Characteristics and referral of head and neck cancer patients who report chewing and dental issues on the Patient Concerns Inventory

IN BRIEF

- Emphasises the importance of dental function and access to dental care following treatment for head and neck (H&N) cancer.
- Identifies the need for close collaboration between the primary dental services and the specialist H&N centres to optimise multidisciplinary support for patients.
- Suggests that the use of checklist guided consultations assists patients in their post-treatment cancer journey.

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Background Patients experience considerable dental-related difficulties following head and neck cancer (HNC) treatment including problems with chewing, dry mouth, oral hygiene, appearance and self-esteem. These can go unrecognised in busy follow-up clinics. The Patient Concerns Inventory (PCI) is specifically for HNC patients, enabling them to select topics they wish to discuss and members of the multi-professional team they want to see. **Aim** The study aimed to identify the clinical characteristics of patients raising dental concerns on the PCI and to explore the outcome of onward referral. Assessments included the PCI and the University of Washington Quality of Life Questionnaire (UW-QOL) version 4, with clinic details collated from hospital and cancer databases. **Method** PCI data were obtained from 317 HNC patients between 2007 and 2011. Their mean age was 63 years and 60% were male. Most had oral squamous cell carcinoma and underwent surgery. The median (IQR) time from treatment to first PCI was 13 (4-42) months. **Results** Three comparison groups were identified: patients with significant chewing problems, patients without significant chewing problems who wanted to discuss dental-related concerns and patients without significant chewing problems who did not want to discuss such concerns. Fifty-two percent reported either a significant chewing problem on the UW-QOL or a wish to discuss dental-related concerns. A quarter specifically asked to talk to a dental professional. Clinical characteristics significantly associated with dental issues were stage, primary treatment and free flap reconstruction. Clinic letters were copied to only 10% of general dental practitioners (GDPs). **Conclusion** Better communication with GDPs is essential.

INTRODUCTION

Chewing, masticatory function and dental health following the treatment of HNC is of considerable importance.[1] Not only does the dentition have a positive impact on patients' health-related quality of life (HRQOL), self esteem[2,3] and appearance, teeth have a social importance too.[4] Patients requiring radiotherapy after surgery report much worse HRQOL than those having surgery alone.[5] The main difference is in pain,[6] saliva function and its impact on chewing.[7] Xerostomia and trismus tend to be persistent side effects following radiotherapy and considerable care is required to maintain dental health.[8-10] Furthermore, extractions in the field of radiotherapy may lead to osteoradionecrosis,[10] which may in turn lead to segmental mandibulectomy and bony reconstruction.

The acute management of oral cancer and subsequent rehabilitation requires considerable multidisciplinary input from both the primary- and secondary care sectors to ensure patients receive the highest standard of care.[11] This includes the patient's general dental practitioner (GDP), who, according to Fisher, refer 36% of oral cancers to secondary care.[12] Their role includes surveillance[13] and the provision of general dental treatment. The complex challenge of oral rehabilitation is sometimes a barrier to treatment and specialist referral is required.[14]

The priority that HNC patients place on dental issues and chewing is reflected in patient reported outcomes (PROMS). An example is the HRQOL questionnaire of the University of Washington in which patients consistently rank chewing as one of the top three items of importance.[15] Also in the Patient Concerns Inventory (PCI), dental-related issues were ranked second to fear of recurrence, and are the most frequent issues patients want to discuss at their follow up consultation.[16] The PCI has been shown to be a useful adjunct in clinics to help identify otherwise unmet needs,[17] such as concerns of fear of recurrence,[18] mood and anxiety,[16] appearance related issues,[19] and pain[6]. Thus far, dental-related concerns identified by the PCI in HNC clinics have not been investigated. Hence the aims of this study were to identify the clinical characteristics of those patients raising dental items on the PCI and to explore the outcome of onward referral.

METHOD

Prospective data collection from HNC patients attending routine follow-up clinics occurred between 1 August 2007 and 31 December 2011. Patients on the Liverpool oncology database were included if they were disease-free and under routine follow-up at least six weeks after completing treatment. Patients were excluded if they were before treatment, palliative, attending the clinic for other post-operative wound management or part of another clinical outcomes study. The study did not always coincide with the patient's actual first visit to clinic following

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treatment completion as the cohort consisted of a convenience sample of patients returning routinely to attend their usual oncology follow-up visits.

