Diagnostic pathway of head and neck cancer patients in Ireland: audit of patterns of first attendance 1983-2019

Précis

Many Irish head and neck cancers (66%) are advanced at diagnosis. General medical practitioners are generally (75%) the first healthcare professional attended. The dental referral pathway remains under utilised.

Abstract

Objectives: This audit explores patterns of head and neck cancer (HNC) patient presentation in primary care in Ireland over four decades and reflects on the possible impact of a 10-year national HNC awareness campaign.

Materials and methods: Trends in patient presentation and diagnosis are presented for 920 HNC patients across three time periods: 1983-1990; 2010; and, 2018-2019. Descriptive analysis was undertaken using SPSS-v27 on basic demographic details, tumour-related details and primary care referral patterns.

Results: Patients were generally male (71%), aged 54+ (71%), and 84% were diagnosed with squamous cell carcinoma (SCC). Larynx, tongue and tonsil were the most common sub-sites. General medical practitioners (GPs) were the first healthcare contact for 75% of cases, with only 13% referred by general dental practitioners (GDPs). This pattern remained consistent across four decades. The GDP's role was higher for tongue, floor of mouth and intra-oral tumours (30-47%), with some increase seen in recent years. While symptomology varied by site, symptom burden remained high across the decades with 99.9% exhibiting 1+ National Institute for Health and Care Excellence (NICE) 'red flag signs' of HNC, suggesting considerable diagnostic delay despite a 10-year national campaign to raise public and professional awareness.

Conclusions: This audit highlights the role of GPs in HNC diagnosis, but reveals suboptimal use of the dental pathway. The high symptom burden reported suggests considerable diagnostic delay. Increased and sustained efforts are required to raise public and professional awareness, encourage regular dental attendance, upskill healthcare professionals in opportunistic screening, and ensure appropriate responses to symptomatic patients.

Key words: Head and neck cancer (HNC), mouth/oral cancer, referral and diagnostic pathway, general medical practitioner (GP), general dental practitioner (GDP), awareness, diagnostic delay, symptoms, National Cancer Registry Ireland (NCRI), early detection.

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Introduction

Head and neck cancer (HNC) is a diverse disease incorporating malignant tumours of 17 sub-sites that play a vital role in many aspects of normal everyday life: talking, smiling, eating, swallowing. HNC incidence is increasing worldwide with 700,000+ new cases (3.9% of cancer registrations) and 350,000+ deaths (3.8% of cancer deaths) recorded in 2018.[1] In Ireland, over

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Table 1: Overview of 920 HNC cases x year x sex, age, histology, referral, symptoms.

Variable	Sub-groups	2018/19	2010	1983-90	Total
Sex	M	268 (73%)	132 (72%)	256 (69%)	656 (71%)
	F	99 (27%)	51 (28%)	114 (31%)	264 (29%)
Age	15-44	14 (4%)	18 (10%)	19 (5%)	51 (6%)
	45-54	77 (21%)	41 (22%)	96 (26%)	214 (23%)
	55-64	130 (35%)	54 (30%)	101 (27%)	285 (31%)
	65-74	102 (28%)	46 (25%)	117 (32%)	265 (29%)
	75+	44 (12%)	24 (13%)	37 (10%)	105 (11%)
Histology	SCC	327 (89%)	154 (84%)	285 (77%)	766 (84%)
	Lymphoma	7 (2%)	7 (4%)	30 (8%)	44 (4%)
	Salivary gl.	14 (4%)	12 (7%)	19 (6%)	47 (5%)
	Other[a]	19 (5%)	10 (5%)	36 (9%)	65 (7%)
Referral source[2]	GP	282 (77%)	149 (81%)	153 (66%)	584 (75%)
	GDP	49 (13%)	20 (11%)	35 (15%)	104 (13%)
	Pharmacy	0 (-)	0 (-)	-	-
	A&E/ENT	23 (6%)	11 (6%)	44 (19%)	94 (12%)
	IP/consultant	13 (4%)	3 (2%)	232/370[b]	Total = 782
Main presenting	Ulcer	24 (7%)	16 (8%)	71 (19%)	111 (12%)
complaint	Hoarseness	37 (10%)	23 (13%)	18 (5%)	78 (8%)
	Dysphagia	37 (10%)	16 (9%)	56 (15%)	109 (12%)
	Pain	88 (24%)	37 (20%)	141 (38%)	266 (29%)
	Neck node	98 (27%)	55 (30%)	24 (6%)	177 (19%)
	Lump/swelling	52 (14%)	23 (13%)	32 (10%)	107 (12%)
	Other[c]	31 (8%)	13 (7%)	28 (8%)	72 (8%)

