubes [14] pre-treatment QoL, comorbidity and stage [15].  
9 However, most studies have used instruments designed to evaluate clinical trial outcomes,  
10 rather than more holistic measures of long-term quality of life.  
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26 The Quality of Life in Adult Cancer Survivors (QLACS) scale was developed specifically to  
27 elicit the issues relevant to people living with cancer in the longer term, including those with  
28 HNC [16, 17]. The QLACS conceptualization of cancer-related quality of life comprises two  
29 key components: the ability to perform everyday activities reflecting physical, psychological,  
30 and social well-being; and patient satisfaction with levels of functioning and control of their  
31 cancer [18]. The QLACS domains were considered highly relevant to HNC survivors as they  
32 included topics such as social avoidance, sexual concerns, financial problems, appearance  
33 and fear of recurrence as well as standard items such as pain and fatigue.  
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48 This cross-sectional study aimed to elicit the quality of life, concerns, unmet needs and  
49 distress associated with living with and beyond a diagnosis of HNC. This paper reports the  
50 QoL of HNC survivors who had completed treatment up to five years previously, and  
51 illustrates which clinical and socio-demographic factors were predictive of poor quality of  
52 life. Data on unmet needs and concerns is reported elsewhere [19].  
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## Materials and Methods

### Data collection

A questionnaire booklet with reply envelope was posted to HNC survivors on the databases of Clinical Nurse Specialists (CNS) in three Scottish health boards. The booklet contained the QLACS [17], the Distress Thermometer (DT)[20], Patient Concerns Inventory (PCI)[21] and an unmet needs inventory adapted from the PCI. Questions were also asked about age, gender, nationality, relationship status, living arrangements, current smoking and drinking habits, treatment type, feeding tube use, employment status, and co-morbidities.

Participants over 18 were eligible if they had completed treatment between three months and five years before the survey was mailed. Survivors were excluded by the CNS if they were receiving palliative care, had a prognosis of < six months, did not speak English, or were considered likely to find the survey distressing.

Anonymised questionnaires, identified only by study number, were returned to the researchers. CNS' sent reminder letters to potential participants who had not returned their questionnaire within four weeks. Data collection took place between May and December 2011. Ethical approval was granted by the Tayside Committee on Medical Ethics.

Study numbers and corresponding unique 10-digit community health index (CHI) numbers were submitted by CNS' to the Health Informatics Centre (HIC -

<http://www.dundee.ac.uk/HIC>), which holds routine clinical datasets, including cancer

registry hospital admission records, on every cancer patient registered with a General

Practitioner (GP) in two of the participating health board regions. International

Classification of Diagnosis (ICD 10) codes for diagnosis, UICC stage, date of diagnosis, and

1 Scottish Index of Multiple Deprivation (SIMD) indices based on home postcode were linked  
2  
3 to questionnaire data for all participants. Because HIC did not hold routine data for our  
4  
5 third participating region, the required clinical and socio-demographic information was  
6  
7 transferred from the CNS to HIC using a secure mechanism. Time from diagnosis was  
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9 calculated from cancer registry or CNS records to the date of survey completion. The  
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11 extended dataset was anonymised and made available to the research team via a secure  
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13 data safe haven.  
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18 The QLACS scale consists of 47 Likert scale items. Patients evaluate statements with  
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20 reference to the preceding four weeks, indicating how frequently (from “never” to “always”)  
21  
22 the statements have applied to them. Questions can be summed to produce domain scores  
23  
24 for generic QoL (including subscales for negative feelings, positive feelings, cognitive  
25  
26 problems, sexual problems, physical pain, fatigue, and social avoidance), cancer-related QoL  
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28 (including subscales for appearance concerns, financial problems, distress over recurrence,  
29  
30 and family-related distress), and benefits of cancer.  
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39 Summary domain scores range from 4 to 28, with higher scores indicating negative  
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41 outcomes (low QoL) for all domains except for the “positive feelings” and “benefits”  
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43 domains (for which higher scores indicate positive outcomes (high QoL). Evaluation of the  
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45 test-retest reliability, internal consistency, validity, and sensitivity to change of QLACS has  
46  
47 shown that its overall reliability is high [16, 17].  
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## 52 **Statistical analysis**

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54 Differences between responders and non-responders were tested using chi-squared tests  
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57 for categorical variables. Data were described as number of subjects (percentages) for  
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1 categorical variables and mean (standard deviation) for continuous variables or where the  
2 distribution was skewed, median and interquartile range (IQR). Blank responses in the  
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5 QLACS questionnaire were handled using case-mean substitution [22] and subscales and  
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7 domains were scored using published procedures [17]. Independent sample t-tests and  
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9 ANOVAs were run to explore the associations between domain scores for generic and  
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11 cancer-specific quality of life and (i) demographic factors – gender, age, SIMD and living  
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13 arrangements; (ii) lifestyle factors – smoking status, alcohol status and employment status;  
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15 (iii) clinical factors – diagnosis (larynx, oropharynx, oral cavity or other), length of time since  
16  
17 diagnosis, type of treatment (surgery alone or treatment including radiotherapy or  
18  
19 chemotherapy) and whether or not feeding tube had ever been fitted. Pearson correlations  
20  
21 were run to explore the association between domain scores for generic and cancer-specific  
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23 QoL and number of comorbidities (self-reported). Hierarchical multiple regressions were  
24  
25 conducted to test the contribution of the demographic, lifestyle and clinical factors to  
26  
27 predicting (i) cancer-specific QoL (ii) generic QoL. Dummy variables were created for  
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29 Diagnosis – oropharynx, oral cavity and other site, with the larynx dummy variable as the  
30  
31 reference. UICC stage was not entered, because of missing data. Where the distribution  
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33 was skewed, differences in continuous variables were examined using a Mann-Whitney test  
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35 or a Kruskal Wallis test. All statistical analyses were performed using IBM SPSS Version 23.  
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## 47 **Results**

