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Issues patients would like to discuss at their review consultation: variation by early and late stage oral, oropharyngeal and laryngeal subsites

A. Kanatas · N. Ghazali · D. Lowe · M. Udberg · J. Heseltine · E. O'Mahony · S. N. Rogers

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Abstract Purpose: The patient concerns inventory (PCI) was developed to help patients raise issues/concerns during routine follow-up and to indicate team members they want to see. This paper reports the use of the PCI across various H&N Cancer sub-sites (oral, oropharyngeal and laryngeal) and stages of disease (early and late) and describes the main concerns that patients want to discuss using a cross-sectional survey comprising the PCI with the University of Washington Quality of Life questionnaire. Patients treated for primary H&N squamous cell carcinoma, 1998–2009, were identified from the University Hospital Aintree H&N Cancer database. 447/775 (58 %) patients responded. Fear of recurrence concerns was common to all clinical groups (range 32–67 %). Speech issues were more common with laryngeal tumours, and saliva issues with oropharyngeal tumours (32 % early, 48 % late). Apart from early-stage laryngeal tumours, patients consistently reported issues concerning dental health/teeth and chewing. The median (IQR) number of concerns overall was 4 (2–7), with significant variation ($p < 0.001$) between clinical groups ranging from 2 (1–6) for early-stage oral to 6 (2–10) for late-stage oropharyngeal and 7 (5–9) late-stage laryngeal. The results indicated that PCI can be readily incorporated into managing HNC patients and supports a holistic multidisciplinary approach to clinic consultations. It accommodates difficult issues such as fear of recurrence and intimacy. Completion of the PCI by patients before consultation can highlight problems and concerns that doctors can target for discussion, thereby streamlining consultations, and ensuring that patient needs are better met, thus creating a more effective service.

Keywords Patient concerns inventory · Oncology · Patient reported outcomes

Introduction

Head and neck cancer (HNC) is defined as cancer of tissues or organs of the head and/or neck and includes mainly oral, oropharyngeal, laryngeal and oesophageal cancers [1]. The treatment employed is dependent on tumour site and stage and often involves a combination of surgery, chemotherapy and radiotherapy. There is evidence of improved survival following HNC and emphasis has been given to patient-

A. Kanatas (✉)
Oral and Maxillofacial Surgery Department, Leeds Teaching Hospitals and St James Institute of Oncology, Leeds, UK
e-mail: a.kanatas@doctors.org.uk

N. Ghazali · D. Lowe · S. N. Rogers
Regional Head and Neck Unit, University Hospital Aintree, Lower Lane, Liverpool L9 7AL, UK
e-mail: naseemghazali@doctors.org.uk

D. Lowe
e-mail: astraglobeltd@btconnect.com

S. N. Rogers
e-mail: snrogers@doctors.org.uk

D. Lowe · S. N. Rogers
Faculty of Health, Evidence-Based Practice Research Centre (EPRC), Edge Hill University, St Helens Road, Ormskirk L39 4QP, UK

M. Udberg · J. Heseltine · E. O'Mahony
Faculty of Medicine, University of Liverpool, Liverpool L69 3BX, UK
e-mail: m.udberg@gmail.com

J. Heseltine
e-mail: jonnyhes@hotmail.co.uk

E. O'Mahony
e-mail: E.M.Omahony@student.liverpool.ac.uk

reported outcomes (PRO) which reflect patients' cancer experience [2–5]. More recently there has been emphasis on people living with and beyond cancer with a focus on personalised care planning and follow-up. Nevertheless, many sufferers experience high levels of unmet needs [6–8]. For HNC patients these unmet needs include psychological distress, financial concerns, appearance issues and intimacy issues, which patients and carers often find more difficult to discuss and assess [9, 10].

