



Health-related quality of life and concerns in patients attending an oral and maxillofacial oncology review clinic: late effects 5- and 10-year following cancer diagnosis

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Background: An increasing number of head and neck cancer (HNC) patients survive many years after treatment. They are at risk of developing late effects and these could be associated with worse health-related quality of life (HRQOL) and influence the nature of any concerns they want to discuss in consultations. The aim of this study was to report their HRQOL and concerns at oral and maxillofacial oncology review clinics, from 5- and 10-year after primary cancer diagnosis.

Methods: The University of Washington quality of life questionnaire (UW-QOL v4) and Patient Concerns Inventory (PCI) were completed by patients attending review clinics from 4th June 2008 to 11th March 2020.

Results: There were 167 with data at least 5 years after diagnosis, with 105 close to 5 years (median 63 months) and 99 at 10 years (median 119 months). Those under review for primary cancer fell from 50% at 5 years to 39% at 10 years, increased for osteoradionecrosis (ORN) from 27% to 36%, and for those seen for second primary or recurrence remained at 24%. HRQOL was notably worse in patients with further disease particularly at 5 years in regard to pain, chewing, taste and both the social-emotional and physical function subscales of the UW-QOL. The median [interquartile range (IQR)] number of PCI items at 5- and 10-year were 3 [1–7] and 4 [2–9] respectively.

Conclusions: There were subtle differences in the frequency of PCI items however items related to dry mouth, dental function, and swallowing predominated. The findings highlight the complex needs of long-term survivors.

Keywords: Head and neck cancer (HNC); late effects; long-term follow-up; health related quality of life; Patient Concerns Inventory (PCI)

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Introduction

The population of head and neck cancer (HNC) survivors is increasing year on year. According to the statistics from Cancer Research UK, in England [2009–2013] the age-standardised 10-year net survival for adults (aged 15–90 years) for oral cavity cancer (C03, C04, C05, C06) was 45.2%, oropharyngeal cancer (C09, C10, C02.4) 57.7%, and laryngeal cancer (C32) 54.7% (1). For oral cancer disease-specific, disease-specific survival improved over the 10-year period from 63% [1992–1995] to 81% [2000–2002] (2).

Improved survival is associated with an increasing number of patients living with long-term side-effects (late effects) (3). Although these consequences occur by the nature of treatment modalities involving combinations of chemotherapy, radiotherapy and surgery, arguably the most potent influence in the development of late effects is radiotherapy (4). Both hard and soft tissues are involved and also functional units such as chewing and swallowing. Longer term deficits include dental demineralization and caries, dysphagia, fibrosis, hearing loss, lymphedema, osteoradionecrosis (ORN), trismus, and xerostomia (5–8). These dysfunctions have a negative impact on health-related quality of life (HRQOL) (9). In spite of a considerable number of papers that touch on the issue of HRQOL and long-term effects (10), the vast majority lack the detail of survivorship up to and beyond 10 years. There is a paucity of data on patient concerns in the long term.

The aim of this study is to report the HRQOL and patient concerns at 5- and 10-year following the cancer diagnosis in patients attending an oral and maxillofacial oncology review clinic. Not only will this data better inform the outcomes and needs of this group, it will also give an indication of the case mix of patients under long-term follow-up. This information can be useful when considering the design of a multidisciplinary late effects clinic. We present the following article in accordance with the STROBE reporting checklist (available at <https://fomm.amegroups.com/article/view/10.21037/fomm-21-93/rc>).

