

The experiences of young oral cancer patients in Scotland: symptom recognition and delays in seeking professional help

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IN BRIEF

- Explores the reasons for delay in seeking help from a GP or a dentist among a group of young oral cancer patients in Scotland.
- The majority did not at first think their symptom was serious; none thought their presenting symptoms were associated with cancer.
- Future oral cancer public awareness campaigns should highlight that if a symptom persists beyond two weeks it needs a professional opinion.

Objectives To explore the early responses of young oral cancer patients in Scotland to the symptoms of their emerging condition, to understand the ways they seek help and to inquire into delay caused by not recognising symptoms associated with cancer. **Setting** The survey was carried out in Maggie's Centres or in patients' own homes in Glasgow and Edinburgh among young patients diagnosed with oral cancer in the three years (2004–7) before the study. **Methods** This study employed qualitative methods. Data were collected by interview using a semi-structured interview schedule. The interview transcripts were analysed using a thematic framework and with the aid of NVivo qualitative analysis software (Version 8). **Results** Most of the cohort knew that smoking and alcohol could cause oral cancer. None thought it would happen to them. Descriptions of symptoms varied widely and several had used self-treatment provided from a pharmacy. There were various causes of 'patient delay' and self-treatment was not the only cause. Reinterpretation of symptoms without seeking professional help was not uncommon. Nobody suspected they had oral cancer until it was confirmed by their GP or GDP. All thought that something so small and painless couldn't be a serious problem. **Conclusions** The study further confirms gaps in understanding and awareness of oral cancer. Most had heard of oral cancer but they didn't think their symptoms were indicative of cancer and they self managed the problem. The culture of not bothering the GP/GDP unless it was perceived as serious is a barrier to earlier access. Findings support that further public awareness of oral cancer and its symptoms is required to alert the public that if their symptoms persist beyond three weeks they need a professional opinion.

INTRODUCTION

Oral cancer remains a lethal disease for over 50% of the patients diagnosed annually largely reflected by the fact most cases are in advanced stages at the time of detection. This is despite easy accessibility for regular mouth examination. Oral cancer affects the lip, mouth or tongue, and around 600 new oral cancer cases are identified in Scotland each year. Within the UK age-standardised incidence is highest in

Scotland (males 16.0 and females 5.5 per 100,000 population).¹ The rising trends in oral cancer in the UK and particularly for Scotland were first described by Macfarlane *et al.*² over a decade and half ago and was reviewed recently.³

Several studies also show an increase in tongue and oropharyngeal cancer, particularly in younger patients.^{4,5} For cancer incidence studies young patients are defined as those under the age of 45 years. The largest population study in Europe among young oral cancer patients was conducted in SE England.^{6–8} The study concluded that risk factors of tobacco use and excessive alcohol consumption were present in the majority (75%) while a distinct group of young patients (25%) may not have exposure to any established risk factors.

Public awareness of oral cancer and the associated risk factors is low in the UK.^{9–10} Awareness of risk factors and symptom recognition by patients is a crucial factor in determining survival rates, as early detection greatly improves the chances of

survival, morbidity and patients' quality of life. A recent study in the NW England showed a five year overall survival of 74% for tumours <2 cm compared with 44% for those over 4 cm ($p < 0.0001$).¹¹ In 2003/4 the West of Scotland Cancer Awareness Programme (WoSCAP) was launched to raise public awareness. WoSCAP is a social marketing campaign designed to improve the early detection and treatment of mouth and bowel cancer in the West of Scotland by raising the profile of these cancers and to encourage those 'at risk' to present earlier to the NHS if they experience any signs and symptoms of either disease. During the campaign 41% of dentists had new patient registrations mostly to receive advice on 'worrying' oral symptoms.¹² As well as lack of awareness, other factors have been implicated in delaying medical consultation including misattribution of symptoms, embarrassment and not discussing health concerns with others.¹³

