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Is detecting oral cancer in general dental practices a realistic expectation? - A population-based study using population linked data in Scotland

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Abstract

Introduction: Despite the increasing burden of oral cancer (OC) – including oral cavity (OCC) and oropharyngeal cancer (OPC) – it remains a relatively low-volume disease in Scotland, with anecdotal evidence suggesting that dentists only see 1-2 cases in their practising careers.

Aims: To examine, for the first time on population-basis via data linkage, whether early detection by general dental practices (GDP) is a realistic expectation by i) estimating the number of OC cases/year a dentist in Scotland may encounter over time, accounting for the deprivation level of practice location and dental registration/attendance rates, and ii) assessing whether patients attended GDPs two years pre-diagnosis.

Materials and Methods: Scottish Cancer Registry data on all OC cases (2010-2012), published NHS Scotland dental workforce and registration/participation statistics, and individual patient data linked with NHS dental service activity were analysed.

Results: Dentists were estimated to potentially encounter one case of OC every 10 years, OCC every 16.7 years, and OPC every 25 years. However, 53.7% of OC patients had made no dental contact two years pre-diagnosis.

Conclusion: Strategies for early detection must consider the rarity of OC incidence and poor dental attendance patterns. These results highlight the importance of improving access and uptake of dental services among those at highest risk to increase the opportunities for early detection.

Keywords: Mouth neoplasms, head and neck neoplasms, oropharyngeal neoplasms, opportunistic screening, dentist

In Brief:

- Informs general dental practitioners that despite increasing rates of oral cancer, it is still a relatively low-volume disease in Scotland, and provides information on their likelihood of encountering a case of oral cancer (approximately 4 cases in a career spanning 40 years).

- Highlights the need for early detection strategies in dental practices to pay cognizance of the rarity of the disease, as well as the importance of strategies that improve access and uptake of primary dental care services, particularly among those at high risk and from socioeconomically deprived backgrounds.

- Demonstrates that a large proportion of those diagnosed with oral cancer did not have frequent contact with GDPs.

Introduction

Oral cavity or "mouth" cancer (OCC) and oropharyngeal or "throat" cancer (OPC) collectively rank as the seventh most common cancers globally.[1] In the United Kingdom, studies using population-based cancer registry data reported that the incidence rates of OCC increased slowly between 1975-2012, while rates of OPC exhibited a rapid surge in the most recent decade (2001-2012).[2,3] Moreover, rates of OPC are predicted to continue to rise rapidly to 2025, while OCC rates are expected to exhibit a much slower increase.[2,3] Males over 60 years of age and those living in the most deprived areas had the highest incidence rates of OCC and OPC.[2]

Guidance and regulatory bodies have an expectation that general dental practitioners will be able to promptly detect and refer patients with suspected oral cancerous lesions[4-6]. However, we believe, the explicit link to the relatively low (albeit increasing) rates of the disease have not yet been made. Early detection via opportunistic screening in dental practices could potentially decrease the impact of these trends.[7,8] A recent review of the prospective evidence on oral cancer (OC) screening considered it potentially feasible as it is frequently preceded by an oral potentially malignant disorder (OPMD) and can thus be detected at an earlier (smaller) stage.[9] However, there was insufficient evidence to support the introduction of a population-wide screening program, and targeted opportunistic screening of high-risk individuals (identified by smoking and alcohol behaviours) was proposed as a potentially cost-effective approach.[7] Examination of dental attendance patterns in Britain using national survey data, however, revealed that these high-risk individuals were also the ones least likely to visit the dentist regularly, thus decreasing the opportunities for early detection.[10,11]

Similar concerns were raised in relation to general medical practitioners in England identifying childhood cancer, where it was estimated that a GP would see one case every twenty years.[12]

Currently, there are limited studies that have attempted to estimate the likelihood of a primary care dental practitioner encountering a patient with OC. In the UK, anecdotal evidence suggests that dentists may encounter "few, if any, cases of mouth cancer during their career".[13] A thorough literature search returned only one Letter to the Editor where a simple estimate based on limited data suggested approximately one

case per 10 dentists in the UK, and approximately 24 premalignant lesions in a year or, in other words, two OPMD cases a month.[14]