HNC-specific Health-Related Quality of Life (HRQOL) questionnaires, such as the University of Washington QOL questionnaire (UW-QOL), can be used for screening [11], but the focus is on the common items such as speech, swallowing, mood and anxiety. The development of assessment tools alongside health-related quality of life assessments in cancer patients is important because HRQOL questionnaires tend to lack the breadth of potential issues of concern and needs of patients during their cancer journey. Other assessment tools like the patient concerns inventory (PCI) can help focus the consultation towards patient needs and promote multidisciplinary care [12–16]. The purpose of the PCI is to allow patients to raise issues that they would like to discuss during their consultation. In the HNC setting, the PCI covers a range of issues including hearing, intimacy, fatigue, financial/benefits, PEG tube, relationships, regret, support for family and wound healing. It also lists multidisciplinary team (MDT) members (tumour board) for patients to see or be referred on to. The practicality of the PCI is enhanced by self-completion using a touch-screen computer (TST) immediately before the consultation [12], making it suitable for routine use in outpatient settings. The PCI is a tool for getting the best use of time from the consultation between patient and consultant with potential benefits to both as it aids doctor–patient communication by focusing on important issues for the patient. So far the development of the PCI has been focused on a one-consultant practice, where early oral cancer patients predominated. The aim of this paper was to report the use of the PCI across various HNC sub-sites (oral, oropharyngeal and laryngeal) and stages of disease (early and late), and to describe the main concerns that these patients want to discuss in their clinic appointments.

Methods

Patients treated for primary head and neck squamous cell carcinoma between 1998 and 2009 were identified from the University Hospital Aintree Head and Neck Cancer database. Patients with cutaneous and salivary gland malignancy, treated with palliative intent, current recurrence or ongoing disease, aged over 85 years of age, with cognitive impairment, living overseas or previously declining to participate in further studies were excluded. Mortality status was tracked via the office of national statistics (ONS). A questionnaire package was distributed in February 2011 with a reminder sent in April 2011. The package contained a covering letter about the survey, consent form, instructions on completing the questionnaires, a stamped addressed envelope, and the questionnaires—the University of Washington Quality of Life questionnaire (UW-QOL) and the PCI.

Questionnaire content

The UW-QOL questionnaire is well established [17, 18]. The UWQOL instrument has been included in this study to evaluate the clinically distinct groups in terms of differences in quality of life. For this study the UW-QOL v4 was analysed in terms of its two subscale composite scores, 'physical function' and 'social-emotional function' as well as a single six-point scale 'overall' QOL measure. Physical function is the simple average of the swallowing, chewing, speech, saliva, taste and appearance domain scores whilst social-emotional function is the simple average of the activity, recreation, pain, mood, anxiety and shoulder domains. 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.

On the PCI patients were asked, 'If you were to attend a clinical consultation today which of the following 55 concerns would you wish to discuss with your head and neck cancer consultant/doctor?' The Yes/No options were arranged alphabetically and were not grouped. Furthermore, patients could tick 'Other' and suggest concerns that were not listed. Next, patients were asked, 'If you were to attend a clinical consultation today which of the following members of staff would you like to see or be referred on to?' There were 14 types of health professional listed and patients could add 'others' not on the list.

Patients were also asked if they ever had radiotherapy as part of their HNC.

Statistical analysis

Results were analysed within clinical subgroups defined by tumour site (oral, oropharyngeal, laryngeal, other (unknown primary) and overall clinical stage (early-stage disease = 0–2, late-stage disease = 3–4) based on the clinical tumour, node, metastases (TNM) classification [19]. The Chi-squared test compared the clinical subgroups with regard to response rate and categorical patient characteristics at the time of survey. The Kruskal–Wallis test compared the clinical subgroups in regard to age, months from primary treatment, UW-QOL overall QOL, UW-QOL subscale scores, number of PCI concerns raised and number of staff members selected. Statistical analyses were performed using SPSS software version 19. Ethical approval for the survey was obtained from the Sefton Research Ethics Committee.

Results

The response to the survey overall was 58 % (447/775) with no notable variation in response ($p = 0.29$) between the seven clinical groups (range 51–64 % in response, Table 1). There was a significant difference ($p = 0.004$) in response by age group with a lower 45 % response from patients aged under 55 years and 57–64 % response in the three older age groups. There was no notable variation in response for other clinical/patient factors listed in Tables 1 and 2, with responses of 52–64 % across all the clinical subgroups. There were considerable differences in how patients in these groups were treated when they first presented, particularly in the increased use of radiotherapy for late-stage tumours and in the increased use of free-flap surgery for late stage oral tumours (Table 1).