There have to date been no detailed investigations of experiences of young

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oral cancer patients or their symptom recognition and paths to referral in Scotland. Patients' views and experiences were documented in a qualitative study undertaken by the National Cancer Alliance¹⁴ but only nine head and neck cancer patients and one carer attended the focus group, none of whom were from Scotland. The latest Scottish clinical guidelines on head and neck cancer specifically identify patients' support needs, experiences and views as an important area requiring further research.¹⁵

In this context we initiated an exploratory study in 2006 to examine the experiences of younger oral cancer patients in Scotland. The study aimed to identify and understand the views of a small group of younger oral cancer patients, with particular reference to patients' responses to emerging symptoms, routes into, and time taken for, specialist referral and diagnosis.

The study objectives were to:

- Investigate the early responses of young oral cancer patients to the symptoms of their emerging condition, to understand the ways they seek help and to present delay caused by not recognising symptoms associated with cancer
- Describe patients' interactions with healthcare professionals, their pathways of entry into the healthcare system and routes of referral including factors facilitating and inhibiting rapid diagnosis and treatment.

This paper presents findings from this exploratory study. We report here the experiences of young oral cancer patients in Scotland before seeking professional help. Additional findings from this study related to patients' care pathway following primary diagnoses and delays experienced at the level of secondary care will be presented elsewhere.

METHODS

This study employed qualitative methods to examine the views of younger oral cancer patients. It involved semi-structured interviews conducted by a Liaison Counsellor working for the National Health Service (NHS).

Subject recruitment was through Clinical Nurse Specialists attached to three surgical oncology units (St John's Livingston,

Canniesburn Unit of the Glasgow Royal Infirmary and the Western General, Edinburgh) who invited patients that fitted the agreed criteria to take part in the study. The study included 15 patients under 45 years of age, previously diagnosed with oral or oropharyngeal cancer (referred to as mouth cancer for this study) in the three years before the study, resident in the central belt of Scotland. The Greater Glasgow Health Board Primary Care Ethics Committee approved the study protocol.

Participants were given a patient information sheet outlining what would be involved and were given an opportunity to ask questions before the interview commenced. At interview they were asked to sign and date a consent form. Interviews took place either in Maggie's Centres in Glasgow or Edinburgh or in the patient's own home, depending on the patient's preference.

Interviews were conducted using a semi-structured interview schedule (available from the authors on request) as a guide, and to ensure a consistency of approach. The schedule was initially piloted on adult volunteers among oral cancer patients known to the study organisers.

During the study interviews the schedule was used flexibly to allow the interviewer to probe certain areas of interest to the study, and to allow research participants to raise topics and concerns which they felt were relevant. This method also allowed for previously unidentified topics to emerge during interviews.

Topics covered in the interviews included:

- Symptom recognition and attitudes towards initial symptoms
- Self-treatment
- Enquiries to, advice from, and treatment by primary care professionals
- Attitudes, expectations and behaviour about this advice or treatment
- Identifiable opportunities for diagnosis missed
- Referral pathways and mechanisms
- Reasons for any delays in the referral process
- Perceptions of the effectiveness of diagnostic and treatment pathways.

The interviews lasted between 20 and 40 minutes, with one lasting an hour. The

interviews were fully audio recorded and then were transcribed. Those interviews that were not transcribed (n = 4) were analysed using the audio file.

DATA ANALYSIS

The interview transcripts were analysed using a thematic framework,¹⁶ and with the aid of NVivo qualitative analysis software (Version 8).

The analytical framework was developed partly before analysis, using broad themes relating to the research questions, as well as those arising from a review of the literature and an initial review of the interview data. Using the analytical framework, interviews within the NVivo package were 'coded', with new themes and sub-themes (and relating codes) generated and refined throughout the process of analysis. A timeline was also drawn up for each interviewee to maintain a clear picture of the chronology of significant events and the timing of events, and to enable some analysis of delays where they occurred.