Methods

Since 2007, the completion of the University of Washington quality of life questionnaire (UW-QOL v4) (11) and Patient Concerns Inventory (PCI) (12) were routinely completed by patients attending out-patients clinic review of the lead author (SN Rogers). Patients attending from 4th June 2008 to 11th March 2020 and who had completed PCI and UW-

QOL data at least 5 years on from their primary tumour diagnosis were included. Data were entered directly onto a computerised system on the Aintree-Hospital secure server by patients themselves prior to being seen by the consultant. When approached in the routine clinic setting virtually all patients participated. The consultant used a print-out of PCI responses in real-time during the consultation. Patient data were extracted from the electronic case notes on SIGMA (System C) and outpatient clinical letters while PCI and UW-QOL data were downloaded from the secure server. Data included patient demographics, head and neck staging [American Joint Committee on Cancer (AJCC) 7] (13), HNC site, diagnosis date and treatment modality, and subsequent details of ORN, recurrence and second primary, date of last follow-up and current outcome status.

The UW-QOL version 4 consists of 12 domains scaled from 0 (worst) to 100 (best) according to response hierarchy (12). UW-QOL domains are presented within two subscales, physical function and social-emotional function (14) with each subscale score being the mean of six domain scores. Criteria derived from earlier work can highlight domains in which patients have a serious problem or dysfunction (15). From 2008 to 2011 the neck cancer-specific PCI (PCI-HN) had 54 items, before ‘dry mouth’ and ‘sore mouth’ were added in 2012.

At each review clinic, patients were classified as to whether they had primary cancer only to that point in time (i.e., without recurrence, 2nd primary or ORN), whether they had had primary cancer followed by ORN only (i.e., without recurrence or 2nd primary), or whether they had experienced recurrence(s) or second primaries or a combination of both. There was a varying number of clinics per patient and this presented a problem for analysis due to the likely clustering of outcome results within patient. For the purpose of enabling a patient-based analysis the review clinics were grouped within time windows (42–89 and ≥ 90 months) and from within each window the clinics closest to 60 and 120 months were selected for each patient with relevant clinic data in these windows.

Statistical analysis

Fishers exact test was used to compare patient groups in regard to overall QOL being less than good and in whether dysfunction was indicated for UW-QOL domains. The Kruskal-Wallis test compared patient groups in regard to the two UW-QOL subscale scores and for the total number of PCI items selected from the prompt list. SPSS v25 was

used for the analyses and $P < 0.05$ was regarded as statistically significant.

Ethical consideration

This study was approved by Liverpool University Hospital NHS Foundation Trust Audit Department (Reference 7448). The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Informed consent is not required as used data were collected as part of routine care.

Results

There were 167 patients with PCI/UW-QOL data at least 5 years after the primary diagnosis, with a total of 884 records, median [interquartile range (IQR)] of 4 [2–8] per patient. Median [IQR] age at primary tumour diagnosis was 56 [49–62] years and 64% [107] were male. Further patient characteristics at the time of primary diagnosis are summarised in *Table 1*. A total of 66 patients only had clinic PCI/UW-QOL data after primary cancer, 23 patients only had clinic data after a recurrence or 2nd primary and 44 patients only after ORN. There were 11 patients with some clinic data after primary cancer and then some later data after ORN, 22 after primary cancer and later after a recurrence or 2nd primary, and 1 patient had data from 5 clinics after a 2nd primary and then from 1 clinic after ORN.

There were 105 patients with clinic data at 5 years (median 63 months; IQR, 58–70 months) and 99 at 10 years (median 119 months; IQR, 110–132 months). UW-QOL outcomes at clinics closest to 5- and 10-year are shown in *Table 2*. By 60 months half (53/105) had either developed ORN in the absence of recurrence or second primary [28] or had been diagnosed with recurrence or a second primary or both [25]. By 120 months the disease mix of patients had shifted further away from primary cancer only (39/99) to having further disease. At 60 months there was an increase in pain dysfunction for patients with further disease (primary cancer 8%, *vs.* recurrence/second primary 20% *vs.* ORN 39%, $P = 0.003$) and a similar observation at 120 months (10%, 33%, 25%, $P = 0.07$). At 60 months there were significant differences with regard to dysfunction in chewing (8%, 16%, 29%, $P = 0.05$) and taste (9%, 28%, 18%, $P = 0.05$) and at 120 months in regard to activity (8%, 29%, 3%, $P = 0.01$). At 60 months there was a significant difference in regard to the physical function subscale score (median: primary cancer 79, recurrence/second

primary 68, ORN 61, $P = 0.01$) and a similar trend for the social emotional subscale score (82, 74, 69, $P = 0.09$). At 120 months the recurrence/second primary group was observed to have the lowest (worst) subscale scores (median: physical: 80, 62, 69, $P = 0.05$; social-emotional: 79, 73, 78, $P = 0.06$).