a Other: Merkel cell, sarcoma, melanoma, anaplastic carcinoma, medullary carcinoma, neuroendocrine, BCC, histiocytoma, mesoepithelioma, schwannoma
b Referral source: 1983-90 source recorded for 232/370
c Other symptoms: Dental issue, lip/face lesion, white lesion, stridor, globus, haemorrhage, excess phlegm, incidental X-ray finding, cough, dyspnoea, blocked nose.

700 people are diagnosed with HNC annually, with 202 cases of mouth cancer, 162 of laryngeal cancer, and 147 pharyngeal cancers;[2] HNC incidence rates increased by 119% in females and 76.3% in males from 2001 to 2010.[3] HNC cases in Ireland are projected to increase by 2,045 (+65%) in males, and by 67% in females.[4] Incidence of mouth cancer has recently increased by 3.3% per annum in women, while oropharyngeal cancer in men increased by 2.5% annually. HNC is still more common in males, particularly laryngeal cancer (7:1), followed by cancer of the mouth and pharynx at 3:1.[2,5]

HNC is a major public health issue due to the high mortality (c.50%) and immense morbidity associated with this disease. In Ireland, four people die every week from HNC and over 2,600 people are living with the consequences:[6] disfigurement; speech impairment; dysphagia; dry mouth; mucositis; rampant caries; trismus; fibrosis; pain; and, osteoradionecrosis.[7,8]

Early detection of HNC improves outcomes and quality of life. Stage of disease at presentation is the single most important prognostic factor in HNC; average five-year survival rates fall from 80% for localised disease, to 30% when regional or distant metastases are present.[9] Patterns of late presentation for HNC have shown little change in four decades, with c.70% of all HNC patients still diagnosed with advanced disease in Ireland and internationally.[2,10,11] This study explores: (i) HNC presentation patterns in primary care in Ireland from 1983-2019; and, (ii) the possible impact of a national HNC awareness campaign on referral patterns.

Materials and methods

The diagnostic pathway for 920 Irish HNC patients was explored across three specific time periods, combining a clinical audit of 550 consecutive new patients referred to the dental oncology clinics in Cork University Dental School and Hospital (CUDSH) and the Dublin Dental University Hospital (DDUH) in 2010 (n=183) and 2018/2019 (n=367), with a retrospective chart review of 370 HNC cases recorded by the Southern Tumour Registry (STR), the forerunner to the National Cancer Registry Ireland (NCRI), for historical comparison.[10,12]

Descriptive analysis was undertaken using SPSS-v27 on basic demographic details, tumour-related details, and primary care referral patterns. Ethical approval was not required as clinical audits involve nothing beyond normal clinical management.

Results

HNC incidence was consistently higher in males, ranging from 69-73% in this series. HNC was recorded in 6% of people under 45 years, with 60% in the 55- to 74-year range.

The most common morphologies were: squamous cell carcinoma (SCC) (84%); salivary cancers (5%); and, lymphomas (4%). Main sites were: oral cavity (40%); larynx (19%); pharynx (16%); and, salivary glands (10%) (**Table 1**).

Table 2: Patterns of referral in 2010 and 2018/2019.