The analysis was an iterative process and involved the repeated re-examining of interview data in the light of emerging themes and ideas. The findings were interpreted by the researchers, in the light of the literature, in order to answer the research questions.

Descriptive categorical data about the participants (Table 1) were entered into an attribute table within NVivo. Due to the small sample size (and the omission of some details by participants) information such as gender was not used as a unit of analysis, but it was used to inform the analysis and interpretation of the interview data, and is detailed in the findings where it was felt to be useful or relevant.

In the results sections that follow, the research participants have been anonymised and their names have been changed.

RESULTS

The results are presented under several emerging themes following the analysis of transcripts and audio tapes.

Awareness

Most of the research participants had some awareness of oral cancer before noticing their own initial symptoms, and this prior knowledge came from a range of sources.

Table 1 Demographic data of the sample

Research name	Age at diagnosis	Gender	Ethnic group	Marital status	Index of deprivation ¹	Employment status	Site of cancer
Alice	48	Female	Caucasian	Unknown	10	Unknown	Osterior maxilla
Andrew	39	Male	Caucasian	Married	3	Unknown	Tongue
David	43	Male	Caucasian	Married	7	Employed	Oropharynx
Deborah	36	Female	Caucasian	Single	1	Employed	Tongue and floor of mouth
Julie	47	Female	Unknown	Married	Unknown ²	Unknown	Tongue (right)
Karen	44	Female	Caucasian	Married	10	Employed	Buccal mucosa
Lynne	43	Female	Caucasian	Divorced	2	Unemployed	Anterior ventral tongue and floor of mouth
Margaret	44	Female	Caucasian	Married	7	Unknown	Buccal mucosa
Mark	43	Male	Caucasian	Unknown	5	Employed	Tongue
Paul	34	Male	Caucasian	Divorced	Unknown ²	Unknown	Tongue
Peter	43	Male	Caucasian	Co-habiting	7	Employed	Floor of mouth
Robert	42	Male	Caucasian	Single	5	Employed	Palate
Sarah	43	Female	Caucasian	Single	8	Unemployed	Lip (Labial aspect)
Simon	43	Male	Caucasian	Married	9	Unknown	Tongue
Susan	42	Female	Caucasian	Single	8	Self-employed	Tongue

1. The Scottish Index of Multiple Deprivation (SIMD) provides a relative measure of deprivation and the SIMD ranks can be used to compare data zones by providing a relative ranking from most deprived to least deprived. It combines 38 indicators across seven domains: income, employment, health, education, skills and training, housing, geographic access and crime. The overall index is a weighted sum of the seven domain scores. In the table deprivation deciles are included from 1 (most deprived) to 10 (least deprived). (Adapted from www.scotland.gov.uk/Topics/Statistics/SIMD/BackgroundMethodology)

2. 'Unknown' indicates that the interviewee did not disclose this information.

However, a few had not been aware of oral cancer at all before it happened to them. The interviewees fall into five categories:

- Those who had seen a TV campaign (WoSCAP)
- Those who knew someone who (had) had oral cancer
- Those who had knowledge acquired through their own work, or contact with health care professionals
- Those who were aware of oral cancer but did not have specific knowledge
- Those that had no prior awareness of this particular cancer.

Of those who had some prior knowledge, several had remembered seeing a TV campaign that was developed as part of the West of Scotland Cancer Awareness Programme and funded by Cancer Research UK. For some interviewees, seeing this TV feature had led them to make an initial appointment with a health professional to investigate their symptoms:

'I remember a few years back there was an advert on the TV with about three or four elderly gentlemen, three of which or two of which were, in clear voices,

explaining how everything was fine and the last one ... couldn't really speak and he was the one that had put off going to see somebody about it.' [Andrew]

'I remember actually one of the things that made me go as quickly as I did was an advert on the TV ... that was the one thing that always stuck in my mind.' [Margaret]

A few had known someone personally who had had oral cancer, some of whom had died of the disease:

