



The Experiences of Younger Oral Cancer Patients in Scotland: From Self-diagnosis to Treatment

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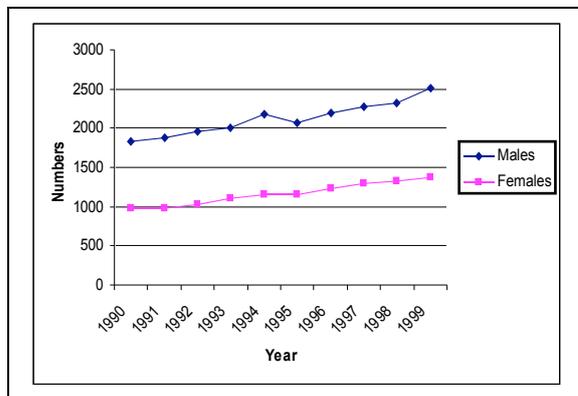
Introduction

Cancer continues to be the leading cause of death in Scotland for people under the age of 75 years (Cancer in Scotland, 2004). The incidence of different forms of cancer in the population varies, but one form of cancer that has become more common in Scotland in recent years is oral cancer. Oral cancer affects the lip, mouth or the tongue, and around 617 new oral cancer cases are identified in Scotland each year and in the UK as a whole in 2006, there were 4,660 cancers of the oral cavity and pharynx.

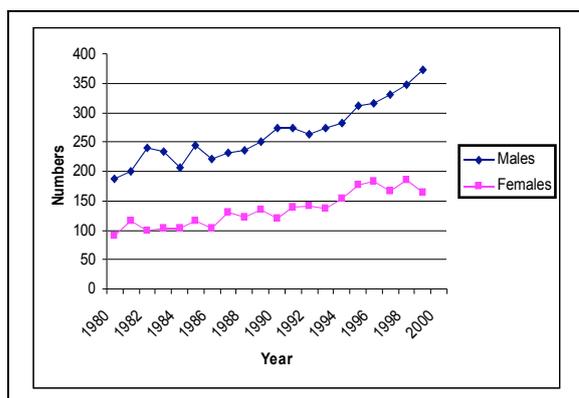
The incidence of oral cancer in Scotland and the UK as a whole varies by age and sex. Incidence increases with age and over 80% of cases occur in people over the age of 50 years (Johnson & Warnakulasuriya,1993). It has traditionally been a disease affecting men, with male : female ratios of 10:1 at the turn of the last century, this gap has reduced dramatically in recent years and is now less than 2:1. The age standardised incidence of oral cancer for men in the UK remained at around 7 per 100,000 males between 1975 and 1989. Since then, however, the rate has increased to reach 10 per 100,000 men in 2005, which is an increase of 41% since 1989 (Cancer Research UK, 2008). Rates have also risen in females, with an average increase of 2.7% each year since 1989 (Cancer Research UK, 2008). The rising trends in oral cancer in the UK and particularly for Scotland are shown in Fig 1.

Fig 1- Trends in incidence of oral cancer in the UK and Scotland, by year and sex: 1980-1999 (Conway et al., 2006)

A. Registrations of Oral Cancer in the UK 1990-99



B. Registrations of Oral Cancer in Scotland 1990-99



These rising trends should be seen in the context that during the same period most countries in Europe (including the UK) are experiencing declining trends in many cancers in other sites (eg. lung, stomach and colorectal in men and breast cancer in women) (Boyle et al 2003; Peto et al 2000). Of particular concern is the fact that rates of oral cancer in young people are increasing (Llewellyn et al., 2001). For men over 80, oral cancer rates has halved since 1975, while rates for men in their late 60s and 70s have remained stable. In contrast, there have been large increases in rates of oral cancer in men in their 40s and 50s. Incidence in this age group has more than doubled from 3.6 to 9.2 per 100,000 for men aged 40-49 and from 11.5 to 25.3 for men aged 50-59. These increases have been particularly marked for cancer of the tongue (Cancer Research UK, 2008). Increases in oral cancer amongst younger patients, usually defined as those aged 45 or less, have been observed in Scotland at similar rates to those identified in the UK as a whole (Conway et al 2006; Scottish Intercollegiate Guidelines Network ,2006).

These trends have been found across Europe (Levi et al., 1995) as well as in USA (Shiboski et al., 2005).

Survival rates for oral cancer are relatively low, with a 5 year survival rate in the UK of 50%. Death to registration ratio (0.44) is worse than for breast cancer (0.35), cervical cancer (0.34) or skin melanoma (0.29) and is comparable to prostate cancer (0.43) (British Dental Association, 2000). Survival rates in Scotland have shown a decline rather than an improvement in recent decades, despite improved treatment techniques for cancer generally (McCann et al, 2000a).

Public awareness of oral cancer and the associated risk factors is low in the UK (Warnakulasuriya et al 1999; Lowry and Craven 1999). 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 (Amir and Kwan 1999). As well as lack of awareness, other factors have been implicated in delaying medical consultation including misattribution of symptoms, embarrassment and not discussing with others (De Nooijer et al 2001).

There have to date been no detailed investigations of current patterns of oral cancer symptom recognition and paths to referral associated with management pathways in Scotland. Glasgow patients have been included in the ongoing multi-centre ARCAGE study (Lagiou et al., 2008) although this study focuses principally on quantifying the role of genetics and alcohol and other epidemiological risk factors, and not on patient understanding. Patients' views and experiences were documented in a qualitative study undertaken by the National Cancer Alliance (NCA, 2002) 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 (Scottish Intercollegiate Guidelines Network 2006). Indeed, one of the recommendations in the Guideline suggests research into "the aetiological factors responsible for the changing incidence and age distribution of head and neck (mouth) cancer". Furthermore, the traditional risk factors of alcohol and tobacco do not seem to always apply in this younger age group. Absence of traditional risk factors can lead to missed diagnosis as stereotyping by GPs and GDPs is a problem and leads to the view: If they don't smoke, don't drink, don't come from a deprived background they cannot have mouth cancer. Examining reasons for delay in diagnosis young people, lower levels of education and those who smoked lower amounts of tobacco were at risk of delay (Llewelyn et al., 2005). Both SIGN and the King's study, (Llewelyn et al, 2004a,b, 2005) supports this. The King's study demonstrates that in 25% of their sample the cause could not be attributed to excess alcohol and/or tobacco use. While changing lifestyles and binge drinking and increasing tobacco use in women, could account for some of the increases in this younger age group, in a quarter of the oral cancer cases this increase is not currently understood.

Symptom recognition and onward referral by medical professionals is also key (Conway et al, 2002), and may currently be inadequate. A need for continuing education programmes for primary care practitioners in oral cancer-related activities was raised in a Scottish study (Macpherson et al, 2003) and other Scottish research has found that 90% of dentists (more recently 84%) are keen to receive further training in the area of oral cancer (McCann et al, 2000b; Carter & Ogden, 2007). Otherwise, there is currently a limited picture in Scotland of experiences with mechanisms of diagnosis and oral cancer and inadequate understanding of the prospects for improved early detection.