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51 488 questionnaires were distributed and 319 (65%) returned. The socio-demographic  
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53 characteristics of responders versus non-responders were compared, with no differences in  
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55 response by gender, age, or time since diagnosis. However, the response rate was  
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57 significantly better for patients from the highest SES group (SIMD 5) (83%) compared to 53%  
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59 from the lowest (SIMD 1);  $p < 0.0001$ .  
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1 Of the 319 questionnaires returned, 39 were from people who had completed treatment  
2 more than five years previously and so were outside the time period defined for the cohort.  
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4 There were some missing data in the remaining 280, but 264 had completed enough items  
5 to be scored on the cancer-specific summary score and 259 on the generic summary score.  
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8 The main demographic, lifestyle and clinical characteristics are shown in Table 1.  
9

10 Participants were aged between 27 and 91 years old with a mean age of 64.28 years (SD  
11 11.27). The time from diagnosis to survey participation ranged from three to 71 months,  
12 with a median of three years (35.72 months). Most respondents were male (73%), married  
13 (63%) with approximately one quarter who lived alone. 112 (41%) were from the lowest SES  
14 populations (SIMD 1 and 2), although respondents were fairly evenly distributed across all  
15 five rankings. Cancers of the oral cavity or larynx affected one third each of the study  
16 population. The remaining third of participants had a diagnosis of oropharyngeal cancer  
17 (20%) or another less common type of HNC, for instance salivary gland tumour or cancer of  
18 unknown primary (13%). Cancer stage was missing or unknown for 25% of the sample.  
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## Quality of life (QoL) scores

QLACS scores for generic QoL ranged from 26 to 181, with a median score of 70 (IQR 39).

Cancer-specific QoL scores ranged from 15 to 94, with a median score of 34 (IQR 25). QLACS scores for generic and cancer-specific QoL were positively skewed, illustrating that the majority of survivors deemed their quality of life to be good, although a tail of poorly scoring participants clearly existed. Median summary scores for individual subscales varied, with the lowest (best) median score for 'financial problems' and highest (worst) for 'distress-recurrence' and 'fatigue' (Table 2).

*Insert Table 2*

## Predictors of cancer-specific quality of life

There were significant differences in mean cancer-specific QoL scores by gender ( $t(260) = -2.635, p = 0.009$ ), age ( $F(4,259) = 6.047, p < 0.001$ ), SIMD ( $F(4,259) = 4.067, p = 0.003$ ), smoking status ( $t(65) = -3.052, p = 0.003$ ), employment status ( $F(2,260) = 11.715, p < 0.001$ ), type of diagnosis ( $F(3,259) = 3.892, p = 0.010$ ), and whether or not a feeding tube had been fitted ( $t(258.99) = -4.636, p < 0.001$ ) (Table 3). Post-hoc analysis revealed that participants who were retired had significantly higher cancer-specific QoL scores than participants who were in employment or out of work (Table 3). Patients with oral cavity cancer had significantly worse cancer-specific QoL scores than patients with cancer of the larynx (Table 3). There was a significant correlation between cancer related QoL and number of comorbidities ( $r = 0.232, p < 0.001$ ). Hierarchical multiple regression analysis revealed that demographic, lifestyle and clinical factors predicted 33.7% of the variance in cancer-specific QoL score ( $F(14,226) = 8.206, p < 0.001$ ). Being younger, having a lower socio-economic status, being

1 out of work, having a greater number of comorbidities, having ever had a feeding tube fitted  
2 and having a diagnosis of oral cavity cancer all independently contributed to poorer cancer-  
3 specific QoL based on the score (Table 4).  
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8 *Insert Tables 3 and 4*  
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### 10 11 **Predictors of generic quality of life**

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16 There were significant differences in mean generic QoL scores by gender ( $t(255)=-2.372$ ,  
17  $p=0.018$ , SIMD ( $F(4,254)=3.531$ ,  $p=0.008$ ), smoking status ( $t(56.48)=-2.148$ ,  $p=0.036$ ), alcohol  
18 status ( $t(257)=2.395$ ,  $p=0.017$ ), employment status ( $F(2,256)=8.099$ ,  $p<0.001$ ), and whether  
19 or not a feeding tube had ever been fitted ( $t(253.96)=-2.311$ ,  $p=0.022$ ). There was a  
20 significant correlation between generic QoL and number of comorbidities ( $r=0.413$ ,  
21  $p<0.001$ ). Hierarchical multiple regression analysis revealed that demographic, lifestyle and  
22 clinical factors predicted 32.8% of the variance in generic QoL score ( $F(14,224) = 7.827$ ,  
23  $p<0.001$ ). Being younger, having a lower socio-economic status, being out of work, and  
24 having a greater number of comorbidities independently contributed to poorer generic QoL  
25 scores (Table 4).  
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### 42 **Sub-scale analysis**