However, to the best of our knowledge, there are no studies that accurately estimate the distribution of OC cases by the location of dental practices, nor take into consideration how these trends may vary with area-based socioeconomic deprivation. Moreover, no studies have investigated via linkage of large population datasets whether patients diagnosed with OC were registered or attended general dental practices (GDP) prior to diagnosis. Additionally, given the changing incidence of oral cancer noted previously, there are no recent estimates of the likelihood of a GDP encountering a patient with OC.As there are relatively ~~low volume of cases~~ low number of cases in Scotland, the feasibility of carrying out screening at the primary care level is unknown, and quantification of the number of cases a practitioner may expect to encounter per year may help us develop a better understanding of whether a more stratified or targeted approach is necessary. Research in this area will also help us understand the distribution of the burden of OC in Scotland and inform strategies for targeting training and future referral pathways.

Thus, the aims of this study were to utilize robust national data sources and the linkage potential of administrative data in Scotland to: i) estimate the number of OC cases a dentist may expect to encounter per year; ii) examine how these estimates may vary by the socioeconomic status of the practice location; and iii) determine the proportion of OC patients that had attended a GDP in the two years preceding diagnosis.

Materials and Methods

Data and ethical approval

This study focused on all cases of OCC [defined as inner lip C00.3-C00.9, other and unspecified parts of tongue C02, gum C03, floor of mouth C04, palate C05, and other and unspecified parts of mouth C06] and OPC [defined as base of tongue C01, lingual tonsil C2.4, tonsil C09, oropharynx C10, and pharynx C14] diagnosed between 2010 and 2012 and registered with the Scottish Cancer Registry.[2] Additionally, the two subsites were also combined and examined as one OC grouping.

Socioeconomic status was measured using the small area-based socioeconomic index, the Scottish Index of Multiple Deprivation (SIMD, 2009 version), which combines data from seven domains of deprivation

including income, employment, education, housing, health, crime and geographical access.[15] It is measured initially at the data-zone ("neighbourhood") level and grouped into fifths of the population (where 1 = most deprived areas, 5 = least deprived areas).

Data on the number of primary care dentists per year (2010 to 2012) per SIMD fifth were available from NHS National Services Scotland,[16] and were used to calculate the mean number of dentists per SIMD fifth over the study period (from 2010 to 2012). In this study, primary care dentists were those working in the general dental services (GDS) including non-salaried and salaried dentists, but excluded Community Dental Services, now known as the Public Dental Services in Scotland. Dental registration and participation rates for 2012 were accessed from NHS Scotland online publications.[18]

Additionally, patients diagnosed with OC (2010-2012) had their individual patient records anonymously linked to their MIDAS (Management Information and Dental Accounting System) NHS dental claims database records in the two years preceding diagnosis using the NHS Scotland unique ID 'CHI' (Community Health Index) number. MIDAS data for the period 2008 to 2012 were collected, and treatment start dates (which included "check-up" appointments) were used as indicators of contact. The data were securely accessed and analysed within the NHS Scotland Safe Haven, managed by NHS National Services Scotland eDRIS (electronic Data Research and Innovation Service), using SAS 9.4.

Ethical approval was obtained from the University of Glasgow, College of Medical, Veterinary and Life Sciences Ethics Committee. Information Governance approval was obtained via the Public Benefit and Privacy Panel for Health and Social Care (PBPP), NHS National Services Scotland.

Statistical analysis

Initial data management included checking for missing variables and assessing the distribution of cases and practitioners. The expected number of cases per dentist per year, based on the assumption that all cases were seen by a dentist, was calculated by dividing the mean number of cases by the mean number of dentists over the study period.

However, given that the whole population was not registered with an NHS dentist and only a proportion of those who were registered attended regularly (Table 2), there is a possibility that this simple calculation was an overestimation. Therefore, registration and participation rates for each SIMD fifth were then

applied[18] to obtain a more accurate estimate of the number of cases that a dentist would likely encounter per year.