Touch-screen technology (TST) was used by patients before consultation to complete the PCI and the University of Washington Quality of Life Questionnaire (UW-QOL). Following registration at clinic patients were invited by a hospital volunteer to complete the TST package. TST data was collected using Microsoft Access and placed directly on to a secure hospital server and was accessible to the clinician during the consultation. The PCI is a holistic, self-reported screening tool for unmet needs/concerns. It asks patients to select issues/concerns from a checklist that they would like to discuss during their consultation. Two of these concerns relate to chewing or dental issues – 'chewing/eating' and 'dental health/teeth'. Patients are also asked to select health professionals who they would 'like to see or be referred to' and options available include dentist, dental hygienist and oral rehabilitation team. Previous work on the PCI has allocated the PCI concerns four defined PCI domains which are used in the analysis.[20]

The UW-QOL questionnaire version 4 is well established[21] and includes questions relating to 12 domains and a single six-point 'overall' QOL measure. The chewing domain is scored on a three-point scale as: (100) I can chew as well as ever, (50) I can eat soft solids but cannot chew some foods, (0) I cannot even chew soft solids. In earlier work[23] we defined a 'significant problem' with chewing as being a UW-QOL domain score of '(0) I cannot even chew soft solids'. In regard to the single item overall QOL scale, patients were asked to consider not only physical and mental health, but also other factors, such as family, friends, spirituality or personal leisure activities important to their enjoyment of life.

Details of onward referrals regarding chewing and dental health arising from consultations were obtained from clinic letters. Clinical-demographic data came from the Liverpool HNC database.

Results were analysed mainly within three patient subgroups defined by reference to whether there was a significant chewing problem reported on the UW-QOL and to whether chewing/eating/dental-health/teeth issues were selected on the PCI. The chi-squared or Fishers exact test was used to compare subgroups in regard to patient and clinical characteristics, and health professionals selected from the PCI. There were many statistical tests performed and accordingly a stricter criteria p <0.01 has been used to represent statistical significance. Missing data is reflected in the slightly varying denominators. As the UW-QOL and PCI TST package is integrated into routine clinical practice in this setting, this study was approved by the University Hospital Aintree Clinical Audit Department in the context of audit/service evaluation.

Table 1 Touch-screen responses from 297 patients to questions about chewing on the UW-QOL and dental-related concerns on the Liverpool PCI before first study attendance at clinic

	Stated on PCI that patient wished to discuss the issue of:			
	NO		YES	
	Stated on PCI that patient wished to discuss the issue of:		Stated on PCI that patient wished to discuss the issue of:	
UW-QoL CHEWING	NO	YES	NO	YES
(0) I cannot even chew soft solids	17	4	9	10
(50) I can eat soft solids but cannot chew some foods	61	29	35	29
(100) I can chew as well as ever	81	17	3	2

The shaded area represents those who had reported 'significant problems' on the UW-QOL (score of 0) or those who had raised concerns on the PCI.

RESULTS

PCI data were obtained from 317 H&N patients attending 829 clinics on 132 different clinic days from 1 August 2007 to 31 December 2011. These patients had a mean (SD) age of 63 years (12) and 60% (191) were male. Primary diagnosis was squamous cell carcinoma for 85% (262/309). Tumour site was oral cavity for 70% (215/308), pharyngeal for 21% (66/308), and other H&N locations for 9% (27/308). Tumour TN stage was advanced T3-4 for 21% (63/297) and N positive for 22% (66/297). Primary treatment was surgery alone for 56% (168/299), surgery with adjuvant radiotherapy for 35% (105/299), and (chemo) radiotherapy alone for 9% (26/299). Of those treated with surgery, 53% (140/262) had free-flaps (110 soft, 30 composite). The median (IQR) time from primary surgery (or from primary diagnosis if no surgery) to first completion of the PCI was 13 (4-42) months, n = 304. UW-QOL data were available for 297 of the 317 patients at their first PCI clinic.

At the first study clinic 13% (40/297) could not even chew soft solids (Table 1), this being regarded as a significant chewing problem as measured by the UW-QOL (Group A). There were also **39% (115) without** significant chewing problems who wanted to discuss chewing/eating/dental-health/teeth-related concerns (Group B) and 48% (142) without significant chewing problems who did not want such discussions. Notably only 58% (23/40) of those who could not even chew soft solids wanted such discussion, while 21% (22/103) of those who could chew as well as ever did want discussion. Overall, for 52% (155/297) there was either a significant chewing problem on the UW-QOL or a wish to discuss dental-related concerns. One quarter, 24% (76/317) wanted to talk with or be referred to a dentist (60), dental hygienist (15) or the oral rehab team (17). Overall, 57% (168/297) either had a significant problem with chewing, or wanted related discussion in the consultation or wanted to see a dentist, dental hygienist or the oral rehab team.