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46 Given that the significant effects of ever having had a feeding tube fitted and type of  
47 diagnosis appeared to be on the cancer-specific QoL score rather than the generic score, we  
48 investigated the relationship between feeding tube and individual sub-scales which  
49 contribute to the cancer-specific summary score (appearance concerns, financial problems,  
50 distress over recurrence, family-related distress and benefits of cancer) to see whether the  
51 effects might be associated with particular sub-scales. Median scores were significantly  
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1 higher (worse) for participants who had ever had a feeding tube fitted in the appearance  
2 concerns, financial problems and family-related distress sub-scales. Median scores differed  
3 significantly by type of diagnosis in the appearance and distress over recurrence sub-scales,  
4 with oral cavity cancer scoring highest (worse QoL) in both sub-scales (Table 5).  
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11 *Insert Table 5*  
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14 In the regression analysis for both generic and cancer-specific QoL, lower SES was found to  
15 be a significant predictor of having worse QoL scores. In order to investigate whether there  
16 was a relationship between SES and particular sub-scales, we explored the median scores  
17 and inter-quartile ranges for each sub-scale (Table 7). Scores were consistently higher  
18 (worse) in the most deprived groups across all sub-scales, however there was only a  
19 statistically significant difference between SIMD groups in the physical pain and fatigue sub-  
20 scales.  
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## 36 **Discussion**

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39 This cross-sectional study investigated the quality of life of survivors of head and neck  
40 cancer in the first five years after the end of treatment. Our first key finding is that, after  
41 controlling for clinical and socio-demographic factors, low socio-economic status, being out  
42 of work, having a greater number of comorbidities and being younger are independent  
43 predictors of reduced cancer-specific *and* generic quality of life in HNC survivors. The  
44 second key finding of our study was that having a diagnosis of oral cavity cancer and ever  
45 having had a feeding tube fitted were also independent predictors of reduced cancer-  
46 specific quality of life.  
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1 Unadjusted analyses suggest that differences in individual QoL domains, particularly those  
2 that are specific to cancer, may exist between groups, with survivors of oral cancer having  
3 poorer scores than those with oropharyngeal or laryngeal cancers. Smoking, age, gender,  
4 unemployment, low socio-economic status and having a feeding tube appear to have a  
5 detrimental effect on cancer-specific and generic QoL, whereas drinking some alcohol  
6 appeared to improve the latter.  
7

