

Barriers and Triggers to Seeking Help for Potentially Malignant Oral Symptoms: Implications for Interventions

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Abstract

Objectives: The detection of oral cancer at an early stage is the most effective means to improve survival and reduce morbidity. However, approximately 30 percent of patients delay seeking help for more than 3 months following the self-discovery of symptoms of oral cancer. This study aimed to increase our understanding of patient delay to inform the development of interventions to encourage early presentation of oral cancer. **Methods:** Newly referred patients (n = 57) with potentially malignant oral symptoms were interviewed to determine influences on the timing of their decision to seek help. "Framework analysis" was used to analyze transcripts from semi-structured interviews. **Results:** Barriers to seeking help related to beliefs about symptoms, the health care professional (HCP), and an individual's circumstances. The main triggers to seeking help included the symptomatology and the presence of another reason for visiting an HCP. **Conclusions:** The results are discussed with reference to their implications for interventions aimed at reducing patient delay.

Key Words: patient delay, oral cancer, qualitative methods, early detection

Introduction

In the United Kingdom, oral cancer develops in approximately 4,000 people every year, and there is evidence that the incidence is increasing (1).

Despite the benefits of early diagnosis [e.g., improved survival, reduced morbidity, disfigurement, duration of treatment, and hospital costs (2)], half of patients with oral cancer are diagnosed with an advanced lesion. This is believed to be due, in part, to delays in diagnosis. "Patient" or "presentation" delay [the time between a patient's initial discovery of symptoms and the first consultation with a health care professional (HCP) for those symptoms] constitutes the largest proportion of the total delay period (3) with approximately 30 percent of patients delaying seeking help for more than 3 months after they have noticed

symptoms of oral cancer (4). Interventions aimed at reducing patient delay require understanding of the influences on help-seeking behavior (5), yet a recent systematic review (6) highlighted that little is known about the reasons for patient delay in oral cancer. Clinical factors (such as the type of symptom or site of the lesion), patient sociodemographics (such as patient's age or sex), or patient's health-related behaviors (such as tobacco use or alcohol consumption) do not appear to be related to the duration of patient delay. Thus, research is urgently required to understand the help-seeking process for symptoms of oral cancer.

Studies into delay at other cancer sites have indicated that a complex matrix of factors influence patient delay (7). Recognition and interpretation of symptoms appear to be

particularly important (8). Patients who do not initially attribute their symptoms to cancer are more likely to delay seeking help compared to those who believe their symptoms are indicative of cancer (9,10). It has been proposed that symptom misattribution is responsible for up to 60 percent of the total time to diagnosis (11).

Although the evidence base on the reasons for patient delays is increasing (5), research into patient's delay has generally ignored facilitators or triggers to seeking help. It has been suggested that people accommodate to symptoms and it is not until "something critical occurs" that medical help is sought (12). As such the question should not only be "why the delay?" but also "why come now?" Answers to both these questions are essential for the development of interventions to encourage early presentation of oral cancer.

The current research aimed to provide an exploratory insight into how patients arrive at their decision to seek help for potentially malignant oral symptoms with focus on both the barriers and triggers to help seeking. Extension of the sample to include those with benign lesions is important because symptoms of oral cancer are not mutually exclusive to oral cancer, and therefore, it is the professional and not the lay public who is expected to differentiate between benign and malignant oral conditions. As such, interventions to reduce patient delay for oral cancer

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will advise individuals to seek help if they experience potentially malignant oral symptoms, and in turn, we need to know what motivates and hinders help seeking for such symptoms.

Method

Participants and Procedure.

Newly referred patients to the Oral Medicine Department and Head and Neck Service at a London teaching hospital who met the inclusion criteria over 18 years of age, English speaking, and had potentially malignant oral mucosal symptoms (i.e., localized nonrecurring ulcer, localized persistent oral pain, a white or red patch, a lump or swelling in the oral cavity) [ICD-10 (13) codes C01-C06] were invited to participate in the study. Patients are primarily referred to the teaching hospital by general dental and medical practitioners. Patients with lesions discovered as an incidental finding were excluded as they had not made a self-discovery of potentially malignant oral symptoms, and therefore, there were no help-seeking decisions to assess.