'An acquaintance of mine died quite suddenly ... and when he died I said to a friend who knew him "what did he die of?" and he said "cancer of the mouth", and I'd never heard of it...' [Lynne]

'Actually one of my aunts died of it [six years previously] ... never smoked or drank in her life and she was the youngest...' [Margaret]

Others had prior knowledge of oral cancer through their work as, or contact with, health care professionals:

'As a student nurse working on an

oncology ward I looked after a lady with tongue cancer. That was the first and last time I came across oral cancer before my diagnosis.' [Deborah]

One interviewee, a health professional, was familiar with the potential risk of oral cancer, although he said that he was still not prepared for his own diagnosis [David]. Another had a pre-existing condition (dysplasia) which meant that she was already receiving regular dental check-ups and was aware of the risks of developing oral cancer at some point in the future [Susan].

In a small number of cases interviewees said that they had heard of oral cancer, but that this did not 'mean anything' to them:

'Well I'd heard about it but I didn't know anything about it ... I was aware it was one of the cancer sites.' [Alice]

Some of the research participants said that they had not been aware of oral cancer before noticing their symptoms, or before diagnosis:

'Some members of my family have died of cancer - but cancer of the back, lung - things

like that - never in the mouth - I wouldn't be looking for it in the mouth.' [Mark]

'Well I knew about cancer, but I didn't know specifically about oral cancer ... it just came out of the blue what I had.' [Robert]

In the majority of the cases the responses seem to suggest that the participants had a prior knowledge of oral cancer. However, this prior knowledge was neither instrumental for them to suspect they may have mouth cancer nor did it prompt them to visit a healthcare professional in the first place. Only two people [Paul and Karen] explicitly stated that their prior awareness of oral cancer (from the TV ad) had led them to make an appointment to see their GP. In [Paul's] case this did not mean that he thought he was sure that he had oral cancer, as he also said that he did not think his symptoms serious before he received his diagnosis. Several interviewees, even those who were aware of oral cancer, said later in the interviews that they had not expected their own diagnosis. Therefore the relationship between having a prior awareness of oral cancer, thinking the symptom might be serious, and making the decision to visit a health care professional is somewhat unclear.

Risk factors

Some of the patients included in the study did drink alcohol to excess ($n = 4$), some do or did smoke but at least two didn't do either. Most of the subjects in this cohort ($n = 12$) knew that smoking and alcohol could cause oral cancer. However, smoking did not figure prominently in the patients' accounts of why they contracted the disease. There was also confusion about the impact of past smoking as a risk factor with several interviewees implying that past smoking was not necessarily linked to their condition. The only indicator of socio-economic status that was collected for almost all participants was post code. An analysis of post code data using the Scottish Index of Multiple Deprivation (SIMD - Table 1) showed that in fact the sample in this study were not primarily drawn from more disadvantaged areas of Scotland. Instead, our sample was mixed, with several participants living in affluent areas.

Self diagnosis and treatment

All the research participants were asked what the first symptom was that they could, in hindsight, attribute to oral cancer. Most ($n = 13$) were able to pinpoint a symptom which they could now recognise as the first indication that they had oral cancer, although for some there was uncertainty as to whether their symptom was actually cancerous at the time, or whether the cancer had developed later.

Some treated their symptom themselves with remedies bought over the counter, or in some cases recommended by a pharmacist, before seeing their GP or dentist ($n = 6$). The amount of time between noticing a symptom and seeing a health care professional varied and for some there was a significant delay in seeking further advice (see 'patient delay' below). Many ($n = 8$) did not feel that the initial symptom was serious until they were referred for further tests, and in three of these cases not until the final diagnosis.