	2010 (n=183)								2018/2019 (n=367)							
SITE	GP		GDP		Hospital[a]		Total		GP		GDP		Hospital		Total	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Lip/face	12	(92%)	0		1	(8%)	13	(7%)	31	(97%)	0	(-)	1	(3%)	32	(9%)
BoT	9	(75%)	1	(8%)	2	(16%)	12	(7%)	27	(87%)	2	(6.5%)	2	(6.5%)	31	(8%)
Tongue	14	(67%)	6	**(29%)**	1	(5%)	21	(11%)	19	(41%)	18	**(39%)**	9	(29%)	46	(13%)
FOM	7	(70%)	3	**(30%)**	0	(-)	10	(6%)	6	(46%)	4	**(30%)**	3	(23%)	13	(4%)
Palate/mouth/upper/ lower gum	8	(53%)	7	**(47%)**	0	(-)	15	(8%)	7	(27%)	16	**(62%)**	3	(12%)	26	(7%)
Salivary	18	(100%)	0	(-)	0	(-)	18	(10%)	33	(89%)	1	(3%)	3	(8%)	37	(10%)
Tonsil	15	(88%)	1	(6%)	1	(6%)	17	(9%)	46	(94%)	1	(2%)	2	(4%)	49	(13%)
Oropharynx	11	(85%)	1	(8%)	1	(8%)	13	(7%)	11	(61%)	6	**(33%)**	1	(6%)	18	(5%)
Nasopharynx	6	(86%)	1	(14%)	0	(-)	7	(4%)	11	(79%)	1	(7%)	2	(14%)	14	(4%)
Hypo/piriform	8	(80%)	0	(-)	2	(20%)	10	(5%)	17	(94%)	0	(-)	1	(6%)	18	(5%)
Larynx	31	(89%)	0	(-)	4	(13%)	35	(19%)	57	(89%)	0	(-)	7	(11%)	64	(17%)
Nodes	7	(78%)	0	(-)	2	(22%)	9	(5%)	12	(86%)	0	(-)	2	(14%)	14	(4%)
Other sites[b,c]	3	(100%)	0	(-)	0	(-)	3	(2%)	5	(100%)	0	(-)	0	(-)	5	(1%)
All cases	**149**	**(81%)**	**20**	**(11%)**	**14**	**(8%)**	**183**	**(100%)**	**282**	**(77%)**	**49**	**(13%)**	**36**	**(10%)**	**367**	**(100%)**

a In-patient, other consultant, ENT/A&E
b Accessory sinus (2010)
c Thyroid 3; middle ear 1; vagus 1 (2018/2019)

Patterns of referral/presentation

Referral source was available for all patients from 2010/2018-2019, with lower levels of detail available for 1983-90, equating to 85% of the entire cohort (782/920). General medical practitioners (GPs) were the most common referral source (75%) and 12% were diagnosed following self-presentation to accident and emergency or ear, nose and throat (ENT) departments, casualty or inpatient stay. One in seven (13%) were referred by a general dental practitioner (GDP), ranging from 15% in 1983-90 to 13% in 2018/19 (**Table 1**). Referral patterns show marked inter-site variation. In 2010 and 2018/19, patients with lip, salivary gland, base of tongue, tonsil, pharyngeal, laryngeal and nodal cancers were referred almost exclusively by GPs or hospital doctors. In 2010, 30% of tongue/floor of mouth cancers and 47% of gum and palate/mouth cancers were initially detected by GDPs (**Table 2**). However, in 2018-19, the role of GDPs increased, referring 62% of gum/palate/mouth, 39% of tongue, 33% of oropharyngeal and 30% of floor of mouth cancers.

Presenting symptoms

One-third presented with pain (24-38%), one-fifth with enlarged cervical nodes (19%), 12% attended regarding ulcers, swelling/lumps and dysphagia, and 8% reported hoarseness (**Table 1**). Almost one-third presented with nodal involvement in 2010/2018-19, with a lower rate of nodal swelling reported by patients from 1983-90 (6%); however, lymphadenopathy was subsequently detected in 21% of this cohort. This concurs with national and international reports of approximately one-third of HNC patients having nodal disease at time of presentation.[10]

Oral cavity cancer symptoms were predominantly ulceration, pain, swelling, dysphagia, and/or nodal involvement. Dental issues were generally associated with floor of mouth and gum/mouth lesions. Tongue base and pharyngeal cancers mainly presented with dysphagia, sore throat and 'neck lumps'. Laryngeal cancers presented classically with hoarseness. Salivary gland cancers typically presented as a lump/gland swelling. Nasopharyngeal cancer symptoms included: nasal obstruction; epistaxis; swelling; ear pain; and, lymphadenopathy.