Table 3 summarises the number of items selected from the PCI prompt list, and also lists the most frequently selected items for the same patient groups as shown in *Table 2*. The main observation was the similarity of the items selected and in how often they were selected, typically 1 in 6 to 1 in 3 patients. In terms of overall consultant workload for the entire sample of 884 clinics the 10 most frequently selected items were dry mouth (28%, 191/681), dental health/teeth (27%, 241/884), fear of cancer returning (27%, 239/884), pain in head/neck (24%, 212/884), swallowing (22%, 197/884), chewing/eating (22%, 191/884), fatigue (22%, 191/884), sore mouth (21%, 141/681), salivation (19%, 171/884) and sleeping (19%, 167/884). Only 1 (spiritual) of the 56 items was not selected. The median [IQR] number of PCI items overall at 5 years and 10 years were 3 [1–7] and 4 [2–9] respectively.

Discussion

The routine collection of patients reported outcomes (PRO) as part of an out-patient consultation visits has helped to provide a unique opportunity to reflect on those patients attending many years after their first HNC diagnosis and treatment. It has been possible to consider the case mix as well as the concerns at the time of the attendance as well as long-term HRQOL of these patients. The PRO were completed on a tablet in clinic at the time of the consultation which means that any loss of clinic data is minimal. There were only a few weeks throughout the 12-year period when the system was not working and this was because of the transition from one information technology (IT) system to another. As the PRO is embedded into routine care (16) and a volunteer is on hand to assist any patients who ask for help to complete, the case mix is representative of the clinic and includes the elderly (17) and lower social-economic groups (18). These PRO measures consisted of the PCI and the UW-QOL v4. Both have been widely reported (10) and a systematic review of unmet needs self-report measures favoured the PCI over thirteen other tools (19). The analysis is limited to one consultants' practice and as an oral and maxillofacial review clinic there is an emphasis on oral cancer follow-up and ORN cases

Table 1 Patient clinical and demographic characteristics at the time of primary diagnosis

Variables	Subgroup	N	%
All patients		167	100
Gender	Male	107	64
	Female	60	36
Age at diagnosis (years)	<55	74	44
	55–64	61	37
	≥65	32	19
Marital status	Married/partner	126	75
	Single	21	13
	Divorced/widowed	11	7
	Not known	9	5
Tumour site	Oral cavity	99	61
	Oropharynx	55	34
	Other	7	4
	Not known	6	–
Diagnosis	SCC	143	86
	Non-SCC*	23	14
	Not known	1	–
Overall clinical stage	Early 1–2	85	56
	Advanced 3–4	68	44
	Not known	14	–
Primary treatment	Surgery only	64	38
	RT only	5	3
	CRT only	21	13
	Surgery & (RT or CRT)	77	46
Free-flap (if surgery)	None	73	52
	Soft	52	37
	Composite	15	11
	Not known	1	–
ASA grade	1	43	27
	2	87	55
	3	28	18
	4	1	0.6
	Not known	8	–

* , adenocarcinoma [2], adenoid cystic carcinoma [4], carcinoma *in situ* [2], keratinizing squamous carcinoma [1], MALT lymphoma [1], mucoepidermoid carcinoma [6], non-keratinising carcinoma + squamous cell car [1], osteosarcoma [1], polymorphous low-grade adenocarcinoma [1], sarcoma [1], verrucous carcinoma [2], carcinoma ex-pleomorphic adenoma (CXPA) [1]. ASA, American Society of Anesthesiologists; CRT, chemoradiotherapy; MALT, mucosa-associated lymphoid tissue; RT, radiotherapy; SCC, squamous cell carcinoma.