The clinical groups were similar in their times from first treatment when surveyed, but there were significant differences in regard to sex, age, whether patients had ever had radiotherapy as part of their head and neck cancer and in quality of life (Table 2). Oropharyngeal tumour patients were notably younger, whilst later-stage patients were much more likely to have had head and neck radiotherapy and also to report much worse levels of quality of life particularly in physical functioning. In regard to the median UWQOL composite scores presented in Table 2, it is relevant to note that in a previous study [20] of non-cancer

Table 1 Response to the survey and responder clinical/treatment profile at time of primary treatment, by clinical group

	Oral				Oropharyngeal				Laryngeal				Other sites[a]	
	Early stage		Late stage		Early stage		Late stage		Early stage		Late stage			
	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*
Questionnaires sent to		239		111		62		140		128		58		37
Response	57	136	51	57	55	34	64	90	60	77	60	35	49	18
Specialty														
MFU	98	133	98	56	56	19	30	27	–	–	6	2	39	7
ENT	2	3	2	1	44	15	70	63	100	77	94	33	61	11
Clinical T														
Tis/1	62	84	9	5	38	13	14	13	66	51	11	4	33	6
2	38	51	18	10	62	21	33	30	34	26	9	3	22	4
3	–	–	14	8	–	–	20	18	–	–	37	13	–	–
4	–	–	60	34	–	–	31	28	–	–	40	14	22	4
NK	1	1	–	–	–	–	1	1	–	–	3	1	22	4
Clinical *N*														
0	100	136	51	29	100	34	17	15	100	77	51	18	28	5
1	–	–	30	17	–	–	21	19	–	–	26	9	17	3
2-3	–	–	19	11	–	–	62	56	–	–	20	7	50	9
NK	–	–	–	–	–	–	–	–	–	–	3	1	6	1
Primary treatment														
Surgery alone	82	112	44	25	50	17	19	17	51	39	29	10	28	5
Surgery + RT[b]	16	22	54	31	41	14	46	41	14	11	49	17	61	11
Primary RT[b]	1	2	2	1	9	3	36	32	35	27	23	8	11	2
Free-flap														
None	65	88	12	7	71	24	72	65	96	74	83	29	72	13
Soft	33	46	42	24	29	10	24	22	3	2	17	6	17	3
Composite	1	2	46	26	–	–	3	3	1	1	–	–	11	2

[a] Other sites comprised metastatic lymph nodes 7/19, neck occult primary 4/7, neck unknown primary 2/3, maxillary antrum 2/2, maxillary sinus 1/2, maxillary tuberosity 1/2, nasal cavity 1/1, valecula 0/1