Discussion

This audit provides an overview of the characteristics and referral pathway of Irish HNC patients between 1983 and 2019. NCRI data confirms that this audit subset is a representative sample of Irish HNC patients regarding gender, age, histology and primary site. Patients were predominantly male (71% versus 73% NCRI). Only 6% were <50 years (14% NCRI), and 71% were over 55 years at diagnosis (NCRI: 69% aged 60-65 years).[6] SCC was the dominant histopathology (84% versus 86% NCRI), followed by salivary gland (5% versus 7% NCRI). Oral cavity, pharyngeal and laryngeal cancers were almost exclusively SCC. Main sub-sites recorded were larynx, tongue and tonsil, which concurs with NCRI data.[5]

GPs are generally the first point of contact for HNC patients internationally, ranging from 91% in the US to 70% in Canada and 50% in the UK.[13-16] The relatively lower level of GP referrals in the UK may be related to the access to dental care provided by the National Health Service (NHS) there. In this series, 87% of patients were diagnosed by GPs or medics, with little variation over four decades. While dentists have ready access to and significant training in examining this area, relatively few patients (3-29%) present to their dentist when they experience HNC symptoms.[13,14,16,17] This concurs with reports that HNC patients tend to be infrequent dental attenders.[10,16,18] In this series, only 13% of cases of HNC were detected by GDPs. However, a more significant dental role was seen for tongue/floor of mouth (30%), and gum, palate and

Table 3: Suspected cancer – NICE guidelines for oral cancer recognition and referral.[21,22]

Consider a suspected cancer pathway referral (for an appointment within two weeks) for oral cancer in patients with either: ▸ unexplained ulceration in the oral cavity lasting for more than three weeks; or, ▸ a persistent and unexplained lump in the neck [2015].	Consider an urgent referral (for an appointment within two weeks) for assessment for possible oral cancer by a dentist in patients who have either: ▸ a lump on the lip or in the oral cavity; or, ▸ a red or red and white patch in the oral cavity consistent with erythroplakia or erythroleukoplakia [2015].	Consider a suspected cancer pathway referral by the dentist (for an appointment within two weeks) for oral cancer in patients when assessed by a dentist as having either: ▸ a lump on the lip or in the oral cavity consistent with oral cancer; or, ▸ a red or red and white patch in the oral cavity consistent with erythroplakia or erythroleukoplakia [2015].

other mouth cancers (47%), particularly in the recent 2018/19 cohort, due perhaps to the annual Mouth Cancer Awareness Day (MCAD) campaigns.

Conversely, in the UK, 43% of oral cancer patients presented to their dentist.[17] Higher dental pathway utilisation in the UK may be due to their traditionally higher rates of dental attendance, with recent polls showing that 61% of people attended an NHS dentist in the previous two years, and 24% attended private dentists, leaving only 15% without dental provision.[16] This contrasts starkly with national reports that approximately 60% of dentate individuals in Ireland "occasionally/never" visit dentists, while 91% of edentulous persons aged 65+ never attend.[19,20] Although 80% of Irish adults qualify for free annual dental examinations, many do not avail of this benefit, non-attendance being highest among medical card holders. Factors associated with low engagement with dental services are also associated with increased HNC risk: male gender; low socioeconomic status; increasing age; long-term tobacco use; symptom denial; nervousness; and, low access to free care.[16]

The high symptom burden reported in this series suggests considerable diagnostic delay. While early-stage HNC is generally asymptomatic, all patients bar one were overtly symptomatic, exhibiting one or more National Institute for Health and Care Excellence (NICE) 'red flag signs' of HNC (**Table 3**).[21] Patients predominantly presented with persistent pain, ulceration, dysphagia and/or nodal involvement, indicative of advanced disease. This is in line with NCRI reports that 66% of Irish HNC patients present in Stage III/IV, and 38% of mouth and 54% of pharyngeal cancers present in stage IV,[5,6] impacting on prognosis, treatment costs, long-term functional impairment and morbidity.