There was no significant association in relation to the three study groups by gender, age and time from primary diagnosis (Table 2). Patients with advanced clinical staging, oropharyngeal tumours, treatment by radiotherapy, free-flap surgery or worse overall UW-QOL reported more problems with chewing on the UW-QOL. There were no significant differences in patient and clinical characteristics in wanting or not wanting discussions in the absence of a significant chewing problem (that is, between groups B and C, Table 2) apart from overall UW-QOL where notably those with very good or outstanding QOL were least likely to want discussion. Patients with significant chewing problems (group A) were also the most likely to report other significant problems on the UW-QOL; notably appearance, swallowing, speech, taste, saliva, pain and anxiety (results not shown).

In regard to the number of PCI concerns overall, groups A and B raised considerably more issues to discuss than group C, the median (IQR) total being 6 (3-13), 6 (3-9) and 2 (1-5) respectively, p <0.001. The most common concerns raised by patients from the 3 groups are shown in Table 3.

With respect to choosing health professionals on the PCI the median (IQR) number chosen was 1 (0-2), 1 (0-1) and 0 (0-1) respectively, p <0.001. There were significant

Table 2 Patient and clinical factors, by patient subgroup at first study clinic

		[A] Significant chewing problem		[B] No significant chewing problem but related item(s) raised on PCI		[C] No significant chewing problem and no related items raised on PCI		P value* [A] *vs* [B] *vs* [C]	P value* [B] *vs* [C]
	Patients	%	Patients	%	Patients	%	Patients		
All patients	297	13	40	39	115	48	142	-	-
Male	177	16	28	38	68	46	81	0.33	0.80**
Female	120	10	12	39	47	51	61		
Age <55 years	75	11	8	39	29	51	38	0.59	0.71
Age 55-64 years	101	18	18	39	39	44	44		
Age 65-74 years	73	14	10	34	25	52	38		
Age 75+	48	8	4	46	22	46	22		
Squamous cell carcinoma (SCC)	244	15	37	41	100	44	107	0.01	0.04**
Other diagnosis	45	4	2	29	13	67	30		
Diagnosis not known	8		1		2		5		
Oral cavity tumour	204	12	25	42	85	46	94	0.003	0.04
Pharyngeal	60	23	14	38	23	38	23	0.10†	0.87†**
Other site***	24	-	-	21	5	79	19		
Site not known	9		1		2		6		
Clinical Tis/T1	110	1	1	40	44	59	65	<0.001	0.30
Clinical T2	106	17	18	40	42	43	46		
Clinical T3/T4	62	31	19	37	23	32	20		
Clinical T not known	19		2		6		11		
Clinical N0	217	10	21	39	85	51	111	<0.001	0.18
Clinical N1	27	19	5	52	14	30	8		
Clinical N2-3	34	35	12	26	9	38	13		
Clinical N not known	19		2		7		10		
Primary surgery only	155	5	8	39	61	55	86	<0.001	0.05
Primary surgery and RT	98	22	22	45	44	33	32		
No surgery, primary RT	26	31	8	27	7	42	11		
Treatment not known	18		2		3		13		
No free-flap	114	4	5	41	47	54	62	0.003	0.18
Soft flap	100	19	19	41	41	40	40		
Composite flap	28	21	6	50	14	29	8		
Flap status not known (if surgery)	11		-		3		8		
Within 12 months of diagnosis	141	15	21	39	55	46	65	0.79	0.98
Within 12-23 months of diagnosis	40	13	5	38	15	50	20		
Within 24-59 months of diagnosis	60	7	4	42	25	52	31		
60 or more months from diagnosis	43	16	7	40	17	44	19		
Time from diagnosis not known	13		3		3		7		
Overall UW-QOL:									
Very poor/poor	27	33	9	30	8	37	10		
Fair	57	16	9	60	34	25	14	<0.001	<0.001
Good	93	11	10	39	36	51	47		
Very good/outstanding	112	9	10	30	34	61	68		
Overall UW-QOL not known	8		2		3		3		