8 Patients with head and neck cancer are assumed to be difficult to reach, however, we  
9 achieved a response rate similar to that of the English patient experience survey, which  
10 gathered postal data from survivors of other more common cancers [23]. We also found  
11 that people of lower SES were significantly less likely to respond, but in our study, there was  
12 no difference in the age of responders versus non-responders. Our QLACS scores were  
13 slightly lower (better) than the sample in Avis et al's (18) study, but they are not directly  
14 comparable because the authors reported mean rather than median scores.  
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16 There is a well-established link between *survival* and low socio-economic status, although  
17 recent studies have found that neighbourhood deprivation may not be an independent  
18 predictor across all HNC types [24, 25]. This could suggest that the measure of deprivation  
19 is acting as a confounder for other unmeasured factors. Our research confirms the results  
20 of several studies establishing an association between employment, income, deprivation,  
21 education or other socioeconomic factors and QoL in this patient group [26, 27]. An under-  
22 powered Turkish study [26] found that after controlling for other factors, only "social  
23 security status" remained a significant predictor of a mental health QoL score. Our study  
24 may therefore be the first with sufficient power to establish that low SES is associated with  
25 reduced quality of life in HNC survivors. We also found that common symptoms including  
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1 pain and fatigue appear to be significantly worse in people from poorer socio-economic  
2 backgrounds, suggesting that careful symptom assessment and management may be even  
3 more important in this group.  
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8 There are a range of complex reasons why low SES may adversely affect outcomes in  
9 survivors of cancer [28] and these apply to head and neck as much as any other cancer. For  
10 example, a large survey found a significant link between deprivation, psychological distress  
11 and, to a lesser extent, social difficulties[29]. People who are socially deprived are more  
12 likely to suffer from a number of co-morbid conditions [30] and make greater use of health  
13 services than people in higher socio-economic groups [31]. A recent review [32] shows that  
14 comorbidity is associated with poorer outcomes (including quality of life) in people with  
15 HNC, and suggests that comorbidity data should be routinely collected by clinical teams.  
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17 Although this is the ideal, our own findings support the potential for self-report of co-  
18 morbid conditions [33].  
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35 Other studies have found that the presence of a gastrostomy tube at one-year post  
36 treatment was associated with poorer quality of life [14, 15], but we found an independent  
37 effect for having a feeding tube at any time during the follow-up period assessed. Most  
38 patients treated with chemo-radiation require a feeding tube during or after treatment and  
39 early nutritional intervention is widely regarded as important [34]. However, the choice of  
40 enteral route and the timing of insertion are controversial. A recent systematic review [35]  
41 concluded that gastrostomy tubes, in particular, may inhibit swallowing function. Our data  
42 add further evidence that the long-term consequences of feeding tubes should not be  
43 under-estimated, and that there are particularly detrimental effects on appearance, family  
44 and finances, although the direction of this relationship is unclear. We acknowledge that  
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1 maintaining adequate nutrition in this patient group is challenging, and further research is  
2 required to determine the long-term impact of feeding tubes and to specify the pathways by  
3 which a feeding tube might affect quality of life.  
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8 Whereas smoking was associated with worse QoL in unadjusted analysis (as in other studies  
9 e.g. [36]), drinking some alcohol appeared to be protective. Social drinking has previously  
10 been associated with improved quality of life although problem drinkers have the worst  
11 outcomes of all [37, 38]. We did not detect a difference between light/moderate and heavy  
12 drinkers but this may reflect inaccurate self-reporting by our participants.  
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22 Our data suggest that being unemployed adversely affects QoL. Patients with HNC appear  
23 to have more problems returning to work than patients with other cancers [39, 40]. Barriers  
24 include anxiety, difficulties with social interaction and social eating, oral and dental  
25 problems, although in a recent Dutch study, 83% still returned to work [41]. Working after  
26 cancer has a range of benefits including financial security, confidence and self-identity, but  
27 qualitative studies illustrate the numerous challenges and changes that people experience  
28 in the workplace and there is a real need to develop interventions that are tailored to  
29 individuals' work-related goals [42].  
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44 This is one of the few cross-sectional studies in HNC to use a measure designed to assess  
45 quality of life beyond the acute stages of diagnosis and treatment, and to link patient-  
46 reported outcomes to reliable routinely collected clinical and socio-economic data. There  
47 are, however, a number of limitations to this study. Firstly, cross-sectional studies only  
48 provide a snapshot of QoL, cannot assess change over time and demonstrate associations  
49 not causality. Their results are inevitably biased towards those patients with the most  
50 favourable survival as they exclude people who have already died (24). Secondly, the  
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1 representativeness of the survey cannot be assumed. Although questionnaires were sent to  
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3 as many patients as the CNS' could identify from their databases, which ensured a clinically  
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5 heterogeneous sample of patients with different cancers and time from diagnosis, it is likely  
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7 that some potential participants were not sent questionnaires. It is also possible that the  
8  
9 quality of life of responders was different to that of non-responders. Some patients  
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11 commented that scoring QoL based on the 'last four weeks' (as per the wording of the  
12  
13 questionnaire) was difficult, as issues were not necessarily relevant to the last month but  
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15 had been relevant at other times. Finally, there is a risk that multiple comparisons could  
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17 generate some false positive results. Further research is required to prospectively assess  
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19 relationships between the variables we have identified.  
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26 There are a number of clinical implications arising from this study. Our results suggest that  
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28 factors associated with poor QoL among survivors can be identified and used to direct  
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30 support to those in most need. Data on SES may not be routinely available to clinicians, and  
31  
32 sensitivity is required if people from lower socio-economic groups are to be targeted for  
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34 additional attention. However, our study suggests that it is important to consider the  
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36 'double whammy' of head and neck cancer treatment in addition to the material,  
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38 psychosocial, environmental, behavioural, intellectual, cultural and physical effects of low  
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40 SES, and that individualised holistic assessment is particularly important in this patient  
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42 group. Clinicians providing follow-up care should also be aware that feeding tubes may be  
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44 associated with long-term consequences on quality of life that are not necessarily directly  
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46 linked to problems with eating and swallowing.  
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## 55 **Conclusion**

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1 Many head and neck cancer survivors experience poor quality of life in the first five years  
2 after treatment. This cross-sectional study shows that younger age, unemployment, low  
3 socio-economic status, increased co-morbidity, and having a feeding tube are important  
4 predictors of poor quality of life in this patient group. These factors must be considered  
5 more carefully in in research and practice, with greater attention paid to the needs of  
6 survivors who are most at risk.  
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16 **Disclosures:** None  
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Table 1 Demographic, lifestyle and clinical characteristics of the respondents (n=280)

Patient Characteristics	N	%
Age		
<45 years	13	5
45 – 54 years	35	13
55 – 64 years	83	30
65 – 74 years	94	34
75 years and over	48	17
Missing	7	2
Gender		
Male	204	73
Female	76	27
Scottish Index of Multiple Deprivation (SIMD)		
Most deprived (SIMD 1)	49	18
2	63	23
3	51	18
4	71	26
Least deprived (SIMD 5)	46	16
Marital status		
Married	173	63
Single	22	8
Not living alone	19	7
Divorced/separated	28	10
Widowed	31	11
missing	7	3
Living Alone		
Yes	66	23
No	204	73
Missing	10	4
Employment at Time of Diagnosis		
Employed	125	45
Out of work	38	14
Retired	109	39
Missing	8	3
Employed Currently		
Yes	84	30
No	76	27
Retired	112	40
Missing	8	3
Current Smoker		
Yes	50	18
No	223	80
Missing	7	2
Current Alcohol Drinker		
Yes	173*	62