The current study

With this background in mind, NHS Greater Glasgow and Clyde and King's College London in partnership with The Ben Walton Trust (charity number SCO24990) www.benwaltontrust.org initiated an exploratory study in 2006 to examine the experience 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.
- identify opportunities for improvements in health education and oral cancer awareness highlighted from patients' individual experiences.
- establish the feasibility and utility of this type of research with this patient group.
- identify issues that would benefit from further research in a larger scale study with a larger sample.

This report presents findings from this exploratory study. It begins by describing the methods used in the research. The main body of the report then goes on to describe findings from interviews with fifteen younger oral cancer patients, and concludes with a discussion of the main findings and suggestions for further research.

2. Methods

This study employed qualitative methods to examine the views of younger oral cancer patients. It involved semi-structured interviews and the data was analysed with the aid of software (see below) for qualitative data analysis. This section of the report describes the sampling approach used, how interviews were conducted, and the process of data analysis.

2.1 Sampling

The study aimed to recruit 15 patients under 45 years of age, previously diagnosed with oral and oropharyngeal cancer (referred to as mouth cancer for this study) in the three years prior to the study, resident in the central belt of Scotland. NHS Greater Glasgow & Clyde Primary Care Ethics Committee approved the study protocol.

Initially, relevant surgeons were contacted through information from SCAN (the South East Scotland Cancer Network) and WoSCAN (the West of Scotland Cancer Network) to contact patients treated in their units that satisfied entry criteria. This yielded no results and so Clinical Nurse Specialists attached to each unit were asked to invite patients who fitted the agreed criteria to take part in the study. With some follow-up phone calls 15 participants were recruited for the study, from three hospitals: St John's Livingston, Glasgow Royal Infirmary (Canniesburn Unit) and the Western

General, Edinburgh. 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.

2.2 Interviews

Interviews were conducted using a semi-structured interview schedule (see Appendix I) 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 and 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; and perceptions of the effectiveness of diagnostic and treatment pathways.

Most of the interviews lasted between 20 and 40 minutes, with one lasting 1 hour. The interviewer was a Liaison Counsellor working in the Oral and Maxillofacial Surgery Unit of St John's Hospital in Livingston.

Interviews were audio recorded. Following recording most of the interviews were transcribed in summary form. Those interviews that were not transcribed (n= 4) were analysed using the audio file.

2.3 Data analysis

The interview transcripts were analysed using a thematic framework (Flick 1998), 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 time-line 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 (see Appendix II) was 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 findings sections that follow, the research participants have been anonymised and their names have been changed.

3. Findings

3.1. Awareness

Most of the research participants had some awareness of oral cancer prior to noticing their own initial symptoms, and this prior knowledge came from a range of sources. 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 advert; 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; and those that had no prior awareness of this particular cancer.

Of those who had some prior knowledge, several had remembered seeing a TV advertisement that was developed as part of the West of Scotland Cancer Awareness Programme and funded by Cancer Research UK. For some interviewees, seeing this ad 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 3 or 4 elderly gentlemen, 3 of which or 2 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 [6 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 dental surgeon, 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 having 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 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 prior to 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 cases the responses seem to suggest that a prior knowledge of oral cancer was instrumental in them either visiting a health care professional in the first place, or in deciding to ask for further checks or a referral. However, this may be an erroneous assumption in at least some cases. 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.

3.2. 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 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. 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 did not feel that the initial symptom was serious until they were referred for further tests, and in some cases not until final diagnosis.

3.2.1 Symptom recognition

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

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 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]

3.2.2 Self-treatment

After noticing their initial symptom several of the interviewees (6) had used some kind of self-treatment provided by a pharmacy. Of these a few had spoken to the pharmacist, and some had spoken to an assistant or bought something over the counter. In several cases they were sold Bonjela or another cream, others mouthwash, 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]

3.2.3 '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 8 weeks, and for half of the sample this period was no more than 4 weeks. There were various causes of this 'patient delay'.

Some interviewees already had appointments booked with their GP or dentist and so waited for this appointment rather than book another:

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 2 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 4 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].

Some 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, Andrew].

3.2.4 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. 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 most were suspicious enough to want to get their symptom checked, many 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]

3.3. Initial Diagnosis

This section covers the research participants' experiences after the initial stages of self-diagnosis and self-care (including treatments supplied by a pharmacist or bought over the counter). The interviewees were asked to describe the process they went through from their decision to make an appointment with a health care professional, through to their eventual referral to a specialist. They all described a series of decisions, events and encounters in either dentist and GP surgeries (in some cases both). Some went to see their GP initially and were referred from there for further tests; some went to see their GP and were either told to visit their dentist, or decided to do so themselves; and some saw their dentist in the first instance. For some interviewees this process involved misdiagnosis and repeat visits to the same or different practitioners. This section will look firstly at the role of General Practitioners in diagnosis, then at the role of Dentists, while recognising that there is some cross-over where the initial diagnostic process involved both. Finally one research participant's account will be described in more detail to give a picture of their experiences in this part of the diagnostic process (Box 1).

3.3.1 Role of the General Practitioner

This section summarises the interviewees' description of the role of the General Practitioner in the diagnostic process, and their experience of contact with their GPs. It includes description of the extent of previous contact and the nature of the relationship between interviewee and GP; details on the number of interviewees that saw a GP for initial advice about their symptom, including those who also then saw a dentist; and descriptions of the onward referrals made by GPs and the interviewees' experience of this.

Patient contact and relationship

Four of the interviewees described themselves as regular visitors to their GP for other medical conditions. One of these four one said that he felt he may have been a 'bit of a hypochondriac' [Andrew]. The rest said that they only went to their GP as and when they needed to. The majority said that they had a good relationship with their GP, although one described the relationship as problematic before she presented with her symptoms:

I was at the same practice from when I was born...until 2002...but it was different doctors all of the time - you never really got one that you would say was one you preferred [Lynne]

GP consultations

Nine research participants, over half of the sample, consulted their GP initially to ask about their symptom, and in most cases had made a specific appointment for this purpose. Two interviewees did not make separate appointments but saw the doctor at regular appointments for other conditions (in one case a nurse-run clinic). In most cases this was within 8 weeks of them first noticing their symptom.

For some this was not a wholly good experience, with some feeling that their concern was not taken seriously:

I had the symptoms of dysplasia for ...about six months and I went to my doctor's and they just kind of pooh-poohed it - nothing there - you're fine - had a quick look - but the problem with dysplasia is that it comes and goes...but I am annoyed - the doctor was really offhand about it [Susan]

I thought at the time that the locum could have taken me a bit more seriously [Deborah]

Early diagnoses

Some interviewees were given diagnoses by their GPs at this initial appointment, a diagnosis which they did not necessarily accept:

When I saw my GP (a locum – I couldn't see my own GP) she suggested some 'Bonjela' as she thought it was an ulcer at worst. [Deborah]

I remember saying at the time I didn't think you got thrush in your mouth - I've never even had thrush [Karen]

Two interviewees visited the doctor twice: one was told to try a mouthwash for a week [Mark] and the other [Lynne] returned when there was no change to her symptom two weeks later. Two GPs told patients [Margaret, Simon] that they would have suggested the self-treatments which the patients had already tried (Bonjela and a 'Q tip'). In all these cases interviewees were then referred on to a specialist.