*Chi-squared test, excluding any not known; **Fishers exact test, excluding any not known; †oral *vs* pharyngeal;***[B] parotid (2), antrum (1), neck (1), pyriform fossa (1); [C] parotid (4), lower lip vermilion (3), upper lip vermilion (2), metastatic lymph nodes primary unknown (2), thyroid (2), forehead (1), maxillary sinus (1), occiput (1), right lower lip (1), tuberosity (1), vallecula (1)

differences between groups in regard to selecting dentist, dental hygienist, oral rehabilitation team, and speech and language therapist (Table 4). About one third of patients with significant chewing problems (group A) selected 'dentist' from the list and also one third selected 'speech and language therapist' while one third of patients without significant chewing problems but wanting discussion (group B) also selected 'dentist'.

Clinic letters after consultation were analysed for 797 of the 829 clinics. Only in 10% (76/797) of letters was the dentist (GDP) copied in, predominantly to inform (64), otherwise to review (1), or to make a request (3), unknown for 8. The requests related to fluoride, tooth smoothing and surveillance. In 23% (181/797) the oral rehabilitation team was copied in, predominantly to inform (102), to make a request (47), to review (20), about prostheses (3), for assessment before radiotherapy (4), for extractions (1) or was not stated (4). The requests were in regard to review (30), prostheses (14), photographs (1), extractions (1) and information regarding CDS (1). Only once was a clinic letter copied in to a dental hygienist. The rates of letter copying for each of the three groups are shown in Table 5.

It was estimated that three quarters of clinic patients (74%, 511/693) still had (some) natural teeth; 48% (47/97) for group A, 77% (171/223) for group B and 79% (278/353) for group C, p <0.001. There was less information available about whether patients had a (high street) dentist at the time of clinic, 86% (276/322) overall; 58% (15/26) for group A, 88% (103/117) for group B, 88% (154/175) for group C, p <0.001.

DISCUSSION

This study emphasises the importance of dental-related issues in HNC follow-up. Furthermore, the use of the PCI and HRQOL questionnaires in routine HNC clinics facilitates better post-op care by encouraging patients to raise concerns and provide the opportunity to refer to other members of the multidisciplinary team for further management. The patient's GDP is integral following treatment, and although some of the needs are complex, shared care between the primary and secondary services is ideal,[14] as the dental needs of oral cancer patients are likely to increase with improved tooth retention, cancer survivorship and an ageing population.

The cohort was comprised mainly of oral cancer patients and it is reasonable to extend the findings to HNC in general as dental-related concerns are important in early or late oropharyngeal and laryngeal tumour sites.[1] It was possible to retrieve and analyse

Table 3 Most common concerns from patients on the PCI by patient subgroup at first study clinic

[A] Significant chewing problem (40)		[B] No significant chewing problem but related item(s) raised on PCI (115)		[C] No significant chewing problem and no related items raised on PCI (142)	
Issue	%	Issue	%	Issue	%
Fear of the cancer coming back	50	Dental health/teeth	67	Fear of the cancer coming back	35
Swallowing	50	Chewing/eating	60	Pain in H&N	18
Chewing/eating	48	Fear of the cancer coming back	42	Fatigue/tiredness	17
Dental health/teeth	35	Swallowing	31	Sleeping	13
Salivation	28	Pain in H&N	30	Shoulder	12
Taste	28	Fatigue/tiredness	27	Anxiety	11
Fatigue/tiredness	26	Speech/voice/being understood	26	Mucous	10
Mucous	26	Taste	24	Salivation	10
Anxiety	25	Mouth opening	23		
Appearance	25	Salivation	23		
PEG tube	25	Pain elsewhere	22		
Speech/voice/being understood	25	Mucous	20		
Appetite	23				
Mood	23				
Shoulder	23				
Coping	22				

Table 4 PCI profile of health professionals that patients wanted to discuss issues with or be referred to, by patient subgroup at first study clinic