This study was part of a larger survey investigating patient delay using a standard questionnaire and semi-structured interview. The results of the interview and parts of the questionnaire (demographic details; duration of patient delay – defined as the time between a patient's initial discovery of symptoms and the first consultation with an HCP for those symptoms) are presented here. After patients had been provided with a provisional diagnosis before treatment began, a semi-structured, 15-30 minute, tape-recorded interview was conducted over the telephone (using a Phonaport TR103 telephone recording adapter). During the interview, participants were asked to describe what had happened from the moment they first became aware of a change in their mouth, up until they consulted an HCP. The patients were then asked in more detail about their experiences, with questions focusing on their help-seeking

decisions, in particular, whether anything had postponed their visit to an HCP and what prompted them to seek help. The study protocol was approved by the local research ethics committee.

Analysis. The tape-recorded interviews were transcribed verbatim and analyzed using framework analysis (14) with the assistance of NVivo computer software (version 2.0.161 QSR International Pty. Ltd.). Framework analysis involves charting and sorting data in a systematic manner to allow comparison and interpretation of key ideas and themes, while remaining grounded in participants' original accounts. The first stage of framework analysis is "familiarization" with the data via repeatedly reading the transcripts. This enabled the identification of important and recurrent themes. Following this identification, an index of major themes and subthemes was produced. This "thematic framework" was applied to the data by annotating each transcript accordingly. The data were then charted by extracting the data from the original transcripts and arranging it in a tabular structure to allow interpretation. Accounts of patients who sought help soon after discovering symptoms (patient delay ≤ 31 days) were compared to those of patients who experienced prolonged patient delay (patient delay > 31 days). NVivo was only used to support the qualitative analysis by electronically annotating the transcripts so that the data could be easily extracted ready for the charting phase.

To ensure reliability of the analysis, 11 (20 percent) transcripts were also read by an independent researcher (VA, a health psychologist with experience in conducting qualitative research) who reapplied the main coding framework. This annotation was then compared with the original coding. Discrepancies were highlighted and discussed until an agreement was reached. Areas of discrepancy included whether to code text regarding events that occurred after the first consultation with the HCP and when participants were

hypothesizing or imagining (i.e., "I probably would have left it"). On the whole, however, discrepancies were minimal.

Results

Response Rates. Eighty-two (66 percent) of the 124 patients who met the inclusion criteria gave informed consent and completed the questionnaire for the larger study. Fifty-seven of these were interviewed, giving a response rate of 46 percent for the qualitative research. Six participants did not wish to be interviewed, 13 could not be contacted, and four returned their questionnaire after "saturation point" of the qualitative data had been reached. Mann-Whitney *U*-tests (used because of the nonparametric nature of the data) indicated that compared to those who were not interviewed (but had completed the questionnaire), the interviewed participants were more likely to be female ($U = 1,423.0$, $z = -2.993$, $P < 0.01$), but did not differ in terms of the definitive diagnosis (benign versus malignant; $U = 1,768.5$, $z = -1.159$, $P = 0.247$).

Characteristics of the Sample. The sample characteristics are presented in Table 1. The mean age at detection of symptoms was 54 years [standard deviation (SD) = 14.2 years]. Ten percent of patients were diagnosed with malignant disease (all squamous cell carcinoma). Thirty-five percent of patients sought help from a GP or practice nurse, and the remaining participants sought help from a dentist or hygienist. The duration of patient delay ranged from 0 to 366 days. Following the removal of an outlier with extremely long patient delay (patient delay > 300 days), the mean duration of patient delay was 71.5 days (SD = 71.3 days) and the median duration was 36 days. Thirty participants (53 percent) waited more than 31 days before seeking help, and thus were considered to have delayed seeking help, and 21 (37 percent) waited more than 3 months.

Barriers and triggers to seeking help. The analysis indicated that although they occurred at different

Table 1
Sociodemographic Details of Participants

Variable	<i>n</i> (%)
Sex	
Female	46 (81)
Male	11 (19)
Marital status	
Married/partner	35 (61)
Single	9 (16)
Divorced/separated or widowed	13 (23)
Ethnic origin	
White Caucasian	45 (79)
Other ethnic origin	12 (21)
Level of education	
No education or compulsory education only	23 (40)
Beyond compulsory education	34 (60)
Alcohol consumption (<i>n</i> = 56)	
Less than three units a day	47 (84)
Three units a day or more	9 (16)
Smoking history	
Never smoked	30 (53)
Used to smoke	20 (35)
Current smoker	7 (12)

n = 57 unless stated otherwise.

time points or had differing levels of impact, the types of barriers and triggers to seeking help were similar in those who sought help promptly and those who delayed seeking help, and therefore, the data are presented as a whole. The main barriers and triggers to seeking help are displayed in Tables 2 and 3. For some, especially those with prolonged patient delay, multiple factors contributed to the postponement of a consultation with an HCP, while for others a single reason stood out as the barrier to seeking help. Barriers could be categorized into three broad groups: “beliefs regarding the oral symptoms,” “factors relating to the HCP,” and “factors relating to the circumstance.”