Table 2 UW-QOL outcomes by patient disease status at clinics closest to 60 and 120 months after primary diagnosis

Variables	Closest review clinic to 60 months*			Closest review clinic to 120 months*				
	Primary cancer only	Recurrence or 2nd primary	ORN only	P value**	Primary cancer only	Recurrence or 2nd primary	ORN only	P value**
Total number of patients	52	25	28	-	39	24	36	-
Median [IQR] months from diagnosis	62 [56-68]	64 [59-75]	62 [58-67]	-	115 [103-122]	120 [112-126]	120 [110-156]	-
Number diagnosed at any time before clinic with								
Primary cancer only	52	-	-	-	39	-	-	-
ORN	-	4	28	-	-	7	36	-
Recurrence	-	12	-	-	-	8	-	-
2 nd Primary	-	11	-	-	-	16	-	-
Median [IQR] months before clinic of most recent diagnosis of ORN/recurrence/2 nd primary	-	17 [7-43]	23 [15-37]	-	-	31 [10-55]	27 [7-59]	-
Overall QOL life: less than good, % [n]	27 [14]	36 [9]	29 [8]	0.73	31 [12]	25 [6]	39 [14]	0.56
Social-emotional subscale dysfunction, % [n]								
Pain	8 [4]	20 [5]	39 [11]	0.003	10 [4]	33 [8]	25 [9]	0.07
Activity	10 [5]	16 [4]	7 [2]	0.59	8 [3]	29 [7]	3 [1]	0.01
Recreation	8 [4]	16 [4]	4 [1]	0.31	13 [5]	17 [4]	11 [4]	0.87
Shoulder	12 [6]	4 [1]	7 [2]	0.66	10 [4]	17 [4]	6 [2]	0.33
Mood	10 [5]	16 [4]	29 [8]	0.09	18 [7]	17 [4]	11 [4]	0.73
Anxiety	17 [9]	12 [3]	21 [6]	0.70	10 [4]	17 [4]	14 [5]	0.75
Physical function subscale dysfunction, % [n]								
Appearance	8 [4]	12 [3]	18 [5]	0.38	10 [4]	17 [4]	6 [2]	0.33
Swallowing	15 [8]	20 [5]	32 [9]	0.22	23 [9]	25 [6]	14 [5]	0.51
Chewing	8 [4]	16 [4]	29 [8]	0.05	15 [6]	21 [5]	8 [3]	0.38
Speech	10 [5]	8 [2]	7 [2]	>0.99	15 [6]	17 [4]	3 [1]	0.13
Taste	8 [4]	28 [7]	18 [5]	0.05	10 [4]	13 [3]	6 [2]	0.68
Saliva	25 [13]	28 [7]	43 [12]	0.28	26 [10]	33 [8]	28 [10]	0.81
Social-emotional subscale, median [IQR]	82 [63-96]	74 [62-87]	69 [56-85]	0.09	79 [65-92]	73 [54-75]	78 [70-91]	0.05
Physical function subscale, median [IQR]	79 [61-95]	68 [53-88]	61 [48-77]	0.01	80 [63-95]	62 [47-86]	69 [55-81]	0.06

*, closest clinic to 60 months from the 42-89-month window and closest to 120 months from the ≥90-month window; **, Fisher's exact test, apart from the Kruskal-Wallis test for the two subscale scores. IQR, interquartile range; ORN, osteoradionecrosis; UW-QOL, University of Washington quality of life questionnaire.