No research participants mentioned receiving any information about oral cancer from their GP, although none made any comment on this except for Deborah:

In hindsight, I realize that, at the time, so few people were aware of oral cancer and I wasn't really in a very high risk group

GP referrals

Of those interviewees who saw their GP first of all, three were advised to see their dentist. Five others were referred straight to a specialist of some kind, either in a dental hospital, MF unit, or an ENT specialist. In most cases this referral was immediate on the first or second appointment (a week later) with the GP.

Two interviewees were not referred on, either to a dentist or a specialist [Karen, Susan - see 'consultation' above]. One felt able to exert some pressure to get a referral:

Because of my nurse training and the fact that the sore had been there a year, I refused to leave the surgery until I'd been referred to ENT for further investigation [Deborah].

3.3.2 Role of the Dentist

This focus of this section is the role of the dentist in the diagnostic process as related by the research participants in the descriptions of their experiences of contact with their dentist, and in some cases other dentists. This includes the extent of previous contact and the nature of the relationship between interviewee and dentist(s); details on the number of interviewees who went to a dentist in the first instance (rather than GP) for advice about their symptom; and descriptions of the onward referrals made by dentists.

Patient contact and relationship

The majority of interviewees said that they visited their dentist regularly for check-ups, some mentioning 6 monthly (though this was not asked of all interviewees). Three did not visit regularly, two because of bad experiences when they were young, and one because she had not been able to access an NHS dentist:

Ashamed to say not for a long time – I was not registered with an NHS dentist and could not afford to pay for private care. However, I found an NHS dentist the year before my diagnosis (that's not to say that I went regularly though) [Deborah]

Over half of the interviewees stated that they had a good relationship with their dentist; although some responses to this question were incomplete, nobody reported having a bad relationship with their dentist, before the event of the oral cancer.

Dental consultations

Five interviewees saw their dentist in the first instance. Two [Robert, Julie] were at routine appointments: one had not noticed anything himself - his dentist noticed the suspicious symptom first:

I did not know I had it... I was going to the dentist for two fillings...and they found some pus at the back of the throat. [Robert]

Three interviewees had made an appointment specifically to have their symptom investigated [Alice, David and Peter].

And then after New Year I went straight to my dentist...as soon as they opened [Alice]

A further four had seen their GP first and three had been advised to make an appointment with their dentist (although in one case the GP had already made the referral immediately before this appointment). The fourth made the decision to ask her dentist about her symptoms as she was not happy with the explanation given by her GP at least 2 weeks previously, who had said that she had a blocked salivary gland. She had since developed a painful swelling in her cheek which she asked to be checked by the dentist, at a routine appointment with the dental hygienist. In hindsight she concluded:

... The dentist sees you probably more frequent than the doctor and I think they are more clued up on the signs [Karen]

One interviewee [Susan] had seen her GP nearly 3 years previously after she had been diagnosed with Dysplasia, but her GP did not refer her for further treatment. Consequently she referred herself to her dentist, and she had repeated investigations, biopsies and other procedures to investigate or treat this condition. More recently she felt that it had got considerably worse and she again asked her dentist to investigate, this time at a routine appointment. It was this more recent referral from her dentist which led to her diagnosis and treatment for oral cancer. Thereafter she referred to her dentist only, and did not return to the GP:

My doctors have just ignored it all, there's been no contact, no nothing...so I just deal with my dentist - she's very good [Susan]

Early Diagnoses

Some dentists did not refer interviewees straight away for biopsies. In some cases they treated them first for other conditions. One [Peter] had his 'blocked salivary gland' drained a few times over an unspecified period; another interviewee's [Andrew] dentist recommended that he use a gum guard to relieve his sore mouth which he had for over 2 years; and another interviewee [Alice] was treated with antibiotics for an abscess for 3 months (though only

for two weeks by her dentist, and then repeatedly after referral to the dental hospital):

I still at that point thought this is an infection related to teeth because I'd only ever heard of an abscess being related to some sort of problem with teeth.... so I had more antibiotics from the dental hospital ...it didn't improve. I went back for another appointment and they gave me more antibiotics, and all in all I think I had about eight lots of antibiotics and at one point I was taking two different types of antibiotics at the same time which actually made me feel very unwell ... I felt rather fobbed off with yet more antibiotics and I felt they should have addressed the issue sooner [Alice]

The interviewee who was a dental surgeon rejected his own dentist's advice and pursued further investigations he thought more appropriate:

He [dental colleague] unfortunately thought it was an Aphthous ulcer and recommended taking some antibiotics to prevent secondary infection. I was unsure as I am pretty clued up on Aphthae. However I did not think it was a bad idea. [David]

These early diagnoses and treatments may well have delayed the final diagnosis for oral cancer for some of the participants in this study.

Dental referrals

Of the interviewees who saw their dentist, most (with the notable exception of the two people who experience a significant delay [Peter and Andrew detailed above] were referred for further tests immediately, either to a dental hospital, or a specialist hospital unit.

Most did not appear to be warned at this stage that they could have oral cancer:

She couldn't say what it was and ...best to go and see a specialist...she said 'I wouldn't worry about it'...she wasn't speculating what it was...she just said it was pus [Robert]

Two interviewees [Karen: case study below, and Andrew] were referred to another dentist or dental practice for a biopsy, and in one case this turned out to be a private dentist who charged for the procedure [See case study: Andrew].

One referred himself for further tests with a colleague:

I contacted an oral surgeon who saw me within a few days and he agreed to biopsy within a week [David, dental surgeon]

The other research participants were referred onwards by their GP. Only one said that she was given information on oral cancer by her dentist [Julie]. Five did not see their GP at all, but were referred by their dentist.

Box 1: Case Study: Karen

Karen (aged 44 at diagnosis) does not smoke or drink alcohol. She is married and was employed at the time of the interview. She visited her dentist every six months for check ups and had additional 3 monthly appointments with the dental hygienist. She saw her GP routinely every six months (for HRT) and described their relationship as good.

She was aware of oral cancer after having seen the TV campaign some time before, and this is what prompted her to go to see her GP:

The only thing that kept coming back into my mind was the advert on oral cancer - that's what actually sparked it and it made me think - well there's been a campaign three year back - and it told you - got a lump in your mouth - don't let it go - get it checked.

Karen first noticed a lump in her mouth in the latter half of 2006 which she was concerned about. As she had a routine appointment booked with her GP for two weeks later, she did not make another:

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.

At this appointment her GP diagnosed what Karen referred to as a 'garybunkle' which was described as a salivary gland that fills up and drains. Her GP did not consider this to be worth any further investigation:

He told me not to worry about it - it's fine.

At the end of November 2007 Karen found that the lump had started to swell and the swelling was travelling to her cheek, which had become painful. At this point she suspected that it was an abscess. She had a routine appointment booked, this time with her dental hygienist and while she was there she asked if the dentist could look at her mouth:

The dentist did have a look at it and he wanted to refer me to the dental hospital in Glasgow... but didn't like the look of the size of the lump so instead he referred me to a friend of his ...it's a high street clinic in Glasgow - to get the lump taken away and a biopsy done...he specialises in taking lumps and abscesses and things like that.