Symptom recognition

Descriptions of the symptoms varied widely. Five interviewees mentioned some kind of 'lump'; a few described a 'white spot', 'mark' or 'patch'; and two described an 'abscess'. Some said their mouth felt 'sore' ($n = 6$), others that there was no pain or soreness ($n = 4$):

'At first I thought it was an ulcer - it was painful to start with but then the pain decreased ... that's when I went to see [the doctor].' [Mark]

'I had a wee white spot just behind my teeth and under my tongue and I thought it was a mouth ulcer ... but it wasn't sore, so I sort of left it - I didn't bother about it but it wasn't going away.' [Lynne]

'It was a big lump on my gum and I was very aware of it, but I couldn't do anything about it because everywhere was shut ... I don't think it was particularly sore.' [Alice]

Self-treatment

After noticing their initial symptom several of the interviewees ($n = 6$) had used some kind of self-treatment provided from a pharmacy. Of these three had spoken to the pharmacist, and three had spoken to an assistant or bought something over

the counter. In four cases they were sold Bonjela or another cream, two were sold a mouthwash (another used a mouthwash she already had), and one a 'Q tip' (on the second visit).

In all cases self-treatment was ineffective:

'It made no difference ... and there was no actual change - if anything it seemed to be increasing in size - that's what made me think 'there's something not quite right here' - that's what made me go to see [the GP].' [Mark]

For all those attempting self-treatment there was inevitable some delay in visiting their GP or dentist. This period of delay in these cases ranged from a few days to two months:

'I suppose after a couple of months I thought this isn't right it's not going away so then I must have gone to the doctor.' [Lynne]

Patient delay

Self-treatment was not the only cause of delay. The period of time which elapsed between the interviewees noticing their symptoms and them making contact with a health care professional varied from a few days to a year. However, most saw someone within eight weeks ($n = 12$), and for half of the sample this period was no more than four weeks. There were various causes of this 'patient delay'.

Two interviewees already had appointments booked with their GP or dentist and so waited for this appointment rather than book another [Karen and Sarah]:

'I actually went to get a prescription for HRT but while I was there I asked the doctor about the lump - just so that - instead of making a separate appointment and wasting two doctors' times I thought I'd get the two things dealt with at the one time.' [Karen, delay two weeks]

'I couldn't blow into the peak flow meter because my mouth was sore and they told me to go and see the dentist.' [Sarah, at asthma check up, delay four weeks]

Two interviewees delayed for significantly longer before making an appointment, both saying that this was because they were not experiencing any pain and therefore did not think their symptom

serious, even though both said that they had been aware of oral cancer beforehand [Deborah and Paul]:

'I had a sore on my tongue ... I thought I had cut it and didn't think too much about it - it was occasionally slightly red but most of the time it was barely visible ... I was so unconcerned that it was a year until I went to see my GP about it.' [Deborah, delay 12 months]

Two saw their dentist immediately, or were receiving regular ongoing treatment for other conditions (which may or may not have been connected with their later diagnosis) and in these cases there was no 'patient delay' as such [David and Andrew].

Seriousness

Whatever the period of delay in seeing a health care professional, most research participants said that they did not at first think their symptom serious ($n = 12$). For some this was because it was small, or painless, or it did not 'bother' them. Most assumed it was some minor condition, such as an abscess or ulcer. Although clearly they were suspicious enough to want to get their symptom checked, they did not seem to make a connection between their symptoms and oral cancer at this stage:

'It didn't cross my mind that it could be cancer...there's no cancer in my family and I just thought it was an infection.' [Alice]

'I'm a carer ... and the funny thing is we deal with cancer and I've had cancer in my own family, but it's been different types of cancer, but you never think it in your mouth - you think it everywhere else but never in the mouth.' [Karen]

DISCUSSION

Oral cancer is an important health issue in Scotland. The disease is not infrequently misdiagnosed and the role of the family physician and dentist in early detection of oral cancer is becoming more important.¹⁷ This exploratory study highlights some early experiences of younger oral cancer patients in Scotland. It shows how the initial phase of the patient journey to see a health care professional can vary significantly between individuals. Differences arise as a result of lack of patient knowledge

and some characteristics. These effects are compounded by system factors (eg access, waiting lists and awaiting tests) which we propose to present in a subsequent journal article.