Additionally, the linked dataset was used to assess the number and proportion of diagnosed cases that had contacted NHS dental services in the two years preceding OC diagnosis.

Results

This study included 1988 cases of OC over the 3-year period, of which 1127 were OCC and 861 were OPC. Patient demographics have been shown in Table 1.

Under the assumption that all cases were seen by a dentist, the overall expected number of cases per dentist per year would be: 0.22 for OC (1 case every 4.5 years); 0.12 for OCC (1 case every 8.3 years); and 0.09 for OPC (1 case every 11.1 years). Applying actual dental registration and participation rates, the following estimates of the number of cases per dentist were obtained: 0.13 for OC (1 case every 7.7 years); 0.07 for OCC (1 case every 14.3 years); and 0.05 for OPC (1 case every 20 years). No obvious pattern or relationship with deprivation fifths of the practice location was observed.

A small difference in the number of cases (1%) was observed after data linkage, but this was considered to be too small to have significantly affected the results. Individual patient data linkage showed that most of the cases diagnosed between 2010 and 2012 (OC: 53.7%, OCC: 50.9%, OPC: 57.1%) had no contact with an NHS primary care dentist in the two years preceding diagnosis (Table 3). There were some inequities observed in dental contacts, as follows: in SIMD 1 (most deprived), 54.92% (n=357) of OC cases, 52.56% (n= 195) of OCC cases and 57.8% (n= 163) of OPC cases had no contact with a dentist in the two years preceding diagnosis, while the corresponding proportions in SIMD 5 (least deprived) were 52.11% (n=741) of OC cases, 57.33% (n=43) of OCC cases, and 46.3% (n=31) of OPC cases (Table 3). ~~Moreover, a greater proportion, albeit still low, of those from SIMD 5 (OC: 47.9 %, OCC: 42.7%, OPC: 53.7%) had contacted a dentist prior to diagnosis compared to those from SIMD 1 (OC: 45.1%, OCC: 47.4%, OPC: 42.2%), irrespective of cancer subsite (Table 3).~~

Applying these dental attendance proportions to calculate the numbers of years elapsed before a dentist would encounter one case, the results were seen to increase to be approximately 10 years for OC, 16.7 years for OCC, and 25 years for OPC (Table 2).

Discussion

This is the first study that has attempted to accurately estimate the number of OCC and OPC cases that a primary care dentist may encounter over time, and assess the proportion of these patients that had attended a primary care dentist in Scotland in the two years preceding diagnosis. Our results showed that the majority of diagnosed cases had made no contact with a dentist in the two years prior to diagnosis, thus decreasing the opportunity for early detection drastically, which was in-keeping with previous studies reporting that high-risk groups were less likely to undergo regular dental check-ups.[10, 11] Upon application of these calculated attendance rates, the number of years that would elapse before a dentist would encounter one case was found to be 10 years for OC, 16.7 years for OCC, and 25 years for OPC.

If published registration and participation rates were applied instead, these numbers decreased to one OC case every 7.7 years, one OCC case every 14.3 years, and one OPC case every 20 years, suggesting that with greater efforts to fully engage with all patients, and to increase regular attendance rates, ~~-~~the potential detection rate could markedly increase. There was no obvious pattern or relationship with deprivation of the practice location. This is partly explained by the fact that although there are inequalities in access to NHS primary care services such as general medical practices in Scotland, the distribution of dental practices does not follow this pattern.[17] Therefore, registration rates do not exhibit the typical inequalities skew, although participation (attendance) rates are lower in the more deprived communities.[18] ~~Resultantly~~As a result, this offsets the higher rates of OC in deprived areas as they are distributed among the higher number of dentists in these same deprived areas.