Her lump was removed in January 2008 (it is unclear whether she knew this was a biopsy at the time), and she was told she would get the results in three weeks. Nearly three weeks later the dentist contacted Karen and asked her to come in:

He [said he] just wanted to have a wee look and see how things were healing

She was given a referral to the MF department at the hospital for the next day. At this stage Karen? did not suspect that she had oral cancer:

I knew there was something but I didn't expect it to be that bad ...I actually thought it was an abscess or a cyst or something like that...I went up on my own 'cos I really didn't expect it to be [cancer] [Karen]

In total there was a delay of over 14 months between Karen first reporting her initial symptom to her GP and her biopsy.

3.4. FINAL DIAGNOSIS

The research participants interviewed reported receiving a variety of diagnostic and treatment procedures. This study does not focus on the details of these procedures, but rather on the interviewees' experiences of moving through the health care system. Therefore we are not able to explore the details of treatment beyond what the interviewees described.

This section includes reports their experiences of receiving their final diagnosis. It summarises the information they were given about their particular condition and treatment (if any), and details any other kind of support they may have received. It also summarises interviewees' experience of trying to understand why they had oral cancer. Box 2 (below) gives details of time between the patients' initial appointment with their GP or dentist, and biopsy. At the end of the section a case study gives a more detailed account of one research participant's experience of the process of diagnosis (Box 3).

3.4.1 The experience of diagnosis

In all cases research participants received their diagnosis of oral cancer within 4 weeks of biopsy, and in over half (8) cases within 2 weeks. Several of the interviewees did not seem to have anticipated that they might receive a diagnosis of oral cancer, until their consultant informed them after their biopsies, and were therefore unprepared for their diagnoses, and did not know what they should ask:

I knew there was something but I didn't expect it to be that bad ...I actually thought it was an abscess or a cyst or something like that...I went up on my own 'cos I really didn't expect it to be [cancer]...there was a lady sitting in the corner and the Consultant just introduced her as [the Macmillan nurse] and I never thought anything of it [Karen]

At that point it was a terrible shock because I had no idea what it was [Alice]

They then give you this diagnosis and you're kind of going 'oh my god, I'm not expecting that' and then ...they're trying to book me in and I'm - 'I'm sure I should ask...' [Alice]

A few interviewees had suspected that they could receive a diagnosis of cancer:

[the GP] didn't say that it was cancer, but obviously by his actions and his urgency I kind of figured out it was something quite majorly wrong and I started to do some research myself...When I met [the consultant] and he gave me the diagnosis that it was cancer, as I said to him at the time 'that's what I thought it was' - because of this research I'd done I'd mentally prepared for that [Mark]

Some clearly found the process of diagnosis confusing and were unclear at what point their symptoms were deemed serious:

I was told by my consultant at the [general hospital] that because I'd mistaken what they'd said at the dental hospital as being benign I didn't realise it was malignant...then I realised how serious it was... I just got the wrong end of the stick [Robert]

Research participants' experiences at the point of diagnosis (i.e. the consultation) were not probed in these interviews but two made negative comments about the delivery of the diagnosis. Although one interviewee had had an otherwise positive experience throughout diagnosis and treatment she was unhappy with the way in which her consultant informed her that she had oral cancer:

The Consultant sat me down in the chair and said 'oh yes we have your results back...you do have cancer' and walked away...the consultant then wrote out a letter and just handed it to us and just walked away and that was it... [my husband] and I walked out onto the street and I didn't know what to do...this was the only one person I could say that I felt was very cold... I think if they'd have given you 5 minutes to come to terms with it... [Margaret]

Another was unhappy with administrative failings, which led to her being unprepared for her diagnosis:

When I met with the consultant for my diagnosis [2 weeks after surgery], firstly I was not expected and my notes were unavailable ...and secondly, he was under the impression that I already knew I had cancer and I learned about it when he began discussing my options. I was seemingly supposed to have had an MRI in the intervening weeks ... The consultant seemed very upset and angry at the situation and I found myself comforting him! ... To be fair, the consultant gave me plenty of opportunity to ask questions, but other staff seemed disinterested. [Deborah]

When asked whether they thought anything could have been done differently some interviewees emphasised that they were pleased with the speed of the referral and diagnostic process:

It's happened pretty quick - but all through the hospital it's been very quick as well... I've never had any great length of time that I've sat and thought 'what's going to happen here?' [Margaret]

The treatment has been first class, the diagnosis was swift - everyone has been great, and the Macmillan side of things...everything has been terrific [Sarah]

Even some of those that waited some time before they received their diagnoses had positive comments on their diagnosis and treatment once they were 'in the system':

Once they had diagnosed initially what it was I had very efficient, timely care [Alice]

One of the things I've constantly said is 'where's the waiting list?' because I've never experienced an issue about seeing anyone - once the ball got rolling [Susan]

However some (including two interviewees quoted above) described negative aspects of their experience. There were a number of general comments on interviewees' experiences dealing with health care professionals, which focused on issues such as trust and communication:

You just take your doctor's opinion - you just go by what your specialist knows. [Karen]

You are completely relying on their expertise - it's not up to the patient to say 'well what about so and so' [Alice, repeated treatment with antibiotics]

Medics need to listen to their patients more, about expectations (on both sides) and to be honest about outcomes and effects of treatment. [Deborah]

One interviewee described repeated episodes where she felt she had been treated unsympathetically and without understanding of her particular condition and circumstances, particularly when she was undergoing tests and procedures as an in-patient:

My constant irritation was my lack of information pre- and post-...my lack of options, my lack of even involvement in that process [Susan, self-employed]

Box 2: Time

Just over half of the sample (8) had a biopsy within 4 weeks of first seeing a health care professional for advice about their symptom, most within 1-2 weeks (the dental surgeon saw a consultant within a few days). Three research participants had biopsies within 3 months and all of them had additional tests or procedures in the intervening period, including treatment with antibiotics. Two biopsies were conducted by dentists in clinics.

Four research participants had gaps of between 8 and 14 months between presenting with their first symptom and their biopsy. One [Paul] had unexplained waits of 2-3 months between appointments and procedures; the other 3 [Deborah, Karen, Susan] had been diagnosed with other conditions [Leukoplakia, a blocked salivary gland, and Dysplasia respectively] and had various appointments and investigations over this time.

Several interviewees moved from seeing doctors and consultants at ENT departments or dental hospitals, to appointments with MF consultants in other hospitals or departments, and this may have contributed in some cases to a delay in receiving a diagnosis.

3.4.2 Follow up

After treatment very few of the interviewees had any kind of follow up at all from their GP, with only one person receiving phone calls to see how she was:

She's phoned me a couple of times at home....when I was in hospital she phoned...after I come home she phoned me...she's really good [Margaret]

One interviewee [Mark] occasionally saw his GP in the street and had an informal chat; another [Robert] said that he only saw the GP to get a sick note. One [Paul] received another referral from his GP for further tests on his tongue, which proved to be scar tissue and no further treatment was required.

Some interviewees expressed surprise that their GP had not taken an interest after diagnosis, but this area was not probed further. None reported any active follow up by dentists, although some mentioned returning to their dentists for check ups, and several said that their dentists were informed by letter of their diagnosis and treatment.

3.4.3 Information

The research participants were asked whether they were given any information to take away, or told where to find out more about oral cancer. The majority said that they were not given any written information either by their GP or their dentist prior to their diagnosis. One interviewee reported picking up a leaflet at her dentist, but it is not clear at what stage she did so, and whether it was her dentist who gave it to her [Julie].