Because of the small sample involved in this study and the qualitative methods used, it is not possible to generalise our findings to younger oral cancer patients as a group. However, some of the similarities in the experiences of those in this study can be identified as important themes, and some have implications for future research. We discuss these themes and in particular, we examine: gaps in understanding and awareness of oral cancer and its risk factors; delay in diagnosis due to non-recognition of emerging symptoms as those related to mouth cancer and patient characteristics.

Understanding and awareness

This study supports previous research that suggests that public awareness of oral cancer and the associated risk factors is low in the UK.⁹⁻¹⁰ At least two interviewees claimed no knowledge of oral cancer before their own symptoms developed while others indicated that they knew it existed but that it did not 'mean anything' to them. Encouragingly, however, in addition to two interviewees who were health professionals and therefore had a better awareness than others, a number specifically recalled a television campaign about oral cancer, suggesting that public information programmes do have a valuable role to play in raising awareness and therefore providing some impetus to patients to examine their symptoms further. The time taken by patients with oral cancer to seek advice from health professionals remains the longest delay¹⁸ and the patients' accounts reported here (Table 1) support this observation.

What is also striking in this study is interviewees' own accounts of why they developed oral cancer, drawn from a mixture of their own beliefs and information obtained from health professionals during the diagnosis and treatment process.

Most patients described awareness of two of the main risk factors for oral cancer, smoking and alcohol consumption, but their views about whether these behaviours were directly linked to their condition were mixed.

Carcinogenicity of tobacco is well publicised and at least 75% of oral cancers are caused by a combination of cigarette smoking and drinking alcohol and about one fourth of oral cancer cases are attributable to cigarette smoking among people who never drink.¹⁹ The reported pooled cancer risk estimate is 3.43 times higher in smokers compared with non-smokers (95% CI, 2.37 - 4.94).²⁰ Yet in this study smoking did not figure prominently in patients' accounts of why they contracted the disease. There was also confusion about the impact of past smoking as a risk factor, with several interviewees implying that past smoking was not necessarily linked to their condition. While it is known that people who stop using tobacco, even after many years of use, can greatly reduce their risk of developing oral cancer, it can take up to ten years for the risk to return to that of a non-smoker²¹ and pooled risk estimates for ex-smokers are higher compared with non smokers (OR 1.40, CI 0.99-2.00).²⁰ These findings suggest that even among people who have the disease, the understanding of the link between tobacco use and oral cancer in Scotland remains weak. Similar accounts were given for alcohol use. This is an issue both for future research and for health promotion campaigns. The ongoing multi-centre ARCADE study²² which includes a Scottish arm does examine the role of genetics, alcohol and other epidemiological risk factors in oral cancer and perhaps would provide more information on the role of alcohol to the communities.

Confusion about risk factors did, however, appear legitimate for some interviewees where smoking and drinking were not an issue and there was no clear evidence about what had caused their cancer. This uncertainty about cause was supported by reported accounts from health professionals. Some talked about 'fate'. Others expressed real frustration that because the causal pathway for development of the disease was not clear. A recent study on oral cancer in young people (under 45 years) demonstrated that in 25% the cause could not be attributed to excess alcohol and/or tobacco use.^{6,7} Absence of a tobacco habit might contribute to delay, as cancer is not suspected immediately⁸ and it is therefore important not to stereotype who may or may not get cancer.