[b] Includes chemo/RT

Table 2 Responder characteristics at the time of survey, by clinical group

	Oral				Oropharyngeal				Laryngeal				Other sites[a]		*p* value[b]
	Early stage		Late stage		Early stage		Late stage		Early stage		Late stage				
	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	
Time from primary treatment															
12–23 months	17	23	25	14	18	6	28	25	23	18	23	8	22	4	0.12
24–59 months	44	60	39	22	53	18	47	42	55	43	43	15	56	10	
≥60 months	39	53	37	21	29	10	26	23	21	16	34	12	22	4	
Median months		50		47		44		41		33		48		41	
Sex															
Male	60	82	65	37	56	19	80	72	91	70	80	28	56	10	<0.001
Female	40	54	35	20	44	15	20	18	9	7	20	7	44	8	
Age at survey															
<55	15	21	11	6	18	6	24	22	4	3	11	4	11	2	<0.001
55–64	27	37	32	18	44	15	46	41	30	23	49	17	61	11	
65–74	41	56	39	22	29	10	22	20	47	36	31	11	11	2	
75+	16	22	19	11	9	3	8	7	19	15	9	3	17	3	
Median age	67	68	62	62	68	64	60								
Ever had RT as part of H&N cancer															
No	68	90	40	22	41	14	2	2	41	30	12	4	6	1	<0.001
Yes	31	42	60	33	59	20	98	85	59	44	88	30	94	16	
UWQoL physical function															
<50	4	6	19	11	12	4	20	18	1	1	9	3	6	1	<0.001
50–69	15	20	40	23	29	10	38	34	12	9	53	18	22	4	
70–89	35	47	28	16	32	11	34	31	26	20	32	11	50	9	
90+	46	62	12	7	26	9	8	7	61	47	6	2	22	4	
Median score	87	68	78	64	94	67	84								
UWQoL social-emotional function															
<50	2	3	14	8	15	5	11	10	3	2	20	7	17	3	<0.001
50–69	18	24	23	13	21	7	18	16	12	9	23	8	11	2	
70–89	40	54	40	23	35	12	47	42	52	40	51	18	39	7	
90+	40	54	23	13	29	10	24	22	34	26	6	2	33	6	
Median score	83	74	77	78	83	73	80								
Overall UW-QOL															
Very poor	1	1	2	1	3	1	1	1	–	–	–	–	–	–	0.001
Poor	4	5	2	1	9	3	4	4	3	2	14	5	–	–	
Fair	11	15	30	17	26	9	28	25	18	14	31	11	22	4	
Good	41	55	40	23	24	8	32	29	30	23	31	11	28	5	
Very good	37	50	26	15	35	12	31	28	45	34	23	8	33	6	
Outstanding	7	9	–	–	3	1	3	3	4	3	–	–	17	3	

A very small number did not answer specific parts of the questionnaire and are excluded from the table

[a] See Table 1

[b] Chi-squared test for sex and if ever had radiotherapy (RT) as part of H&N cancer, otherwise the distributions of actual values (ordinal scores for overall QoL) are compared using the Kruskal–Wallis test

persons routinely attending general dental practice we reported median (IQR) normative scores of 100 (95–100) for physical function and 90 (74–100) for social-emotional function. Using these as reference values then the deficits reported by patients in this study for physical function are of a far greater magnitude than deficits for social-emotional function. Overall, in response to the question about the PCI the ten most prevalent concerns that patients wanted to discuss in clinic were fear of the cancer coming back (39 %, 174), dental health/teeth (28 %, 123), chewing/