Several studies have employed similar methodologies to estimate the number of emergency events that a dentist would likely encounter per year.[19-21] However, to our knowledge, no other studies have applied this methodology to estimate the time elapsed before a dentist would encounter an OC case. A simple calculation of the headline distribution of OC cases in relation to the location of dentists in the UK suggested there would be one case for every 10 dentists.[14]

In this study, registration rates included all individuals in the general population who were registered with an NHS Dentist, while participation rates represented the proportion of registered patients who had contacted a GDS for either examination or treatment (or both) in the last two years.[18] These published rates were used to obtain a more accurate estimation of the likelihood of a dentist encountering a patient with

OC. Furthermore, our linkage study revealed that there was a large proportion of those patients who had not contacted a dentist in the previous two years, and applying these actual rates ~~(which showed even lower contact among those from the most deprived communities)~~ further reduced the likelihood of encountering a patient with oral cancer.

Another factor that ought to be taken into consideration when interpreting these results is that this study considered the deprivation status of the dental practices, and not that of the patients themselves, to calculate the number of cases per dentist. Our linkage study, on the other hand, considered the SIMD fifth of the patient's area of residence to better elucidate if deprivation had any effect on their likelihood of attending a dentist. This, however, raises the possibility of ecological fallacy as a patient who lives in a particular SIMD fifth may not necessarily attend a dental practice within the same SIMD fifth, just as the registration profile of a practice may not necessarily reflect the SIMD fifth his/her practice is located in.

The results of the examination of dental attendance patterns by subsite do not intend to "over-burden" general dental practitioners in Scotland by creating an expectation for early detection of oral cavity cancer and oropharyngeal cancer separately. Instead, the purpose of this additional exploration by subsite was to examine the potential opportunities for early detection of the two subsites, and highlight the need for vigilance and awareness of certain signs and symptoms that could suggest involvement of a particular subsite (given that national guidance includes clinical, visual, and tactile examination plus symptom and sign recognition of both subsites).[22] Despite OPC being the fastest rising cancer, our data shows that it still exhibits relatively low incidence rates and number of cases, and the proportion of patients exhibiting regular dental attendance patterns was still lower (43%) than OCC, thus further reducing opportunities for early detection.

The main strengths of this study lie in the robust nature of the detailed, routinely collected administrative data used. The Scottish Cancer Registry data have been reported to exhibit high levels of accuracy, completeness, and reliability, particularly in relation to diagnostic and treatment details and demographics.[23-25] Registration/participation rates are also highly accurate, as are data from the MIDAS database which is the payment system for NHS dental practitioners in Scotland and is, therefore, dependant on practitioners submitting claims for payment.

One data limitation of this study was that headcounts of dentists were used for all calculations, and whole-time equivalents of each practitioner was unknown. It would be fair to assume that many of these practitioners were employed part-time, and this may have affected the estimates of likely time to see a case. The second unknown limitation is in relation to the accuracy and completeness of the data linkage. The CHI completeness and accuracy is very high (approximately 99%) on both the Scottish Cancer Registry and MIDAS. Therefore, records of OC patients that did not link to a dental record in MIDAS would be because they did not have a dental contact rather than because their CHI numbers did not match or that data linkage was unsuccessful. Thirdly, this study only considered NHS primary care dentists, and did not include those belonging to the private sector. However, a series of national Dental Workforce reviews showed that the private sector mainly attracted patients with higher incomes, relatively good oral health, and low future dental care needs, and only 17% of adults received private treatment only over a 12-month period in 2012.[26, 27] Moreover, the majority of the patients included in this study were from the most deprived areas of Scotland,[2] suggesting that the non-inclusion of private dentists in this study would likely have minimum impact on the results reported. Fourthly, the data were only available over a three-year period, although the datasets had complete national coverage for this duration. Finally, despite the wealth of treatment code data, the MIDAS database had no diagnostic data on oral potentially malignant lesions, symptoms and signs of oral cancer, or any information related to referral (either urgent or routine). Nevertheless, the potential opportunities for early detection via contacts with dental services (either for check-up or treatment) could still be robustly assessed.