SIGN Guideline 90 quotes the need for patients to have a meeting about their treatment plan separate to that concerning the diagnosis. In addition, there is sometimes the need for individualised materials giving information concerning the specific treatment plan, tests, staff involved in delivering care etc.

Several said that they were either given or picked up leaflets or other written materials at the hospital, or after their diagnosis. Some interviewees looked up oral cancer on the internet (or had relatives who looked it up), although none appeared to have been directed to relevant websites by a health care professional:

I just [did a] general search on Google for mouth lesions, ulcers...and that's when I spotted just exactly what I had - or looked like what I had [Mark]

Most of those who did use the internet to research their condition did not seem to have found this particularly helpful, possibly because they were not sure where to look, or could not find information specific to oral cancer, or their cancer site. One interviewee said she felt it had been a mistake to look on the internet:

I couldn't get any specific information on [my cancer site] on the internet - all I could get was information on head and neck cancer which was too vague and

it also gave a lot of statistics about survival rates which I wish I hadn't read [Alice]

After diagnosis a few interviewees were given e-mail or phone details for nurses (one mentioned Macmillan nurses, one 'liaison nurses', and one the 'clinical nurse') but only one reported making contact. It is not clear that they found this useful, or the most appropriate route for receiving information:

[The Macmillan nurse] said if I needed pamphlets - any information at all - just to ask her... but I think it takes you a wee while to get used to the initial shock and you don't think straight [Karen]

Communication's not good...the liaison nurses are there but they won't give you information - they pass everyone onto the consultant... of course I'm anxious, but I actually wanted information [Susan]

Some interviewees had specific suggestions on how communication might be improved, and anxiety reduced:

I think the one phrase that everybody must not say is 'don't worry' because you do anyway ...and that makes you worry... because you think 'what are they not telling you?' [Susan]

I think certainly to have been offered some information about the... specific [cancer] site... that would have been very helpful [Alice]

Information is paramount. I am a Dental surgeon who knows far more than a member of the general public, yet not even I knew the full extent of what might lie in store and how to cope with these things. Staff of all levels were truly excellent in terms of compassion and attempting to explain things. There is a massive talking information overload. [David, written response]

David recommended the production of a DVD which was cheap, accessible and could be viewed repeatedly by those receiving a diagnosis of oral cancer.

3.4.4 Support

Research participants were also asked if they had spoken to anyone else about their oral cancer, including family and friends, and many mentioned the notion of 'support'.

The majority of interviewees (12) said they had told partners or family members about their diagnosis and some mentioned their importance as a source of support:

They have been my rock and without them I couldn't have got through it. [Deborah]

My sister's a nurse so I spoke to her and she was a great support through it - my brother was suffering from... cancer at the time so I was speaking to him about different treatments and things... so I had a lot of support from friends and family [Sarah]

Two interviewees mentioned the support of close friends, one whose close friends were nurses. One did not mention the support of friends or family, and said that she had told very few people about her cancer:

I'm quite a private person...I don't want people to make things bigger than they are [Susan]

A few mentioned health care professionals in terms of the support they provided, including Clinical Nurse Specialists and staff at a 'Maggie's Centre'. However one interviewee referred to the fact that she was not aware that she could access this service:

I was aware of the existence of 'Maggie's Centre' but it would have been helpful to have been 'referred' there for information and support (I thought that patients had to be referred officially so it didn't occur to me to go there) [Deborah, written response]

Some participants said that they would have liked more support; including the opportunity to talk to another person who had had oral cancer. However one interviewee who did this did not in fact find it particularly helpful as the other patient had a different cancer site:

I went to the Maggie's Centre they were very supportive but there wasn't anybody else there - or any information - about my particular cancer site and that made me feel quite isolated... I did meet one other woman who had a mouth cancer but it was different to mine... there wasn't anybody else there to talk to about it - that could give me any advice - or understand [Alice]

3.4.5 Explanations

Near the end of each interview, each patient was asked if they knew why they had got oral cancer. The reasons given included references to smoking, drinking, trauma to the tongue and 'fate', and some said that they could not give a reason.

Some acknowledged that this was because they were smokers, or ex-smokers, or that it was, at least in part, connected to their heavy drinking:

I smoked a lot - quite heavily - and I had a drink problem as well... but I got over that by the time this appeared ... [Lynne]

I suspect it's a mixture of biting my tongue, or the constant scratching of my tongue, and drinking probably a bit too much alcohol because I don't smoke [Andrew]

Some of those who smoked or drank regularly were not convinced that this was the cause of their cancer, and some of them reported that they had been told there was no obvious explanation, and that this is what they believed:

When I spoke to the consultant about it he said - no they couldn't pinpoint that smoking was the reason for it - if it was directly in the mouth, right in the tongue or on the mouth itself...but because mine was...coming from the salivary gland out into the mouth, not going into it...[Robert]

It could be a result of me biting my tongue, as I believe, or it could be age related as [the consultant] stipulated, or it could be the lottery of life ...there is a link - even though it hasn't be proven - there is a link to smoking [Mark, still a smoker]

Several interviewees (including some who smoked or drank) referred to 'fate' or the reason they got cancer being 'just one of those things'.

I remember years ago my mother saying 'what's for you won't go by you' and it's just stuck in my mind [Margaret]

Others, who did not smoke or drink heavily, could not identify what had led them to develop cancer, and some found this hard to accept:

You think 'how could this happen?' I don't smoke, I don't drink - very heavy - I'll have three units if I'm out and that's it [Karen]

that's the big unanswered question - why I got it - its very difficult to accept that - also in a practical sense - you are desperate for it not to come back and you want to know what you can do to stop it coming back - well if you're told actually there's nothing you can do to stop it coming back - that's very difficult ...it's all about feeling completely out of control [Alice]

...it is quite a burning frustrating mind damaging question! [David]

Box 3: Case Study: Andrew

Andrew (39 at the time of diagnosis, and married with a young child) is a non-smoker, although he did smoke 'a little' when he was younger, and does not drink heavily, although he says he used to drink 'rather a lot' up until his 30's. He was aware of oral cancer, having seen a TV ad some time ago. He recalls that he twice bit his tongue badly, ten and five years ago, and thought that this, along with his drinking, might have some connection with his cancer, which developed in the same part of his tongue. Around 3 years ago he visited his GP as his tongue had become sore:

It was very definitely just down the side of where the tumour was but originally it was just the whole tongue that was sore

His GP took a 'very quick look' and told him to see his dentist, which he did. His tongue was sore for over 2 years and at his 6 monthly check-ups he repeatedly told his dentist that it was bothering him:

Whenever I went to the dentist the first thing she would always say to me 'so how have you been Mr. [Smith]' and my standard response was 'teeth are fine tongue is sore'

Although the dentist did check his tongue, he was not referred in this time:

Every time I'd go I'd say 'teeth are fine - tongue's sore'...she kept on pondering sending me to the dental hospital

Andrew was told to wear a gum guard, and renewing the gum guard was the only treatment the dentist suggested. In January 2007 Andrew felt that his tongue had got harder and went back to the dentist. This time the dentist did refer him to another dentist in the same practice who did a biopsy. Andrew was not aware that this was a private dentist:

He did a biopsy - and then he told me that would cost me £100 which I wasn't best pleased about

Andrew received a phone call from the hospital a few weeks later to arrange for him to come in for his results, and at his appointment he received his diagnosis. Up to this point he had not expected that he might have cancer:

I walked in and the first thing I noticed there was about three other people in the room... but even then I didn't really think much of it...he said 'do you know why you're here' and I said 'yes its because of my tongue' and he said 'what do you think it is?' and I said 'its just sore - I don't think its cancer or anything'...and then he basically said 'what if I told you it was cancer?'...if I hadn't been sitting I'd have keeled over...it was just total shock

His operation was arranged very quickly as his wife was pregnant at the time of his diagnosis.