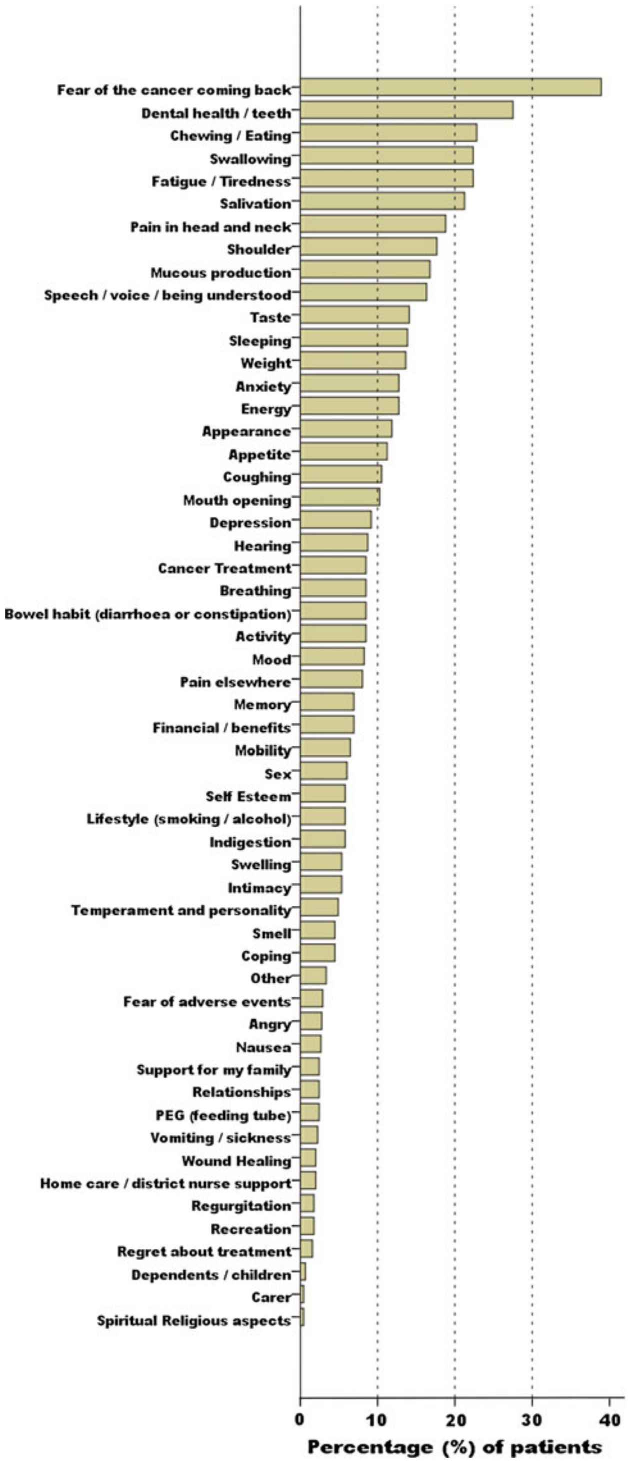

Fig. 1 Patient concerns inventory (PCI): percentage response to each concern when patients were asked ‘If you were to attend a clinical consultation today which of the following 55 concerns would you wish to discuss with your head and neck cancer consultant/doctor?’ ($N = 447$ patients)

eating (23 %, 102), swallowing (22 %, 100), fatigue/tiredness (22 %, 100), salivation (21 %, 95), pain in head and neck (19 %, 84), shoulder (18 %, 79), mucous production (17 %, 75) and speech/voice/being understood (16 %, 73); the full range is shown in Fig. 1. The ten most prevalent concerns of each clinical group are shown in Table 3. Fear of recurrence concerns were reported consistently by one-third or more patients (range 32–67 %) and were the dominant concerns of patients with early-stage tumours. For late-stage patients fear of recurrence was just one of many concerns of similar prevalence. Speech issues were more often raised by patients with laryngeal tumours than by other patients whilst issues relating to saliva were particularly common for patients with oropharyngeal tumours (32 % early, 48 % late). Apart from early-stage laryngeal tumours, patients consistently reported issues concerning dental health/teeth and chewing. The median (IQR) number of concerns raised overall was 4 (2–7) and there was significant variation ($p < 0.001$) between clinical groups ranging between 2 (1–6) for early-stage oral to 6 (2–10) for late-stage oropharyngeal and 7 (5–9) late-stage laryngeal.

Overall, the members of staff that patients would like to see at clinic or be referred on to are summarised in Fig. 2, with the five most common per clinical group shown in Table 4. Wanting to see the surgeon was dominant (range 26–44 %) across all clinical groups apart from late-stage laryngeal patients. Surgeon, dentist or dental hygienist, clinical nurse specialist, speech and language therapist, dietician and radiotherapist/oncologist consistently occupied the top five selections made by these clinical groups. The median (IQR) number of staff members selected overall was 1 (0–2) with little difference between clinical groups.

Discussion

This cross-sectional study using the PCI and UW-QOL in HNC survivors identified a common issue they wished to have addressed in clinic, namely fear of recurrence (FoR). FoR is a common concern of patients that is not possible to identify based on clinical parameters [13] and it is an issue that does not come readily into discussion during the clinical consultation. Evidence [13] would suggest that FoR is unrelated to the stage of disease at presentation or to specific treatment. The PCI may thus be a valuable tool to allow patients to express this concern.