Symptomology (change in symptoms, persistence, pain) and presence of another reason to visit the HCP were the main or “dominant” triggers to seeking help. Other important, but less frequently noted, triggers included the desire for an early diagnosis, need to resolve uncertainty, emotional responses (worry, dislike of symptoms), and advice from significant others.

Discussion

In this study, 53 percent of participants waited 31 days before seeking help from an HCP, and 37 percent waited more than 3 months. These figures are in line with other reports of patient delay in patients with oral cancer (15) and in patients with cancer elsewhere in the body (16). Timing of help-seeking behavior is often presumed to rely on the severity of symptoms (17,18), yet the results of this study indicate that the decision to seek help is more complex. The nature of the symptom is not always the driving factor behind help seeking. Instead, cognitive and emotional responses to the detection and presence of symptoms, the circumstances in which the symptoms present, and the individual’s beliefs about obtaining help play an important role in the decision to seek help.

The qualitative findings indicated that participants’ initial interpretation was related to the decision to seek help, with attribution of symptoms to a minor, self-correcting condition resulting in postponement of help seeking. Relatedly, a change in symp-

toms or persistence of symptoms was regarded as an indication that something was wrong and in turn triggered a visit to an HCP. This reflects findings from other cancer sites (19,20) and supports the premise of the theoretical models of help-seeking behavior that cognitive representations guide responses to health threats (11,21). This indicates that early detection interventions should help people evaluate oral symptoms more accurately. Accurate symptom evaluation would reduce misattribution and the associated maladaptive behaviors such as prolonged self-medication. A simple way to evaluate oral symptoms is by the symptom duration. The oral mucosa generally heals within 2 weeks, and therefore, any oral change that lasts for 3 weeks should be regarded as suspicious or “unexplainable” (thus incorporating the trigger of “uncertainty”) and checked by an HCP. If “at-risk” individuals are introduced to this “3-week rule,” it would standardize the duration given for symptoms to resolve. Furthermore, if it were emphasized that HCP’s *want* to see any oral change that lasts more than 3 weeks, this may reduce the patients’ concern of wasting HCP’s time and raise confidence in help seeking. Provision of a concrete symptom duration has been found to be effective in an intervention to reduce patient delay for symptoms of myocardial infarction (22).

Reflecting the nature of their symptom interpretations and the impact of symptoms, patients often prioritized other responsibilities/concerns over seeking help for their symptoms. This barrier of competing responsibilities has been documented in previous research (23,24). Obviously, interventions will not be able to change the occurrence of life events, but instead they could stress the importance of seeking help promptly for potentially malignant oral symptoms and ensure affordable and accessible services so that the barrier of competing responsibilities is lessened and perceived ability to seek help is enhanced. As the qualitative data indicated that the