In hindsight Andrew said that he wished he had 'pushed' his dentist more for an earlier referral, and that he was annoyed that the dentist did not seem to want to investigate the problem further:

...I always got the impression... they were more interested in trying to persuade me to get a fresh gum guard

Perhaps because of this emphasis on gum guards, he reflects that he was totally unprepared for his diagnosis, and this has had an impact on the way he feels about his experience:

I know it sounds daft...even though I'd had a biopsy...I just never even...although I knew about oral cancer...I wasn't in any way stressed...I just thought they would say maybe we'll give you a bigger gum guard...or even cut a bit of my tongue off, but not because they were getting rid of a tumour...I had no idea what I was going to be told.

At the time of the interview, a year after his operation, Andrew said that he would like to be able to 'give something back' by supporting other patients. He also said that since he had been telling people about his experience with oral cancer, at least 4 other people he knew had made appointments to see a dentist to have something in their mouth checked. Although he was unhappy with his treatment pre-diagnosis, Andrew said that he had not been able to find another dentist, and had since returned to the same practice for his regular check-ups. He did not receive a refund of the £100 charge for the biopsy.

4. Discussion

This exploratory study highlights both differences and similarities between the experiences of younger oral cancer patients in Scotland. It shows how the patient journey – from initial identification of a symptom, through diagnosis and treatment, can vary significantly between individuals. Differences arise as a result of patient knowledge and characteristics and also system factors – whether that be the availability and accessibility of advice and treatment or the knowledge and experience of health professionals. 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 implications in this concluding section of the report. In particular, we examine: gaps in understanding and awareness of oral cancer and its risk factors; delay in diagnosis and treatment; the experience of diagnosis and treatment; 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 (Warnakulasuriya et al 1999; Lowry and Craven 1999). 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 advertising 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.

What is also striking in this study is interviewee’s 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.

For example, research shows that up to 94% of adults with oral and pharyngeal cancer have been or are current smokers (Blot et al, 1988). The reported pooled cancer risk estimate is 3.43 times higher in smokers compared with non-smokers (confidence intervals 2.37 to 4.94) (Gandini et al 2008). Yet in this study smoking did not figure prominently in patient’s 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 10 years for the risk to return to that of a non-smoker (Warnakulasuriya et al 2008) and pooled risk estimates for ex smokers are higher compared with non smokers (CI 1.40 , CI 0.99-2.00) (Gandini et al 2008). These findings suggest that even amongst 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.

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, health professionals could not tell them how to avoid a recurrence. Developing a second cancer was a fear for many interviewees.

This study also highlights that patient's understanding was not particularly enhanced by the provision of any written information from health professionals or advice about where to go for further support. The majority of interviewees could not recall being given any written information from their dentist or GP, although a small number did obtain a leaflet during hospital visits. Accounts of the usefulness of information obtained from internet searches were mixed. Interviewees were more enthusiastic about the verbal explanations offered by health professionals which most found reassuring and helpful. Some were also provided with email or phone details of specialist support services (such as Macmillan nurses) although it was unclear from the study to what extent interviewees had chosen to access this kind of help. At least one patient was not given information about help that they could have accessed ('Maggies Centre') and expressed regret that she had not been referred there for more support and advice after receiving her diagnosis.

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 cancer patients (Scott 2006, Scott et al 2007, Leydon et al, 2003, NCA, 2002) and particularly with younger people in Southern England (Llewellyn et al., 2005).

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 (Scott et al, 2006). In this 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 bonjella) to treat inflammation, for example or merely 'waited' to see if their symptoms would pass without intervention. 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 (Scott et al, 2006). In the SE England study the median delay in presentation among young people was 5 weeks (Llewellyn et al., 2005). 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. 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 (Smith et al, 2005).

In addition to patient delay, interviewees also describe elements of system delay. In most cases this delay occurred after an initial appointment with a health professional. Nine interviewees made contact with their GP in the first instance and a number of these individuals described delay between this consultation and referral for diagnosis and treatment. At least two interviewees described not being 'taken seriously' by their GP when they expressed concern about their symptoms. Both these individuals had to go back to their GP before receiving an onward referral. A third interviewee, a nurse, described how she had to 'push for referral' after experiencing symptoms for almost a year.

Five interviewees went to their dentist in the first instance. In at least one case it was in fact the dentist who first noticed that something was amiss (the symptom being pus at the back of the throat) in the context of a routine appointment and referred the patient on. Another interviewee went to her dentist after being unhappy with the outcome of her GP consultation. Although the small size of our study sample makes general statements about the responsiveness of primary care professionals inappropriate, the overall impression from interviews was that dentists were more likely to take the patient seriously and arrange onward referral and/or further tests than GPs. Initial appointments with dentists were not without their problems, however. One interviewee in particular described repeated appointments and advice from a dentist to wear a mouth guard before further tests were carried out. Two others described treatment with antibiotics and remedial action (draining a gland) before onward referral. These findings echo those of studies in other parts of the UK that have identified considerable variation in practice in both GPs and dentists in ability to recognise symptoms or take patient concerns seriously, and in willingness to arrange onward referral (Leydon et al, 2002, NCA, 2002).

Experience of treatment

Following referral to either a dental hospital or ENT department all the patients in this study had a biopsy, and all received a diagnosis of cancer within four weeks of the biopsy being conducted – some sooner. While the study did not examine the experience of cancer treatment beyond this stage in any detail, interviewees were asked about how the news of their diagnosis was delivered. Some patients reported no problems with this process and were very happy with the explanation and information provided, as well as the care and treatment they received after that point. Others were less positive.

The National Cancer Alliance has recommended that a diagnosis of cancer should be delivered by a consultant with a trained nurse specialist present and information and support should be available for both patients and their families (NCA, 2002). Although the issue of who was present at diagnosis was not specifically probed with interviewees, it was apparent from the accounts of some patients that this ideal scenario was not always played out in practice. Some interviewees described the process of diagnosis as confusing with different information being provided at different stages or by different health professionals. One interviewee complained about the manner in which her diagnosis was conveyed by a consultant who offered little in the way of advice or support regarding what would happen next. One other described administrative failings which involved a consultant wrongly assuming that the patient had already received the diagnosis. These experiences are not unique to oral cancer patients but reveal the importance of the delivery of diagnosis in the context of the patient experience.