Delay

The younger oral cancer patients in this study experienced delays in their diagnosis and treatment in two main forms – patient delay and system delay. Both these concepts have been the subject of previous research with patients presenting with cancer or precancer^{23–25,14} and particularly with younger people in Southern England.⁸

Early detection of oral cancer is key to reducing mortality and possible disfigurement, but previous studies have shown that patients delay seeing a health professional after noticing symptoms.²³ In the present study, most interviewees reported that they attempted some form of self-treatment before seeking help – and this process of self-treatment lasted anything from a few days to a few months. Interviewees purchased over the counter remedies (such as Bonjela) to treat inflammation, for example, or merely ‘waited’ to see if their symptoms would pass without intervention. Reinterpretation of symptoms without seeking professional help was not uncommon in the group. Scott and colleagues have described the time between first awareness of symptoms and the first appointment with a health professional regarding those symptoms to be the duration of patient delay.²³ In the SE England study the median delay in presentation among young people with oral cancer was five weeks.⁸ For those with potentially malignant lesions (precancer) the delay was longer; 30% of patients waited more than three months before seeking attention.²⁴ In this study, that period varied between a few days and one year, but for most interviewees the appointment was made within eight weeks of first noticing that something was wrong. Three particular forms of patient delay are worth noting, however. First, it was apparent from interviews that those patients who were not experiencing pain as part of their symptoms were less likely to feel a sense of urgency about making an appointment. Secondly, some waited until they were due to see their GP or dentist for other reasons (a routine dental appointment for example) rather than making a specific appointment following their identification of symptoms. There are grounds to believe that the culture of not bothering the GP/GD unless it was really important is a barrier to earlier access. Finally, it was apparent from some interviewees that a concern

about ‘wasting the time’ of a health professional or appearing to be a hypochondriac was a factor in delaying consultation – a concern echoed in other studies of delays in cancer presentation.²⁵

Patient characteristics

The oral cancer patients interviewed for this study were all in their thirties and forties (Table 1). As older patients were not included in this research it is not possible to draw any conclusions about how the experience of these younger patients may have contrasted with those who contract cancer later in life. In contrast to previous studies, we also did not identify any tangible differences in the experiences of men and women.²⁶ However, it is worth reflecting on the role of socio-economic deprivation as a growing literature identifies this as an important determinant of oral cancer.²⁷ Poverty still undoubtedly has a role to play in both the likelihood of developing the disease and the manner in which patients from more disadvantaged groups negotiate the healthcare system and are treated by health professionals. Munro²⁸ has suggested that deprivation makes some patients more vulnerable not only to developing cancer but also to experiencing a delay in their diagnosis, problems in communicating with professionals, an increased risk of complications and poorer treatment outcomes.

Given the small sample involved in this study it is not possible to make general statements about the role that deprivation played in their experiences and we have little in the way of socio-economic data. The only indicator of socio-economic status that was collected for almost all participants was post code. An analysis of post code data using the Scottish Index of Deprivation (Table 1) showed that in fact the sample in this study were not primarily drawn from more disadvantaged areas of Scotland. Instead, our sample was mixed, with several participants living in affluent areas. Previous studies have highlighted that a higher proportion of affluent people may be found among young cancer groups compared to older patients with oral cancer.^{6–7}

CONCLUSION

This small study provides an insight into the experiences of younger oral cancer

patients in Scotland, particularly relating to the period before treatment. Our findings support those of other studies including Leydon and colleagues who state:²⁶

‘It is clear that difficulties can and sometimes do exist during the pre-diagnostic journey and that the pre-diagnostic cancer journey is important at service level and an individual patient level. Not only can it set the tone – good or bad – for the remainder of the illness experience, but its duration and nature may have long term implications for access to treatment and, ultimately, the patient’s chance of survival.’

Findings from this study support that further public awareness of oral cancer and its symptoms is required combined with continued investment in public information campaigns that can prompt those with symptoms to consult a health professional and therefore assist with early detection of the disease. The results of this research have implications for future public health initiatives particularly with reference to patients’ interpretation of emerging symptoms. Mouth Cancer Action Month (www.dentalhealth.org.uk) in the UK attempts to provide the focus for this activity and Scottish media should be further encouraged to play their role during the Action Month. Finally, in the context of young people further research is needed if we are to learn more about how to improve interpretation of cancer symptoms and to engage them in improving health behaviour to avoid self-managing perceived symptom. Any future public awareness programs should reflect on advising people to seek professional help if symptoms persist beyond three weeks.

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