Table 2
Barriers to Seeking Help for Potentially Malignant Oral Symptoms

Barrier	Subtheme and description	Examples
Beliefs regarding oral symptoms	Symptom interpretations and beliefs about those interpretations. As patients often believed symptoms were indicative of transient, minor oral conditions that would resolve naturally, they decided that a visit to an HCP was unnecessary.	"I didn't really . . . I mean as it wasn't causing me pain, I didn't think it was anything particularly important as such. I was under the impression if it was something important it would give me pain." (M, 43 years; PD = 31 days)
	Belief that you could or should try to cope with symptoms yourself prior to seeking help. The time patients took to verify whether their attempts of self-care had been effective and acted as a barrier to seeking help.	"A lot of things you think well it will go away automatically, erm, it must be nothing, I'll just try mouthwash this and that and the other and before you know it, its 6 months." (F, 34 years; PD = 181 days)
Factors relating to the health care professional	Beliefs about the appropriate timing and circumstance of a visit to an HCP Patients believed people must not waste an HCP's time by attending with a minor ailment and relatedly that one must not seek attention at the first sign of illness.	"I thought well, I didn't really want to bother him with the mouth thing, thinking it was nothing really important you know." (F, 58 years; PD = 31 days) "I thought oh well lets see . . . I thought that'll probably clear it up, if not I'll go and see the doctor – I'm not a runner to the doctor I'm afraid." (F, 64 years; PD = 14 days)
	Real or perceived problems with access to an HCP These problems included the distance needed to travel, the perceived hassle of visiting an HCP, finding a "good" dentist, the cost of a consultation, and inconvenient surgery opening hours.	"I think it's just a case of well it'll probably cause too much hassle so just put up with it and the dentist is 200 miles away in Birmingham and you have to book up 5 weeks in advance." (M, 34 years; PD = 61 days)
	Negative attitudes toward HCPs These attitudes arose from previous unpleasant experiences with the HCP, apprehension regarding the consultation, or low perceived efficacy of the HCP.	"I've always had a chronic fear of . . . well extremely bad fear of dentists. The thought of going to a dentist . . . because I thought that's the only way you would ever get anything fixed . . . it was a very large bridge to cross." (M, 46 years; PD = 211 days) "There's no point unless somebody's going to be able to do something with me." (F, 48 years; PD = 31 days)
Factors relating to the circumstance	Competing responsibilities/priorities Circumstances (e.g., comorbidities, child care, marital conflict, work commitments, holidays) viewed as more important than their oral symptoms led patients to prioritize activities other than seeking help and/or reduced their time available to seek help.	"I mean I have four children, my life doesn't have time for my own little worries." (F, 47 years; PD = 366 days) "I think . . . I couldn't see anything and it was just a little bit uncomfortable and . . . as I say I've got quite a lot of other health problems and I'm afraid I . . . it was probably near the bottom of the list really!" (F, 56 years; PD = 62 days)

HCP, health care professional; M, male; F, female; PD, duration of patient delay.

accessibility, affordability, and availability of the HCP influenced patients' help-seeking decisions, ensuring patients are able to seek and receive help is vital in achieving reductions in delay.

The data suggested that emotions play a role in the help-seeking

process. Previous work has indicated that fear of consultation (in terms of embarrassment and to the idea of cancer) may prevent a patient from seeking help for cancer symptoms (8). This study has indicated that emotions can also act as a trigger to help seeking. Models of health behavior

such as the self-regulatory model (21) and protection motivation theory (25), and investigations of patient delay have noted that emotional representations of the health threat such as anxiety and emotional distress can be motivating factors for action (26,27). The low public awareness of

Table 3
Triggers to Seeking Help for Potentially Malignant Oral Symptoms

Trigger	Description	Examples
Change in symptoms	If symptoms changed, worsened, or became more numerous, patients felt this was an indication that the symptoms required dental or medical attention.	"Because it started to get bigger I started to worry. That's when I thought I'd better have it . . . you know something done." (F, 43 years; PD = 92 days)
Persistence of symptoms	Persistent symptoms indicated that something might be "wrong." The definition of "persistence" varied greatly between individuals. In turn, this trigger surfaced at different time points for different patients.	"I thought this ought to be better by now. It was just the longevity of it all, that was the reason." (F, 54 years; PD = 14 days)
Pain	The need to relieve pain or discomfort was a trigger to seek help.	"Erm, actually we were going on holiday, we were going on a cruise and you know the thought of actually going on a cruise with my tongue as it was . . . so the trigger was actually to get something to relieve it before we went on this holiday." (F, 48 years; PD = 31 days)
Presence of another reason for visit – "going anyway"	Patients often informed an HCP of their oral symptoms at an appointment booked for another reason. Some patients indicated they would not have made an appointment for their symptoms, instead they mentioned their symptom "in passing" while visiting the HCP.	"Well I didn't really go about that. I went for other things and just mentioned by the way I have this recurring mouth sore . . . what should I do about it?" (F, 59 years; PD = 75 days) "I really didn't think it was that serious. You know I don't suppose I would have made a special appointment to go to see the doctor at all really." (M, 59 years; PD = 21 days)
Desire early diagnosis	Some patients thought it was best to seek help "sooner rather than later" to avoid negative consequences such as worsening symptoms or poor prognosis that may occur if undiagnosed.	"I thought to myself . . . I'm not waiting 'til this flares up into something. I'm 72 now, I haven't got all that long to go so at least the bit of what I've got left I've got to take care of it." (F, 71 years; PD = 213 days)
Need to resolve uncertainty	Patients who became unsure as to the explanation for their symptoms were prompted to seek help in order to receive a diagnosis, which in turn would provide understanding and clarity.	"Part of it was to sort of find out what was going on – what it was that was in my mouth." (M, 29 years; PD = 105 days) "Well it was just you know a little bit uncomfortable and I thought well what on earth is this? I really ought to go and try and find out what was causing it." (F, 66 years; PD = 238 days)
Worry/concern about symptoms	Some patients decided to consult an HCP once they became worried, believing the consultation would not only alleviate the symptoms but also the worry.	"I kind of thought well if I just go and get it sorted you know and get it done . . . I haven't got to worry about it anymore." (F, 25 years; PD = 31 days)
Dislike of symptoms	When the patients found the appearance, nature, or interference of symptoms to be unpleasant, annoying, or irritating, they were prompted to seek help.	"It was because I mean I didn't like it, it was ugly. Even when you open your mouth you can see it so it's not really nice." (F, 31 years; PD = 37 days)
Advice of significant others	Some patients noted that it was the advice of their friends and family that made them seek help.	"As the weeks went on . . . and it started to get slightly painful and my partner kept saying go to the doctors. Then when . . . it was really painful he went 'If you don't go to the doctor's, I'm going to take you down there myself.'" (F, 38 years; PD = 112 days)