Patient Characteristics

The oral cancer patients interviewed for this study were all in their 30s and 40s, as the table in Appendix 2 illustrates. 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 (Leydon et al, 2002). However, it is worth reflecting on the role of socio-economic deprivation in shaping the views of oral cancer patients as a growing literature identifies this as an important theme.

The incidence of oral cancer in Scotland is increasingly linked to deprivation, with those living in deprived areas more likely to develop the disease than those in more affluent communities (Conway et al, 2007). The link with deprivation is not as clear for younger oral cancer patients (Llewellyn et al 2004) and in one study deprivation did not seem to be a major detrimental factor in delay (Rogers et al., 2007). 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 health care system and are treated by health professionals. Munro (2005) 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 postcode data using the Scottish index of deprivation (see Appendix 2) 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. This suggests the younger oral cancer patients in this study may not be typical of many others in Scotland. Further research targeting more disadvantaged – Linda, just wondering why further research should dictate targeting the more disadvantaged given the findings of this study borne out against patients not in that criteria? groups, who are or should be a priority for early diagnosis and treatment, is needed.

5. Conclusion

This small study provides an insight into the experiences of younger oral cancer patients in Scotland, particularly relating to the period prior to treatment. Our findings support those of other studies including Leydon and colleagues who state (Leydon et al, 2002, pg. 325):

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. Mouth Cancer Action Week (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 Week. The study also identified gaps in knowledge about oral cancer symptoms and appropriate referral pathways in particular for GPs and in some cases dentists and this topic would merit further exploration. An audit on knowledge and adherence to NICE guidelines of Head and neck referral (NICE, 2004) by GPs and dentists would be timely. As this study focused largely on the pre-diagnostic phase with more limited information gathered on patients' experiences of treatment, additional research exploring how treatment was received and patients' and

their families views about outcomes would also be valuable. Finally, in the context of widening inequalities in the incidence of oral cancer in Scotland, further research with younger oral cancer patients from more deprived areas is required if we are to learn more about how to improve diagnosis and treatment for this group. Oral cancer could also affect affluent groups among young people and therefore research should be broad and critically evaluate social determinants for disease causation as well as delays in diagnosis in respective groups.

Contributions by authors:

Karin Silver and Linda Bauld for data analysis, literature review and writing the manuscript

Liz Grant - Setting up and managing the study and assisting with the recruitment of research participants and transcription of interviews

Saman Warnakulasuriya - Contributions to planning, design and ethics approval phases of the study and acting as a working group member monitoring the progress of the study. Editing the manuscript.

Rosemary Day- Designing the project methodology

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References

Amir Z, Kwan SYL et al. Diagnostic delays in head and neck cancers. *European Journal of Cancer Care* 1999 8(4): 198-203.

Blot, WJ, McLaughlin, JK et al. (1988) Smoking and drinking in relation to oral and pharyngeal cancer. *Cancer Research*, Vol. 48: 3282-3287

Boyle P, d'Onofrio A, Maisonneuve P, Severi G, Robertson C, Tubiana M, Veronesi U. Measuring progress against cancer in Europe: has the 15% decline targeted for 2000 come about? *Annals of Oncology* 2003; 14:1312-1325

Cancer in Scotland: Sustaining Change (2004)
<http://www.scotland.gov.uk/Publications/2004/05/19344/36943> (accessed October 2008)

Cancer Research UK (2008) *UK oral cancer incidence statistics*,
<http://info.cancerresearchuk.org/cancerstats/types/oral/incidence/#trends>
(accessed October 2008)

Carter LM, Ogden GR. Oral cancer awareness of general medical and general dental practitioners. *British Dental Journal*, 2007 Sept 8; 203(5):E10; discussion 248-9. Epub 2007 Jul 13

Conway DI, Macpherson LM et al. (2002) Oral cancer: prevention and detection in primary dental healthcare. *Primary Dental Care*, 9, 4, 119-23.

Conway DI, Stockton DL, Warnakulasuriya KAAS, Ogden G and Macpherson LMD (2006) Incidence of oral and oropharyngeal cancer in United Kingdom (1990-1999) – recent trends and regional variation. *Oral Oncology*, 4, 6, 586-592.

Conway DI, Brewster, DH, McKinney, PA, Stark, J, McMahon, AD and Macpherson, LMD (2007) Widening socio-economic inequalities in oral cancer incidence in Scotland, 1976-2002. *British Journal of Cancer*, 96, 818-820.

De Nooijer J, Lechner L et al. A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersens model of total patient delay. *Patient Education and Counselling* 2001 42(2): 145-157.

Flick, U., *An Introduction to Qualitative Research*. 1998. London: Sage.

Gandini S, Botteri E, Iodice S, Boniol M, Lowenfels AB, Maisonneuve P, Boyle P. Tobacco smoking and cancer: A meta-analysis. *Int J Cancer* 2008; 122:155-164.

IARC Alcohol Related Cancers and Genetic Susceptibility in Europe (ARCAGE). European study of cancers of the head and neck. International Agency for Research on Cancer (IARC), Lyon (Protocol) 2002
<http://www.iarc.fr/ENG/Units/arcage/arcage2.html> (Accessed September 2005)

Johnson NW, Warnakulasuriya KAAS. Epidemiology and aetiology of oral cancer in the United Kingdom. *Community Dental Health* 1993;10, Supplement 1 : 13-29

Lagiou P, Georgila C, Minaki P, Ahrens W, Pohlman H, Benhamou S, Bouchardy C, Slamova A, Schejbalova M, Merletti F, Richardi L, Kjaerheim K, Agudo A, Castellsague X, Macfarlane TV, Macfarlane GJ, Talamini R, Barzan L, Danova C, Simonato L, Lowry R, Conway SI, McKinney PA, Znaor A, McCartan BE, Healy C, Nelis M, Metspalu A, Marron M, Hashibe M, Brennan JP. *Eur J Cancer Prev*. 2008 Sept 30.

Lewin, F, Norell, S et al. (1998) Smoking tobacco, oral snuff, and alcohol in the etiology of squamous cell carcinoma of the head and neck. *Cancer*, Vol. 82 (7): 1367-1375.

Leydon, GM, Bynoe-Sutherland, J, Coleman, MP (2003) The journey towards a cancer diagnosis: the experiences of people with cancer, their family and carers, *European Journal of Cancer Care*, 12, 317-326.

Llewellyn Carrie D, Johnson NW, Warnakulasuriya KAAS. Factors associated with delay in presentation among younger patients with oral cancer. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod* 2004; 97:1-7

Llewellyn CD, Johnson NW, Warnakulasuriya KAAS. Risk factors for squamous cell carcinoma of the oral cavity in young people – a comprehensive literature review. *Oral Oncology* 2001;37:401-418

Llewellyn CD, Linklater K, Bell J, Johnson NW, Warnakulasuriya KAAS. An analysis of risk factors for oral cancer in young people: a case-control study. *Oral Oncology* 2004 Mar;40(3):304-313.

Llewellyn CD, Johnson NW, Warnakulasuriya KAAS. Risk factors for oral cancer in newly diagnosed patients aged 45 years and younger: a case-control study in Southern England. *J Oral Pathol Med* 2004; 33: 525-32

Lowry RJ and Craven MA Smokers and drinkers awareness of oral cancer: a qualitative study using focus groups. *British Dental Journal* 1999 187(12): 668-70.