No	100	36
Missing	7	2
Diagnosis		
Larynx	92	33
Oropharynx	57	20
Oral cavity	94	34
Other	36	13
Missing data	1	<1
Stage (UICC)		
I	64	23
II	43	15
III	38	14
IV	66	24
Unknown primary	3	1
Missing data	66	24
Time since diagnosis		
Up to 1 year	25	9
1-2 years	62	22
2-3 years	53	19
3-4 years	70	25
>4 years	70	25
Treatment (self-report)		
Surgery only (includes 2 laser)	73	26
Radiotherapy	48	17
Surgery and radiotherapy	32	11
Surgery and chemotherapy	2	1
Chemoradiotherapy	50	18
All (surgery, RT, chemo)	64	23
Missing data	11	
Feeding-tube History		
Ever fitted	150	56
Never fitted	120	44
Missing data	10	
Duration of feed-tube required		
Up to 3 months	81	54
3-6 months	32	21
7-12 months	14	9
13 - 18 months	1	<1
Still in place	17	11
Missing data	5	
Total no. listed co-morbid conditions		
None	99	35
1	84	30
2	35	13
3	21	8
4	20	7

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5 or more	9	3
Co-morbid conditions (self-report)		
Diabetes	33	11
Heart problems	47	15
Lung problems	28	9
Stroke	12	4
Arthritis	51	17
Other cancer	27	9
Heartburn	56	18
Other condition	87	28

\* of whom 80 described themselves as moderate and 7 as heavy drinkers

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Table 2 Domain and subscale median scores (n=280)

	Median	Inter-quartile range
Generic Quality of Life <sup>#</sup>	70	39
Negative feelings <sup>#</sup>	10	7
Positive feelings <sup>*</sup>	22	10
Cognitive problems <sup>#</sup>	9	6
Sexual problems <sup>#</sup>	10	11
Physical pain <sup>#</sup>	8	7
Fatigue <sup>#</sup>	13	9
Social avoidance <sup>#</sup>	8	8
Cancer-Specific Quality of Life <sup>#</sup>	34	25
Appearance concerns <sup>#</sup>	6	7
Financial problems <sup>#</sup>	5	6
Distress over recurrence <sup>#</sup>	12	9
Family-related distress <sup>#</sup>	7	8
Benefits of cancer <sup>*</sup>	18	10

<sup>#</sup>higher scores indicate poorer quality of life

<sup>\*</sup>higher scores indicate better quality of life

Table 3 Demographic, lifestyle and clinical factors and their association with cancer-specific and generic quality of life scores.

	Mean Cancer-Specific QoL Score <sup>#</sup> (sd)	P	Mean Generic QoL Score <sup>#</sup> (sd)	p
Gender				
- Male	36.21 (16.80)	0.009	73.32 (30.24)	0.018
- Female	42.62 (18.97)		83.81 (33.52)	
Age				
- <45 years	43.81 (21.07)	<0.001	83.77 (31.19)	0.118
- 45 – 54 years	46.84 (19.98)		82.94 (38.27)	
- 55 – 64 years	40.54 (18.68)		79.79 (35.59)	
- 65 – 74 years	34.07 (13.87)		69.98 (26.83)	
- ≥75 years	31.46 (15.51)		73.32 (22.16)	
SIMD				
- 1 (most deprived)	44.03 (22.16)	0.003	87.47 (39.39)	0.008
- 2	41.88 (18.57)		81.86 (31.60)	
- 3	34.65 (13.52)		73.22 (29.93)	
- 4	36.28 (16.54)		72.13 (28.98)	
- 5 (least deprived)	31.93 (13.91)		65.93 (22.56)	
Living arrangements				
- Another person lives in household	37.77 (17.28)	0.954	75.86 (30.83)	0.895
- Lives alone	37.63 (17.99)		76.50 (33.71)	
Smoking status				
- Non-smoker	36.03 (16.47)	0.003	73.59 (28.52)	0.036
- Smoker	45.40 (20.22)		86.98 (40.58)	
Alcohol status				
- Non-drinker	39.70 (19.02)	0.211	82.20 (33.26)	0.017
- Drinker	36.75 (16.71)		72.55 (29.85)	
Employment status				
- Out of work	44.48 (20.26)	<0.001	87.97 (37.76)	<0.001
- Employed	38.76 (16.75)		70.61 (26.43)	
- Retired	32.16 (14.20)		71.61 (27.66)	
Diagnosis				
- Larynx	33.69 (17.25)	0.010	73.14 (29.64)	0.357
- Oropharynx	36.85 (14.65)		73.17 (29.73)	
- Oral cavity	42.56 (17.66)		80.84 (32.72)	
- Other	38.01 (20.19)		76.88 (34.13)	
Length of time since diagnosis				
- Up to 1 year	35.10 (16.08)	0.795	73.82 (30.39)	0.980
- 1-2 years	36.77 (14.46)		73.61 (32.39)	

- 2-3 years	39.95 (19.51)		75.88 (27.88)	
- 3-4 years	38.47 (17.26)		76.29 (27.12)	
- >4 years	36.68 (18.94)		77.04 (37.20)	
Type of treatment				
- Surgery alone	38.26 (18.08)	0.773	79.64 (33.82)	0.243
- Other treatment~	37.56 (17.29)		74.47 (30.43)	
Feeding tube fitted				
- Never	32.39 (14.73)	<0.001	71.16 (25.71)	0.022
- Ever	41.93 (18.53)		79.92 (35.00)	

~ Treatment including chemotherapy or radiotherapy

# higher scores indicate poorer quality of life

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Table 4 Summary of hierarchical regression analysis for variables predicting cancer-specific and generic quality of life