Interpreting our estimates of the time for a dentist to encounter a patient with OC in relation to early detection has to be in the context of the current guidelines for early detection and referral of head and neck cancer (HNC) which suggest that identification of mucosal abnormalities require urgent referral.[22, 28] A recent systematic review and meta-analysis found that the conversion rate, that is, the proportion of patients referred within two weeks who had OC was approximately 10%, while the detection rate, that is, the proportion of patients with OC who had been referred under the two-week rule was approximately 40% and increasing.[29] This suggests that approximately 60% of patients with OC are referred out-with the two-week referral pathways. Moreover, there appears to be an increasing number of patients with head and

neck conditions including OPMDs that are being referred, but fewer patients are being diagnosed with HNC.

Previous authors have noted that patients with OC do not present at general dental (or indeed medical) practices.[30] Therefore, the question of whether early detection of OC is feasible has been raised, given the complex range of factors associated with referral pathways into care and definitive diagnosis and treatment. One major factor may be the fact that early OCC and OPC may be asymptomatic or cause subtle mucosal changes. Access to primary care dental or medical services may also be more difficult or limited among those at highest risk, that is, those from poorer socioeconomic circumstances or among older groups.[31] Other problems associated with early detection and referral delays include professional issues such as limited capability to undertake full clinical examination, training issues, or potential capacity issues (scheduling issues, payment etc.).[32] To this complex mix of factors, we propose that the underlying burden of disease is an additional factor that needs careful consideration.

In conclusion, despite being a low volume cancer, these results show that the hitherto encountered anecdote that a dentist may come across only two cases of OC in his/her lifetime is not quite true. Our original question "is early detection of OC a realistic expectation?" remains somewhat rhetorical. Although our findings confirm that the rarity of the condition compounded by the lower attendance among those who were diagnosed with oral cancer will likely impact on the dentist's ability to detect oral cancer early. It is worth reiterating that national guidelines do not expect general dental practitioners to make a diagnosis of oral cancer – but rather to identify sustained abnormalities and refer in a timely manner.[22, 28]

Our findings indicate the importance of developing early detection strategies for primary care dental services that consider the changing patterns and rarity of the condition. Moreover, it is important to continue to work to develop and evaluate innovative strategies for dental services to reach out to those who do not attend regularly, to better network dental with and other primary care services, and to explore the possibility of early detection strategies in alternative settings.

Conflicts of Interest: All the authors declare that they have no conflicts of interest.

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Table 1: Demographics of patients diagnosed with OC, OCC and OPC

Variable	OCC (n, %)	OPC (n, %)	Oral Cancer (n, %)
Sex			
Male	646 (57.3)	634 (73.6)	1280 (64.4)
Female	481 (42.7)	227 (26.4)	708 (35.6)
SIMD			
1 (Most deprived)	291 (25.8)	237 (27.5)	528 (26.6)
2	244 (21.7)	183 (21.3)	427 (21.5)
3	245 (21.7)	177 (20.6)	422 (21.2)
4	194 (17.2)	153 (17.8)	347 (17.5)
5 (Least deprived)	153 (13.6)	111 (12.9)	264 (13.3)

OCC: Oral cavity cancer; OPC: Oropharyngeal cancer; SIMD: Scottish Index of Multiple Deprivation 2009;

Table 2: Estimates of number of expected and actual oral cancer cases expected to be seen per dentist, taking participation, dental registration, and actual attendance rates into consideration, and number of years elapsed before one case seen- 2010 to 2012