Macpherson LM, McCann MF, Gibson J, Binnie VI, Stephen KW. The role of primary healthcare professionals in oral cancer prevention and detection. *British Dental Journal* 2003; 195: 277-81.

McCann MF, Macpherson LM et al (2000a) The role of the general dental practitioner in detection and prevention of oral cancer: a review of the literature. *Dental Update* 2000 27(8): 404-408.

McCann MF, Macpherson LM, Binnie VI, Stephen KW. (2000b). A survey of Scottish primary care dental practitioner's oral cancer-related practices and training requirements. *Community Dental Health* 2000; 17: 24-30

McLeod NMH, Saeed NR, Ali EA. Oral cancer: Delays in referral and diagnosis persist. *British Dental Journal* 2005; 198, 681-684.

The Mouth Cancer Foundation, www.mouthcancerfoundation.org (accessed October 2006).

Munro, A. (2005) Deprivation and survival in patients with cancer: we know so much, but do so little, *Lancet*, 6, December 2005, 912-913.

National Cancer Alliance (2002) *Patient Views and Experiences*. Oxford: NCA.

Peto R, Darby S, Deo H, Silcocks P, Whitley E, Doll R. Smoking, Smoking cessation and lung cancer in the UK since 1950: combination of national statistics with two case-control studies. *BMJ* 2000 :321 : 323-9

Rogers SN, Pabla R, McSorley A, Lowe D, Brown JS, Vaughan ED. An assessment of deprivation as a factor in the delays in presentation, diagnosis and treatment in patients with oral and oropharyngeal squamous cell carcinoma. *Oral Oncology* 2007; 43: 648-655

Sapkota A, Hsu CC, Zaridze D, Shangina O, Szeszenia-Dabrowska N, Mates D, Fabianova E, Rudnai P, Janout V, Holcatova A, Brennan P, Boffetta P, Hasibe M.

Dietary risk factors for squamous cell carcinoma of the upper aerodigestive tract in central and eastern Europe. *Cancer Causes Control* 2008 Dec;19 (10): 1161-70. *Epub* 2008 May 30

Scott, SE, Grunfeld, EA, Main, J and McGurk, M (2006) Patient delay in oral cancer: a qualitative study of patients' experiences, *Psycho-oncology*, 15, 474-485.

Scottish Intercollegiate Guidelines Network, 2006

<http://www.sign.ac.uk/guidelines/fulltext/90/index.html> (accessed October 08)

Shiboski CH, Schmidt BL, Jordan RCK. Tongue and tonsil carcinoma: Increasing trends in the U.S population ages 20-44 years. *Cancer* 2005;103: 1843-9.

Smith, L, Pope, C, Botha, J (2005) Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis, *Lancet*, 366, 825-831.

Warnakulasuriya KAAS et al. (1999) An alarming lack of public awareness towards oral cancer. *British Dental Journal* 1999, 287(6): 319-22.

Further Information

SIGN Guideline 90 Diagnosis and Management of Head and Neck Cancer

Head And Neck Imaging CD-Rom

CD-ROM, publication date: DEC-2002

ISBN-13: 978-0-323-00943-0

ISBN-10: 0-323-00943-3

Imprint: MOSBY

Appendix I: Interview Schedule

A pilot study into younger oral cancer patients' experiences during their journey through pre-diagnostic NHS care.

Initially

What did you first notice that made you visit your G.P. / G.D.P./Pharmacist?
Pain? Discomfort eating or other reasons?
In retrospect, were any of these issues related to your mouth cancer?

Before visiting a healthcare professional

Did you try to take any medication yourself before visiting the professionals?
What was it?
Where did you get it from?
Did you get advice from anyone? If so, who

GP visit- if applicable

If your visit was to the doctor, did you see him regularly for other issues?
If not, what kind of experience did you have? e.g. helpful, easy to talk to or other.
Did you talk to family/friends before you visited the professional?
If so, what did they say?

GDP visit- if applicable

Did you visit your dentist regularly? If not, why not?
Again, were there any pre-existing conditions that may have been indicative of mouth cancer?
What did you think of your dentist and your past experiences?
Did you talk to family/friends before you visited the professional?
If so, what did they say?

Pharmacy visit- if applicable

If you visited the pharmacist first, what advice did they give you?
Did they refer you on to another health professional?
Would you ever ask advice from the pharmacist?
Did you talk to family/friends before you visited the professional?
If so, what did they say?

First appointment with doctor or dentist

How long after noticing the first signs did you get your first appointment and was that with your doctor or dentist?
What happened next when you spoke to the doctor or dentist?
How long did the consultation last?
Was this the only reason you went or did you have other issues to talk about?
What did they say?
What did they do?
What did you think about it?
How did you feel afterwards?
Did they prescribe anything e.g. antibiotics/antifungals?
How long did this go on for and, in retrospect, did this slow down referral?
Did they give you information to take away/ tell you where to find out more?
Did you find the consultation useful or could it have been better?
When after visiting your doctor/dentist did you start to think it might be something more serious?
What prompted that?
How did you feel?
What did you do?
Did you talk to anyone about it?
What did they say?
Did they try to find out anything about it (e.g. looking on internet)

Subsequent medical visit

When did you next see about it medically?
Where was that visit?
How much later was that?
Who did you see?
What did they say?
What advice did they give you?
What information did they give you?
Did you talk to any family or friends after you had seen your G.P./dentist?
Was there any follow up, e.g. did your G.P. get in touch with you?
What did they say/do?

Looking back

Can you tell me about when you first noticed anything that you could now say was a symptom of oral cancer?
What was that symptom?
What did you think about it at the time?
Had you ever heard of oral cancer?
Do you feel you know why it happened?
Do you smoke? If so how many
Do you drink? If so, how much.
Looking back, what do you think could have been done differently?
Would anything have made it easier for you?
How do you think things could be improved for someone in the same situation in the future?

Appendix II: Participant Table

Research name	Age at diagnosis	Gender	Ethnic group	Marital status	Index of deprivation	Employment status	Site of cancer
Alice	48	Female	Caucasian	Unknown	10	Unknown	Left posterior maxillo
Andrew	39	Male	Caucasian	Married	3	Unknown	Tongue
David	43	Male	Caucasian	Married	7	Employed	Oral pharynx
Deborah	36	Female	Caucasian	Single	1	Employed	Left tongue and floor of mouth
Julie	47	Female	Unknown	Married	Unknown	Unknown	Tongue (right)
Karen	44	Female	Caucasian	Married	10	Employed	Buccal Mucosa (salivary gland) Anterior ventral tongue and floor of mouth
Lynne	43	Female	Caucasian	Divorced	2	Unemployed	Buccal Mucosa (salivary gland)
Margaret	44	Female	Caucasian	Married	7	Unknown	Buccal Mucosa (salivary gland)
Mark	43	Male	Caucasian	Unknown	5	Employed	Tongue
Paul	34	Male	Caucasian	Divorced	Unknown	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	Inside lip
Simon	43	Male	Caucasian	Married	9	Unknown	Tongue (left anterior)
Susan	42	Female	Caucasian	Single	8	Self-employed	Tongue (right)

SIMD: Scottish Index of Multiple Deprivation. 1 reflects the most deprived and 10 reflects the least.