HCP, health care professional; M, male; F, female; PD, duration of patient delay.

oral cancer (28) may explain why fear was not a hindrance to help seeking in this group. The results also indicated that emotions surrounding help seeking (e.g., dental anxiety) are important and also highlighted that HCPs must be aware that previous encounters may influence future help-seeking decisions.

The decision to seek help was often made irrespective of the presence of potentially malignant oral symptoms in that a major trigger to seek help was the timing of another appointment or the presence of another reason to visit an HCP. It is well-documented that patients often consult HCPs with more than one problem (17,29). The point at which people seek help for their oral problems is seemingly often defined by the presence of a comorbidity that requires medical or dental attention, or the timing of a routine checkup. This may explain why it has been difficult to identify reliable predictors of patient delay in previous research. The trigger of "going anyway" has implications for service provision. Regular routine appointments provide the opportunity for people to highlight symptoms that otherwise may not be brought to an HCP's attention. However, the gap between appointments has the potential to prolong delay as some individuals may wait until their next prebooked checkup to consult an HCP about the discovery of oral symptoms. The trigger of "going anyway" points to a lack of perceived urgency to seek help, indicating that patients often believed the presence of oral manifestations was not a sufficient reason for visiting an HCP. As such, interventions should not only encourage accurate symptom interpretation, but also highlight the importance of prompt consultation, and this could incorporate the desire for an early diagnosis which was noted as a trigger to seek help in this study.

The current study adds to previous research on patient delay for symptoms of oral cancer by including both malignant and benign cases, and addressing reasons for seeking help in addition to investigating bar-

riers to consultation with an HCP. However, the study has limitations which should be considered. First, the interview was administered after a provisional diagnosis had been given to the patients. Receipt of a provisional diagnosis may have influenced patients' responses to the interview. Second, given that the response rate was low and that the relatively small sample included patients with low self-reported alcohol consumption and a high proportion of women, the generalizability of the sample to an oral cancer population is questioned. However, these factors have been shown to be unrelated to delay in previous research (3,6). Furthermore, studies of delay at other cancer sites that have included nonmalignant cases have found that the reasons for delay are the same in those who develop cancer and those who do not (19). Finally, a common limitation to patient delay research is the accuracy of participant recall because of the retrospective study design. Patients' memory of the events is likely to be prone to bias and error. However, the level of detail in participants' accounts suggests that their narrative is still valid.

Overall, this exploratory study demonstrates the complexity of patients' help-seeking behavior. The qualitative methodology enabled insight into the decision to seek help which in turn provides guidance as to the content of interventions aimed at reducing patient delay. However, to maximize resources, we need to know the most important triggers and barriers in order to guide the focus of interventions. Given that similar barriers and triggers occurred regardless of duration of delay, future research could assess the magnitude of the impact of each barrier and trigger and also investigate interactions between barriers and triggers.

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