Other issues common to all sub groups apart from early laryngeal were in relation to dental health/teeth/chewing. These issues were expected and highlighted the importance of oral function and aesthetics for feeding as well as body image, self esteem and social interaction. The PCI identified concerns mainly related to function. Physical function impacts most profoundly in late-stage disease subgroups and these patients selected a greater number and wider

Table 3 The ten most common concerns raised by patients on the PCI within each of the seven clinical groups

Rank	Oral				Oropharyngeal				laryngeal				Other sites ($n = 18$)	
	Early stage ($n = 136$)		Late stage ($n = 57$)		Early stage ($n = 34$)		Late stage ($n = 90$)		Early stage ($n = 77$)		Late stage ($n = 35$)			
	Item	%	Item	%	Item	%	Item	%	Item	%	Item	%	Item	%
1	Fear of the cancer coming back	38	Fear of the cancer coming back	32	Fear of the cancer coming back	44	Salivation	48	Fear of the cancer coming back	42	Swallowing	43	Fear of the cancer coming back	67
2	Dental health/teeth	30	Dental health/teeth	32	Swallowing	32	Chewing/eating	40	Speech/voice/being understood	27	Speech/voice/being understood	40	Appearance	33
3	Chewing/eating	19	Chewing/eating	28	Salivation	32	Swallowing	38	Fatigue/tiredness	19	Fatigue/tiredness	40	Dental health/teeth	33
4	Fatigue/tiredness	17	Taste	23	Fatigue/tiredness	26	Fear of the cancer coming back	37	Coughing	18	Coughing	40	Moth opening	22
5	Pain in head and neck	15	Swallowing	23	Dental health/teeth	21	Dental health/teeth	34	Breathing	14	Mucous production	37	Shoulder	17
6	Sleeping	15	Fatigue/tiredness	19	Chewing/eating	21	Pain in head and neck	30	Mucous production	14	Fear of the cancer coming back	37	Self-esteem	17
7	Shoulder	14	Appetite	19	Shoulder	18	Taste	29	Cancer treatment	13	Dental health/teeth	34	Salivation	17
8	Weight	13	Speech/voice/being understood	18	Pain in head and neck	18	Shoulder	29	Weight	13	Appetite	29	Pain in head and neck	17
9	Swallowing	13	Salivation	16	Pain elsewhere	15	Fatigue/tiredness	28	Swallowing	12	Pain in head and neck	29	Fatigue/tiredness	17
10	Speech/voice/being understood	13	Pain in head and neck	16	Mucous production	15	Mucous production	26	Shoulder	12	Weight	26	NINE different concerns	Each 11
	Salivation	13	Mucous production	16	Anxiety	15					Shoulder	26		
			Anxiety	16	Depression	15					Chewing/eating	26		
Total number of concerns per patient:														
Median (IQR)	2 (1–6)		4 (2–6)		4 (3–6)		6 (2–10)		3 (1–6)		7 (5–9)		4 (3–6)	
Mean	4.1		5.4		4.5		6.7		3.9		7.5		4.3	

range of items on the PCI. In patients with laryngeal site, speech issues were more common. Saliva is a significant issue in UW-QOL and was inconsistently reported on the PCI across site and stage. It was a key issue for one-third of patients with early oropharyngeal tumours and for one-half with late-stage oropharyngeal tumours. However, in spite of the myriad of issues that patients would like to raise in their consultation, there were relatively few referral requests specific to MDT (tumour board) persons. Previous work [15] concluded that the use of the PCI enabled patient issues to be adequately addressed in the clinic with little need for additional onward referrals to colleagues in the MDT (tumour board).

Patients with more advanced cancer suffer more cancer-induced tissue destruction and also require more radical treatment, which may inflict further damage. This implies that more advanced cancer results in a greater deficit in function and thus a greater list of healthcare needs, and this was reflected by these patients in this study raising more concerns on the PCI that they would want to discuss.