Diagnostic delay may arise due to delayed patient presentation or failure of the clinician first consulted to recognise the sinister nature of the lesion and to organise timely and appropriate referral. Patients frequently self-manage symptoms, considering them innocuous, and are reluctant to 'bother' the practitioner;[10,22] reports suggest an average patient delay of approximately four months for HNC and 3.5-5.4 months for oral cancers.[14] Low public awareness of HNC risk factors and warning signs is well documented. In Ireland, 94% of participants (n=2,926) attending HNC events in CUDSH and DDUH in 2010 reportedly never received any information on HNC, 97% had no knowledge on self-examination and limited knowledge of risk factors.[23,24] Similarly, symptomatic patients attending an 'urgent suspicion of cancer' clinic in Scotland, who were subsequently diagnosed with HNC, had little knowledge of red-flag symptoms of HNC, and one-third had 'no concern' about their symptoms.[25]

Patient delay may be compounded by professional delay in some instances due to misdiagnoses, inappropriate prescribing, multiple referrals, imaging/procedural work, and lack of patient and professional awareness of signs and symptoms of HNC.[14,16] Studies in medical/dental students and practitioners in the US, UK and Ireland reported poor knowledge of HNC. Almost 70% of Irish GPs reported lack of training and low confidence in examination/diagnosis of oral malignancies, highlighting an important educational gap.[26]

Educational campaigns to raise public and professional awareness of HNC have long been advocated.[3,7,10,22] In 2009, Mouth Head & Neck Cancer Awareness Ireland (MHNCAI) was established to promote public/professional awareness of HNC through national and community-based campaigns. Irish Mouth Cancer Awareness Day (MCAD) was launched in September 2010 with 25,000+ free oral cancer examinations undertaken between 2010 and 2014.[24,26] Details of the significant role of Irish GDPs in providing free examinations and information on multimedia campaigns highlighting avoidable risk factors, warning signs and importance of early detection are available on www.mouthcancer.ie. While it is difficult to gauge the impact of media campaigns on individual behaviour, the number of internet searches in Ireland increased significantly between 2010 and 2013 ($p<0.001$), peaking mid-September, coinciding with the annual MCAD event.[28] The increased dental role in oral cancer detection in the 2018/19 cohort suggests that the annual MCAD campaigns are improving education, engagement and awareness.

Despite efforts to raise public and professional awareness, encourage regular dental attendance, upskill medical/dental professionals, and advocate opportunistic screening and appropriate responses to symptomatic patients, HNC diagnostic delay remains a significant barrier to improved outcomes. Patients continue to present with advanced disease, waiting until symptoms become impossible to ignore. Despite the slight increase in intra-oral cancers diagnosed by GDPs in 2018/19, the dental referral pathway remains under utilised. While awareness campaigns can change knowledge, attitudes and beliefs, translating this knowledge into behavioural change requires a comprehensive, long-term, multi-faceted approach, and an understanding of the determinants of health and health behaviour theory. Educational and fiscal actions are required to:

(i) encourage greater GDP engagement by acknowledging the intrinsic value of time spent on patient education and risk factor modification;

(ii) develop a nationwide culture of lifelong dental attendance among the general public to improve access to and utilisation of the dental pathway; and,

(iii) reduce widespread acceptance of poor oral health as the 'norm', which should enhance early detection and lead to sustained benefits.

Conclusions

This audit provides valuable insight into primary care diagnostic/referral pathways for HNC in Ireland over four decades, an area where there is a paucity of research. It highlights the continued importance of GPs in HNC diagnosis, and the under-utilisation of dental and pharmacy teams. However, it is encouraging to note increased detection of mouth cancers by GDPs in 2018/19. It provides site-specific symptomology, which may be beneficial to attending physicians, and highlights the degree to which patients delay presentation. It highlights the need to further increase public awareness of HNC and improve the process by which cancer symptoms are recognised and actioned in primary care, to facilitate timely presentation and appropriate diagnostic/referral decisions, and enhance outcomes. Future awareness campaigns must be designed to deliver sustainable, measurable benefit.

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