	Cancer-specific quality of life				Generic quality of life		
	Model 1 (Demographics)	Model 2 (Demographics + Lifestyle)	Model 3 (Demographics, Lifestyle +Clinical)		Model 1 (Demographics)	Model 2 (Demographics + Lifestyle)	Model 3 (Demographics, Lifestyle +Clinical)
Variable	$\beta$	$\beta$	B	$\beta$	$\beta$	B	
Female	0.148*	0.131*	0.090	0.142*	0.106	0.098	
Age	-0.280**	-0.264**	-0.292**	-0.158*	-0.153*	-0.213**	
Living alone	0.030	0.031	0.000	0.009	0.017	0.003	
SIMD	-0.213**	-0.152*	-0.168**	-0.221**	-0.150*	-0.145*	
Current smoker		0.114	0.095		0.128*	0.074	
Current non-drinker		-0.068	-0.028		-0.135*	-0.074	
Not employed or retired		-0.224**	-0.144*		-0.227**	-0.150*	
Time since diagnosis			0.030			-0.016	
Number of comorbidities			0.243**			0.389**	
Treatment other than surgery alone			0.090			-0.003	
Feeding tube ever fitted			0.204**			0.112	
Oropharynx diagnosis			-0.047			-0.039	
Oral cavity diagnosis			0.172*			0.034	
Other site diagnosis			0.061			0.030	
$\Delta R^2$	0.147**	0.068**	0.122**	0.098**	0.083**	0.147**	
Total R <sup>2</sup>	0.147**	0.215**	0.337**	0.098**	0.181**	0.328**	

\*p<0.05

\*\*p<0.01

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Table 5 Cancer-specific quality of life subscale median scores for feeding tube and type of diagnosis

	Appearance concerns	p	Financial problems	p	Distress over recurrence	p	Family related distress	p	Benefits of cancer	p
<b>Feeding Tube</b>										
<b>Median (IQR)</b>										
Ever Fitted	9 (11)	<0.001	7.5 (8)	<0.001	12 (10)	0.069	7.33 (9)	0.044	18 (10)	0.524
Never Fitted	4 (3)		4 (4)		11 (9)		5.33 (8)		16.5 (10)	
<b>Type of Diagnosis</b>										
<b>Median (IQR)</b>										
Larynx	4 (5)	0.009	4 (5)	0.073	10 (9)	0.001	5.33 (7)	0.105	18 (10)	0.631
Oropharynx	6 (6)		8 (9)		11 (8)		7.33 (8)		18 (13)	
Oral Cavity	8 (9)		6 (7)		15 (10)		8.66 (9)		18 (8)	
Other	5 (10)		4 (4)		12 (11)		6 (9)		16 (12)	

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Table 6 QLACS sub-scale median scores by SIMD category

	SIMD 1	SIMD 2	SIMD 3	SIMD 4	SIMD 5	p
Generic Quality of Life	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	
Negative feelings <sup>#</sup>	11 (9)	10 (6)	9 (6)	9 (5)	9 (6)	0.146
Positive feelings <sup>*</sup>	22 (13)	21 (9)	22.5 (10)	22 (9)	22 (7)	0.370
Cognitive problems <sup>#</sup>	11 (12)	9 (5)	9 (6)	8 (7)	7 (6)	0.085
Sexual problems <sup>#</sup>	10 (9)	14 (12)	10.5 (12)	10 (11)	9 (9)	0.125
Physical pain <sup>#</sup>	10 (9)	9 (9)	8 (8)	7 (6)	6 (5)	0.004
Fatigue <sup>#</sup>	16.5 (10)	12 (9)	12 (8)	12 (8)	12 (6)	0.046
Social avoidance <sup>#</sup>	10 (11)	8 (11)	7.5 (9)	7 (7)	7 (7)	0.227
Cancer-Specific Quality of Life						
Appearance concerns <sup>#</sup>	7 (11)	8 (11)	6.5 (7)	5 (6)	5 (5)	0.173
Financial problems <sup>#</sup>	7 (10)	6 (7)	4 (4)	6 (7)	4 (5)	0.067
Distress over recurrence <sup>#</sup>	15.5 (15)	14 (11)	12 (7)	11 (9)	10 (6)	0.067
Family-related distress <sup>#</sup>	7.16 (9)	9 (8)	5.5 (8)	6.66 (9)	5.33 (6)	0.108
Benefits of cancer <sup>*</sup>	17 (10)	18 (10)	18 (10)	18 (11)	19 (10)	0.477

\*higher scores indicate better quality of life

<sup>#</sup>higher scores indicate poorer quality of life

NB SIMD 1 = most deprived; SIMD 5 = least deprived



Table 1 Demographic, lifestyle and clinical characteristics of the respondents (n=280)

Patient Characteristics	N	%
Age		
<45 years	13	5
45 – 54 years	35	13
55 – 64 years	83	30
65 – 74 years	94	34
75 years and over	48	17
Missing	7	2
Gender		
Male	204	73
Female	76	27
Scottish Index of Multiple Deprivation (SIMD)		
Most deprived (SIMD 1)	49	18
2	63	23
3	51	18
4	71	26
Least deprived (SIMD 5)	46	16
Marital status		
Married	173	63
Single	22	8
Not living alone	19	7
Divorced/separated	28	10
Widowed	31	11
missing	7	3
Living Alone		
Yes	66	23
No	204	73
Missing	10	4
Employment at Time of Diagnosis		
Employed	125	45
Out of work	38	14
Retired	109	39
Missing	8	3
Employed Currently		
Yes	84	30
No	76	27
Retired	112	40
Missing	8	3
Current Smoker		
Yes	50	18
No	223	80
Missing	7	2
Current Alcohol Drinker		
Yes	173*	62