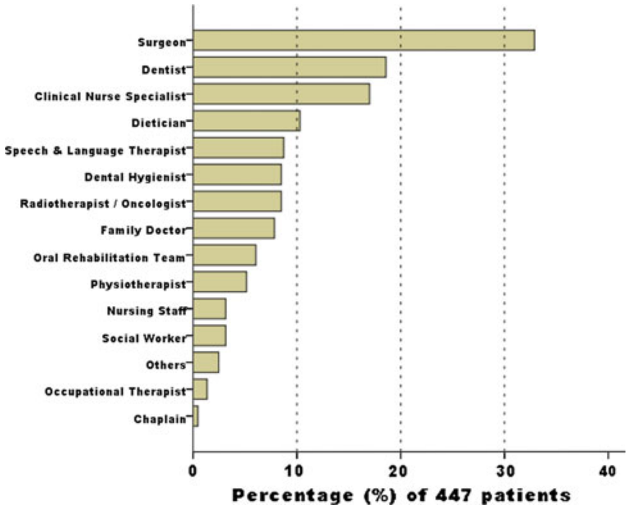

Fig. 2 Members of staff (PCI): percentage response to each member when patients were asked 'If you were to attend a clinical consultation today which of the following members of staff would you like to see or be referred on to? ($N = 447$ patients)

So far the PCI has been shown to be acceptable in routine patient care in HNC, integrating into routine outpatient review [14]. The average length of consultation is unaffected when compared with the standard traditional clinic even with the extra and diverse issues that are raised and that traditionally would not be discussed, for example, fear of recurrence or intimacy [15]. The introduction of the head and neck PCI has shown high levels of patient satisfaction and has promoted more holistic MDT support [14, 15].

It is recognised that there are some deficiencies in this study. The response to the survey overall was 58 % and although this is in line with surveys reported in the literature some caution is required in the interpretation of the findings. Also, it was a cross-sectional study and thus unable to provide an insight into changes over time especially since the patients were at different points of time within and beyond their own 5-year follow-up regime. Also patients were asked to raise issues as if they were coming to the clinic and hence the outcomes may not be representative of being asked whilst at clinic. However, the findings in this study are consistent with those found in previous work where the PCI was used by just one consultant with oral cancer patients [15].

The PCI is a tool that can be readily incorporated into the management of HNC patients and supports a holistic approach to clinic consultations. In a busy clinical environment it can quickly identify issues that patients want to talk about. Patients want to discuss a wide range of issues and if these go undetected and not discussed there could be an adverse effect on patient satisfaction and HRQOL. Completion of the PCI by patients before their consultation can highlight problems and concerns that doctors can target

Table 4 The five members of staff that patients would want most to see or be referred on to, by clinical group

Rank	Oral				Oropharyngeal				Laryngeal				Other sites ($n = 18$)	
	Early stage ($n = 136$)		Late stage ($n = 57$)		Early stage ($n = 34$)		Late stage ($n = 90$)		Early stage ($n = 77$)		Late stage ($n = 35$)			
	Member	%	Member	%	Member	%	Member	%	Member	%	Member	%	Member	%
1	Surgeon	32	Surgeon	44	Surgeon	32	Surgeon	29	Surgeon	35	Clinical nurse specialist	40	Surgeon	33
2	Dentist	19	Dentist	16	Dental Hygienist	18	Dentist	22	Clinical nurse specialist	19	Dentist	31	Dentist	22
3	Clinical nurse specialist	10	Clinical nurse specialist	16	Dentist	15	Clinical nurse specialist	19	Speech and language therapist	14	Speech and language therapist	31	Clinical nurse specialist	22
4	Dietician	12	Speech and language therapist	12	Clinical nurse specialist	9	Radiotherapist/oncologist	18	Family doctor	12	Surgeon	26	Oral rehabilitation team	17
5	Dental hygienist	9	Dietician	11	Occupational therapist	6	Dietician	17	Radiotherapist/oncologist	12	Dietician	14	Dental hygienist	11
					Nursing staff	6							Radiotherapist/oncologist	11
					Family doctor	6								
					Dietician	6								
Total number selected per patient:														
Median (IQR)	1 (0–2)		1 (1–1)		1 (0–2)		1 (0–2)		1 (1–2)		2 (1–3)		1 (0–0.2)	
Mean	1.1		1.4		1.2		1.6		1.2		1.9		1.2	

for discussion, thereby streamlining consultations, promoting multidisciplinary care and ensuring that patient needs are better met, thus creating a more effective service.

Conflict of interest The authors have no conflict of interest to declare.

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