SIMD		100% dental registration and participation rates assumed				Application of published registration and participation rates					Application of actual attendance rates		
		Mean no. of cases over 3 years	Mean no. of dentists over 3 years	Estimation of number of cases/dentist	Estimation of no. of years before 1 case encountered	Registration rates (%)	Participation rates (%)	Estimation of no. of cases visiting dentist in last 1 year	Estimation of number of cases/dentist	Estimation of no. of years before 1 case encountered	Proportion of cases that contacted dentist in 2 years before diagnosis (%) **	Estimation of number of cases/dentist	Estimation of no. of years before 1 case encountered
Oral Cancer	**All Scotland**	**662.66**	**3025.33**	**0.22**	**4.55**	**73.7**	**78.7**	**384.35**	**0.13**	**7.69**	**46.3**	**0.10**	**10.00**
	1 (Most deprived)	176.00	771.33	0.23	4.35	77.8	73.6	100.79	0.13	7.69	45.1	0.10	10.00
	2	142.33	790	0.18	5.56	74.2	77.2	81.53	0.10	10.00	44.2	0.08	12.50
	3	140.66	631	0.22	4.55	71.5	79.2	79.65	0.12	8.33	47.6	0.12	8.33
	4	115.66	439	0.26	3.85	71.7	81.5	67.59	0.15	6.67	48.7	0.13	7.70
	5 (Least deprived)	88.000	478.66	0.18	5.56	73.2	82.0	52.82	0.11	9.10	47.9	0.09	11.11
OCC	**All Scotland**	**375.66**	**3025.33**	**0.12**	**8.33**	**73.7**	**78.7**	**217.89**	**0.07**	**14.29**	**49.1**	**0.06**	**16.67**
	1 (Most deprived)	97.66	771.33	0.12	8.33	77.8	73.6	55.92	0.07	14.29	47.4	0.06	16.67
	2	81.33	790	0.10	10	74.2	77.2	46.58	0.05	20.00	47.9	0.05	20.00
	3	81.66	631	0.13	7.69	71.5	79.2	46.24	0.07	14.29	49.8	0.06	16.67

	4	65.00	439	0.15	6.67	71.7	81.5	37.98	0.08	12.5	55.1	0.08	12.50
	5 (Least deprived)	51.00	477.66	0.11	9.09	73.2	82.0	30.61	0.06	16.67	42.7	0.05	20.00
OPC	**All Scotland**	**287**	**3025.33**	**0.09**	**11.11**	**73.7**	**78.7**	**166.47**	**0.05**	**20.00**	**42.9**	**0.04**	**25.00**
	1 (Most deprived)	80.00	771.33	0.10	10	77.8	73.6	45.80	0.05	20.00	42.2	0.04	25.00
	2	62.33	790	0.07	14.29	74.2	77.2	35.70	0.04	25.00	39.6	0.03	33.33
	3	59.33	631	0.09	11.11	71.5	79.2	33.59	0.05	20.00	44.6	0.04	25.00
	4	51.00	439	0.12	8.33	71.7	81.5	29.80	0.06	16.67	40.9	0.05	20.00
	5 (Least deprived)	37.00	477.66	0.07	14.29	73.2	82.0	22.20	0.04	25.00	53.7	0.04	25.00

OCC: Oral cavity cancer; OPC: Oropharyngeal cancer; SIMD: Scottish Index of Multiple Deprivation 2009.

**Taken from Table 3

Table 3: Number and percentages of OC, OCC, and OPC cases (2010-2012) who made contact with a GDS practitioner in the two years preceding diagnosis- all Scotland by SIMD

Contact		SIMD (n, %)						
		1 (Most deprived)	**2**	**3**	**4**	**5 (Least deprived)**	**Missing SIMD**	**Total**
OC	**Yes**	294 45.23	182 44.39	195 47.45	164 48.81	68 47.89	8	**911** **46.43**
	No	356 54.7	228 55.61	216 52.55	172 51.19	74 52.11	5	**1051** **53.57**
	Total	**650**	**410**	**411**	**336**	**142**	**13**	**1962**
OCC	**Yes**	175 47.43	112 47.86	118 49.79	103 55.08	32 42.67	4	**544** **49.10**
	No	194 52.57	122 52.14	119 50.21	84 44.92	43 57.33	2	**564** **50.90**
	Total	**371**	**234**	**237**	**187**	**75**	**6**	**1108**
OPC	**Yes**	119 42.35	70 39.77	77 44.25	61 40.94	36 53.73	**4**	**367** **42.97**
	No	162 57.65	106 60.23	97 55.75	88 59.06	31 46.27	**3**	**487** **57.03**

Contact		SIMD (n, %)						
		1 (Most deprived)	2	3	4	5 (Least deprived)	Missing SIMD	Total
	Total	282	177	175	149	67	7	854

OCC: Oral cavity cancer; OPC: Oropharyngeal cancer; SIMD: Scottish Index of Multiple Deprivation 2009;

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