No	100	36
Missing	7	2
Diagnosis		
Larynx	92	33
Oropharynx	57	20
Oral cavity	94	34
Other	36	13
Missing data	1	<1
Stage (UICC)		
I	64	23
II	43	15
III	38	14
IV	66	24
Unknown primary	3	1
Missing data	66	24
Time since diagnosis		
Up to 1 year	25	9
1-2 years	62	22
2-3 years	53	19
3-4 years	70	25
>4 years	70	25
Treatment (self-report)		
Surgery only (includes 2 laser)	73	26
Radiotherapy	48	17
Surgery and radiotherapy	32	11
Surgery and chemotherapy	2	1
Chemoradiotherapy	50	18
All (surgery, RT, chemo)	64	23
Missing data	11	
Feeding-tube History		
Ever fitted	150	56
Never fitted	120	44
Missing data	10	
Duration of feed-tube required		
Up to 3 months	81	54
3-6 months	32	21
7-12 months	14	9
13 - 18 months	1	<1
Still in place	17	11
Missing data	5	
Total no. listed co-morbid conditions		
None	99	35
1	84	30
2	35	13
3	21	8
4	20	7

5 or more	9	3
Co-morbid conditions (self-report)		
Diabetes	33	11
Heart problems	47	15
Lung problems	28	9
Stroke	12	4
Arthritis	51	17
Other cancer	27	9
Heartburn	56	18
Other condition	87	28

\* of whom 80 described themselves as moderate and 7 as heavy drinkers

Table 2 Domain and subscale median scores (n-280)

	Median	Inter-quartile range
Generic Quality of Life <sup>#</sup>	70	39
Negative feelings <sup>#</sup>	10	7
Positive feelings <sup>*</sup>	22	10
Cognitive problems <sup>#</sup>	9	6
Sexual problems <sup>#</sup>	10	11
Physical pain <sup>#</sup>	8	7
Fatigue <sup>#</sup>	13	9
Social avoidance <sup>#</sup>	8	8
Cancer-Specific Quality of Life <sup>#</sup>	34	25
Appearance concerns <sup>#</sup>	6	7
Financial problems <sup>#</sup>	5	6
Distress over recurrence <sup>#</sup>	12	9
Family-related distress <sup>#</sup>	7	8
Benefits of cancer <sup>*</sup>	18	10

<sup>#</sup>higher scores indicate poorer quality of life

<sup>\*</sup>higher scores indicate better quality of life

Table 3 Demographic, lifestyle and clinical factors and their association with cancer-specific and generic quality of life scores.

	Mean Cancer-Specific QoL Score <sup>#</sup> (sd)	P	Mean Generic QoL Score <sup>#</sup> (sd)	p
Gender				
- Male	36.21 (16.80)	0.009	73.32 (30.24)	0.018
- Female	42.62 (18.97)		83.81 (33.52)	
Age				
- <45 years	43.81 (21.07)	<0.001	83.77 (31.19)	0.118
- 45 – 54 years	46.84 (19.98)		82.94 (38.27)	
- 55 – 64 years	40.54 (18.68)		79.79 (35.59)	
- 65 – 74 years	34.07 (13.87)		69.98 (26.83)	
- ≥75 years	31.46 (15.51)		73.32 (22.16)	
SIMD				
- 1 (most deprived)	44.03 (22.16)	0.003	87.47 (39.39)	0.008
- 2	41.88 (18.57)		81.86 (31.60)	
- 3	34.65 (13.52)		73.22 (29.93)	
- 4	36.28 (16.54)		72.13 (28.98)	
- 5 (least deprived)	31.93 (13.91)		65.93 (22.56)	
Living arrangements				
- Another person lives in household	37.77 (17.28)	0.954	75.86 (30.83)	0.895
- Lives alone	37.63 (17.99)		76.50 (33.71)	
Smoking status				
- Non-smoker	36.03 (16.47)	0.003	73.59 (28.52)	0.036
- Smoker	45.40 (20.22)		86.98 (40.58)	
Alcohol status				
- Non-drinker	39.70 (19.02)	0.211	82.20 (33.26)	0.017
- Drinker	36.75 (16.71)		72.55 (29.85)	
Employment status				
- Out of work	44.48 (20.26)	<0.001	87.97 (37.76)	<0.001
- Employed	38.76 (16.75)		70.61 (26.43)	
- Retired	32.16 (14.20)		71.61 (27.66)	
Diagnosis				
- Larynx	33.69 (17.25)	0.010	73.14 (29.64)	0.357
- Oropharynx	36.85 (14.65)		73.17 (29.73)	
- Oral cavity	42.56 (17.66)		80.84 (32.72)	
- Other	38.01 (20.19)		76.88 (34.13)	
Length of time since diagnosis				
- Up to 1 year	35.10 (16.08)	0.795	73.82 (30.39)	0.980
- 1-2 years	36.77 (14.46)		73.61 (32.39)	