Table 3 PCI item selection by patient disease status at clinics closest to 60 and 120 months after primary diagnosis

Variables	Closest review clinic to 60 months*			Closest review clinic to 120 months*		
	Primary cancer only	Recurrence or 2nd primary	ORN only	Primary cancer only	Recurrence or 2nd primary	ORN only
Total number of patients	52	25	28	39	24	36
Number diagnosed at any time before clinic with						
Primary cancer only	52	-	-	39	-	-
ORN	-	4	28	-	7	36
Recurrence	-	12	-	-	8	-
2 nd primary	-	11	-	-	16	-
Median [IQR] number of PCI items**	3 [0-5]	3 [1-8]	5 [2-8]	4 [2-9]	5 [2-10]	4 [1-9]
Most frequently selected PCI items ≥ 15%	Fear of recurrence 25	Breathing 20	Chewing/eating 36	Dental health/teeth 33	Dry mouth 44	Dry mouth 47
	Dental health/teeth 23	Chewing/eating 20	Dental health/teeth 36	Fear of recurrence 33	Fatigue/tiredness 38	Dental health/teeth 39
	Fatigue/tiredness 19	Pain head/neck 20	Salivation 36	Dry mouth 31	Dental health/teeth 29	Mouth opening 31
	Salivation 19	Pain elsewhere 20	Swallowing 36	Fatigue/tiredness 31	Fear of recurrence 29	Salivation 31
	Swallowing 17	Sleeping 20	Dry mouth 35	Pain head/neck 28	Swallowing 29	Swallowing 28
	Dry mouth 16	Swallowing 20	Sore mouth 30	Salivation 23	Energy levels 25	Chewing/eating 25
	Chewing/eating 15	Weight 20	Fatigue/tiredness 25	Shoulder 23	Pain head/neck 25	Pain head/neck 25
	Energy levels 15	Dry mouth 18	Pain head/neck 25	Swallowing 23	Mucus 25	Speech 25
	Pain head/neck 15	Appetite 16	Mouth opening 25	Chewing/eating 21	Sore mouth 22	Sore mouth 22
		Dental health/teeth 16	Fear of recurrence 21	Anxiety 18	Salivation 21	Taste 22
		Fear of recurrence 16	Sleeping 21	Breathing 18	Shoulder 21	Fatigue/tiredness 19
		Hearing 16	Cancer treatment 18	Speech 18	Speech 21	Anxiety 17
		Mouth opening 16	Energy levels 18	Weight 18	Sleeping 21	Appetite 17
		Mucus 16	Mood 18	Appearance 15	Coughing 17	Fear of recurrence 17
		Shoulder 16	Appetite 15	Appetite 15	Depression 17	Mood 17
			Mucus 15	Mucus 15	Hearing 17	Wound healing 17
					Mouth opening 17	

From 2008 to 2011 the PCI-HN had 54 items, before 'dry mouth' and 'sore mouth' were added in 2012. *, closest clinic to 60 months from the 42-89-month window and closest to 120 months from the ≥90-month window; **, Kruskal-Wallis test for the number of PCI items selected: comparison of the three groups at 60 months, P=0.19; comparison of the three groups at 120 months, P=0.87. IQR, interquartile range; ORN, osteoradionecrosis; PCI, Patient Concerns Inventory; PCI-HN, neck cancer-specific PCI.

referred by our Ear Nose and Throat (ENT) colleagues. However, as the UW-QOL and PCI profile for early and advanced oropharyngeal, laryngeal and other sites is available (20), it is possible to infer as to the type of issues and outcomes that might be reported in an ENT based long-term review clinic.

The study sample at 5- and 10-year was considered in three groups namely primary cancer reviews, those who have had a recurrence or second primary some with ORN, and a third group seen for ORN. It is not surprising that there was a change over time related to survivorship and the needs of the patients. The proportion of primary tumours reduced as this will in part be due to death from HNC or other causes related to comorbidity and age, as well as patient choice to be discharged back in to primary care for surveillance.