	[A] Significant chewing problem (40)		[B] No significant chewing problem but related item(s) raised on PCI (115)		[C] No significant chewing problem and no related items raised on PCI (142)	
Who did patient wish to talk with/be referred to;	%	Patients	%	Patients	%	Patients
CHAPLAIN	-	-	1	1	-	-
CLINICAL NURSE SPECIALIST	3	1	2	2	1	2
DENTAL HYGIENIST**	18	7	7	8	-	-
DENTIST**	33	13	30	34	8	11
DIETICIAN	10	4	6	7	1	2
NURSING STAFF	5	2	-	-	1	2
OCCUPATIONAL THERAPIST	5	2	3	3	1	1
ORAL REHABILITATION TEAM*	15	6	8	9	1	2
PHYSIOTHERAPY	8	3	6	7	4	5
RADIOTHERAPIST /ONCOLOGIST	8	3	2	2	1	2
SPEECH AND LANGUAGE THERAPIST**	30	12	9	10	3	4
SOCIAL WORKER	5	2	3	3	3	4
SURGEON	10	4	17	19	12	17
FAMILY DOCTOR	5	2	3	4	4	5
SOMEONE ELSE NOT ON THIS LIST	5	2	2	2	4	5

*0.001 <p< 0.01 [A] vs [B] vs [C] chi-squared test; **p <0.001 [A vs [B] vs [C] chi-squared test

Table 5 Copying of clinic letters after consultation

	[A] Significant chewing problem		[B] No significant chewing problem but related item(s) raised on PCI)		[C] No significant chewing problem and no related items raised on PCI	
	107 letters		241 letters		423 letters	
GP copied in	3%	3/107	13%	31/241	10%	41/423
Oral rehabilitation team copied in	33%	35/107	31%	74/241	17%	72/423

most clinic letters, imaging and clinical correspondence by accessing electronic patient records. The only difficulty was in ascertaining the dental status of some patients where radiographs and comprehensive dental charting was absent.

Just over half the patients had either a significant chewing problem on the UW-QOL or a wish to discuss related PCI concerns. Patients with significant chewing problems reported worse overall quality of life. Furthermore, a quarter of all patients wanted to talk to or be referred to a dental healthcare professional, despite admittedly limited data suggesting 86% of all patients being known to have a dentist (though this was only 58% of the patients with a significant chewing problem). Encouraging patients with significant chewing problems to obtain a dentist should be a priority to improve shared care and perhaps their chewing problems. This is especially important, as access to dental services can be problematic.[25]

Patients with advanced clinical staging, who have undergone free flap surgery or radiotherapy tended to report more chewing-related problems on the UW-QOL. While there is evidence to support this trend,[22,26] chewing difficulties will arise as a result of extensive surgical disruption to the masticatory apparatus. Duke *et al.* found that many effects of cancer treatment disappear between 12-36 months.[26] However, following radiotherapy, good oral hygiene is essential to prevent radiation-induced caries and periodontal disease, so regular fluoride supplementation and periodontal therapy is necessary.

The data obtained indicated the correlation of significant problems across the UW-QOL (appearance, swallowing, speech, taste, saliva, pain, anxiety) with significant chewing problems. Evidence suggests that worse function is associated with higher levels of anxiety, depression and coping issues.[27] Our data and evidence would suggest that improving physical function would prove significantly beneficial not only to physical parameters, but also to social-emotional parameters.

Significant chewing problems were found more commonly in the edentulous, and there is a role for oral rehabilitation in selected patients.[28] Evidence demonstrates a psychological morbidity associated with those who don't receive oral rehabilitation.[1] Furthermore, implant rehabilitation has shown to improve quality of life.[29,30] Therefore, it would be prudent to consider all edentulous patients for oral rehabilitation to improve their functional and potential psychological morbidities.

The vast majority of clinical letters (96%) from the clinic were scrutinised and only in 10% of cases were GDPs included in correspondence. Interestingly, the patients with significant chewing problems had the least correspondence with the GDP (3%). Probably the commonest reason for the unit failing to correspond with the GDP is a deficit in recording the details of the GDP at initial referral and during at follow-up appointments. Communication difficulties have proven a problem for healthcare professionals involved in HNC care,[31] with inadequate communication providing a barrier to the provision of dental care.[32] What further complicates matters is that patients often visit their GP to report oral lesions.[33] The patient's GDP has a clear role in surveillance for recurrence or second primary HNC. The management of oral cancer requires a variety of healthcare professionals and relies on effective communication between them. In this study, despite dental-related problems being highlighted in clinic, the correspondence to the patient's dentist was poor. This needs to be rectified and a protocol has been developed in the unit by which all patients are routinely asked about the details of their dentist, in the same way as they are for their doctor. A re-audit is planned to monitor improvements in correspondence to the patient's GDP.

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