- 2-3 years	39.95 (19.51)		75.88 (27.88)	
- 3-4 years	38.47 (17.26)		76.29 (27.12)	
- >4 years	36.68 (18.94)		77.04 (37.20)	
Type of treatment				
- Surgery alone	38.26 (18.08)	0.773	79.64 (33.82)	0.243
- Other treatment~	37.56 (17.29)		74.47 (30.43)	
Feeding tube fitted				
- Never	32.39 (14.73)	<0.001	71.16 (25.71)	0.022
- Ever	41.93 (18.53)		79.92 (35.00)	

~ Treatment including chemotherapy or radiotherapy

# higher scores indicate poorer quality of life

Table 4 Summary of hierarchical regression analysis for variables predicting cancer-specific and generic quality of life

	Cancer-specific quality of life				Generic quality of life		
	Model 1 (Demographics)	Model 2 (Demographics + Lifestyle)	Model 3 (Demographics, Lifestyle +Clinical)		Model 1 (Demographics)	Model 2 (Demographics + Lifestyle)	Model 3 (Demographics, Lifestyle +Clinical)
Variable	$\beta$	$\beta$	B	$\beta$	$\beta$	B	
Female	0.148*	0.131*	0.090	0.142*	0.106	0.098	
Age	-0.280**	-0.264**	-0.292**	-0.158*	-0.153*	-0.213**	
Living alone	0.030	0.031	0.000	0.009	0.017	0.003	
SIMD	-0.213**	-0.152*	-0.168**	-0.221**	-0.150*	-0.145*	
Current smoker		0.114	0.095		0.128*	0.074	
Current non-drinker		-0.068	-0.028		-0.135*	-0.074	
Not employed or retired		-0.224**	-0.144*		-0.227**	-0.150*	
Time since diagnosis			0.030			-0.016	
Number of comorbidities			0.243**			0.389**	
Treatment other than surgery alone			0.090			-0.003	
Feeding tube ever fitted			0.204**			0.112	
Oropharynx diagnosis			-0.047			-0.039	
Oral cavity diagnosis			0.172*			0.034	
Other site diagnosis			0.061			0.030	
$\Delta R^2$	0.147**	0.068**	0.122**	0.098**	0.083**	0.147**	
Total R <sup>2</sup>	0.147**	0.215**	0.337**	0.098**	0.181**	0.328**	

\*p<0.05

\*\*p<0.01

Table 5 Cancer-specific quality of life subscale median scores for feeding tube and type of diagnosis

	Appearance concerns	p	Financial problems	p	Distress over recurrence	p	Family related distress	p	Benefits of cancer	p
Feeding Tube Median (IQR)										
Ever Fitted	9 (11)	<0.001	7.5 (8)	<0.001	12 (10)	0.069	7.33 (9)	0.044	18 (10)	0.524
Never Fitted	4 (3)		4 (4)		11 (9)		5.33 (8)		16.5 (10)	
Type of Diagnosis Median (IQR)										
Larynx	4 (5)	0.009	4 (5)	0.073	10 (9)	0.001	5.33 (7)	0.105	18 (10)	0.631
Oropharynx	6 (6)		8 (9)		11 (8)		7.33 (8)		18 (13)	
Oral Cavity	8 (9)		6 (7)		15 (10)		8.66 (9)		18 (8)	
Other	5 (10)		4 (4)		12 (11)		6 (9)		16 (12)	



Table 6 QLACS sub-scale median scores by SIMD category

	SIMD 1	SIMD 2	SIMD 3	SIMD 4	SIMD 5	p
Generic Quality of Life	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	
Negative feelings <sup>#</sup>	11 (9)	10 (6)	9 (6)	9 (5)	9 (6)	0.146
Positive feelings <sup>*</sup>	22 (13)	21 (9)	22.5 (10)	22 (9)	22 (7)	0.370
Cognitive problems <sup>#</sup>	11 (12)	9 (5)	9 (6)	8 (7)	7 (6)	0.085
Sexual problems <sup>#</sup>	10 (9)	14 (12)	10.5 (12)	10 (11)	9 (9)	0.125
Physical pain <sup>#</sup>	10 (9)	9 (9)	8 (8)	7 (6)	6 (5)	0.004
Fatigue <sup>#</sup>	16.5 (10)	12 (9)	12 (8)	12 (8)	12 (6)	0.046
Social avoidance <sup>#</sup>	10 (11)	8 (11)	7.5 (9)	7 (7)	7 (7)	0.227
Cancer-Specific Quality of Life						
Appearance concerns <sup>#</sup>	7 (11)	8 (11)	6.5 (7)	5 (6)	5 (5)	0.173
Financial problems <sup>#</sup>	7 (10)	6 (7)	4 (4)	6 (7)	4 (5)	0.067
Distress over recurrence <sup>#</sup>	15.5 (15)	14 (11)	12 (7)	11 (9)	10 (6)	0.067
Family-related distress <sup>#</sup>	7.16 (9)	9 (8)	5.5 (8)	6.66 (9)	5.33 (6)	0.108
Benefits of cancer <sup>*</sup>	17 (10)	18 (10)	18 (10)	18 (11)	19 (10)	0.477

\*higher scores indicate better quality of life

<sup>#</sup>higher scores indicate poorer quality of life

NB SIMD 1 = most deprived; SIMD 5 = least deprived

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