Of those patients under long-term review for whatever reason their overall quality of life was relatively poor with a quarter to over one third reporting less than good overall QOL. The worst overall QOL was reported in ORN patients at 10 years (39% less than good). All groups reported poor saliva function as a common dysfunction. Saliva dysfunction was highest in those with ORN at 5 years (43%) and ideally long-term survivors should have access to dental health advice and given options to attempt to alleviate their xerostomia. In terms of the UW-QOL profile the best outcomes were seen in the long-term patients reviewed for their initial primary. Anxiety levels were relatively high particularly at 5 years (17%) and it is probable that those patients opting for long-term review are likely to be more anxious than those who have been discharged back into primary care. The ORN group tended to do worse especially in respect to pain, saliva and swallowing at 5 years. The poor HRQOL of patients with ORN has previously been reported (21) and this current study helps to compare this group with other long-term clinic attendees. There were big differences in the social-emotional and the physical function subscale and this serves to highlight the multidimensional problems experienced with ORN and the impact on key aspects of HRQOL.

The findings from the PCI serve to highlight the multitude of issues that survivors experience. Some items were extremely common with more than one third of patients wishing to talk about certain concerns in spite of the long time under follow-up. The concerns point to the need for multi-disciplinary support. Aspects of oral function are common such as dry mouth, salivation, dental health, mouth opening, chewing and eating and

swallowing. These can be addressed in collaboration with appropriately trained nursing staff as well as primary dental care. Fear of recurrence (FoR) remains a commonly raised issue and supports previous findings that around one third of patients will have FoR at various time points and this is associated with co-existing anxiety or low mood (22). It seems that patients appreciate the opportunity to be checked and to maintain their link with the cancer centre. Also, HNC survivors may develop post-traumatic stress syndrome after many years post-treatment. Patients with such high levels of anxiety tend to become hypervigilant and develop reassurance seeking behaviour. Dysphagia as a recognised late effect is evident in the UW-QOL scores and PCI. There is growing evidence of radiotherapy related swallowing impairment (23) and also late xerostomia, dysphagia, and neck fibrosis (5). Lymphedema and fibrosis are common yet overlooked late effects of HNC and its therapy (6). Functional swallowing and mouth opening problems are substantial in this patient cohort more than 10 years after organ-preservation chemoradiotherapy (CRT). Patients treated with intensity-modulated radiotherapy (IMRT) had less impairment than those treated with conventional radiotherapy (8). Late radiation-induced cranial neuropathy in 10-year survivors has been reported (7). Götze *et al.* (24) identified problems in the mental health and stressed the importance of psycho-oncological survivorship-care-plans, which go beyond the time of rehabilitation. Also, attention should be given to the financial situation of patients in long-term follow-up care.

There is limited evidence concerning the duration and benefit of HNC follow-up (3–5 years or lifelong) (25). Generally, HNC survivors are discharged back to primary care after 5 years post-treatment but there is consideration given to patients' preference. Although data is lacking, it is possible that a late deterioration in QOL (10-year) in HNC survivors reported by (26), could be attributed to long-term distress associated with treatment related dysfunction and emotional concerns from being discharged from clinic review; others have reported good or better overall QOL at 10 years in a cohort where clinic review is flexible based on patient preference and there is adaption in survivorship (27).

This study highlights the complex needs of long-term HNC survivors and therefore, an approach giving priority to a multidisciplinary care involving a speech and swallowing expert, dietician, dentist, and psychologist may indeed be more relevant (28). There is a scope for the role of virtual or nurse-led long-term/late effects clinics. These clinics can serve as the first point of contact for HNC survivors

to seek help and to be directed to the appropriate team for further management. The PCI prompt list could facilitate this approach and allow for targeted inter-professional intervention based on need (29). Additional questionnaires might be helpful but are yet untested, such as the European Organisation for Research and Treatment of Cancer (EORTC) QOL cancer survivorship questionnaire (30).

In conclusion, patients attending an oral and maxillofacial oncology review clinic 5- and 10-year following cancer diagnosis report a wide range of late effects. There is potential in the long-term for a substantial number of unmet needs. The complex nature of these lends itself to a multi-disciplinary holist approach.

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University Hospital NHS Foundation Trust Audit Department (Reference 7448). Informed consent is not required as used data were collected as part of routine care.

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