**Cognitive and Emotional Processes Influencing Patient Presentation or Non-Presentation of Oral Cancer Symptoms to Healthcare Professionals.**

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**ABSTRACT**

*Objective*: Greater time that patients take to present symptoms to health care providers (HCPs) increases the likelihood of later stage cancer, which increases mortality and morbidity in symptomatic cancers. The common-sense model (CSM) is used to understand time to first consultation with a healthcare provider, but inconsistencies exisy between its current use and important empirical findings. *Method*: To resolve inconsistencies, we conducted a qualitative examination **to determine how the CSM could be revised to better account for these findings**. We conducted in-depth interviews of a consecutive sample of 38 recently diagnosed patients **who described events from first noticing symptoms to first consultation**. Framework analysis was used to develop a theoretical model of processes leading to presentation or non-presentation. *Results*: Patients reported median presentation times of 3-4 weeks. Early presentation was facilitated by pre-symptomatic perceptions of vulnerability to serious illnesses and beliefs that early intervention could mitigate illness. These patients **rarely tried to** identify symptoms. They responded inductively, seeking help because symptoms were unusual. Where patients did not describe pre-symptom perceptions of vulnerability, many deductively tried to identify symptoms but misattributed them to minor conditions. Pre-symptomatic perceptions of vulnerability could also prolong presentation. When vulnerability was characterized by intense fears of cancer and cancer treatment, patients **tended to avoid** thinking about symptoms which extended presentation time. *Conclusion*: Risk perception theories explain how participants’ pre-symptomatic perceptions of vulnerability and potential treatment outcomes influence presentation time. Incorporating risk perception perspectives into the CSM can improve its ability explain responses to ambiguous symptoms.

**Keywords**: cancer; oncology; presentation time; presentation delay; oral squamous cell cancer; avoidance; symptom misattribution

During 2014, total UK cancer incidence was 356,860 cases, with ten-year survival of about 50% [1]. **Later stage cancers are associated with higher mortality and morbidity. A key modifiable cause of later stage cancers is time to commence treatment** [2], with time mostly taken between patients first detecting symptoms and first presenting to a health care professional (HCP) [3]. Oral squamous cell carcinoma (OSCC) is a symptomatic cancer that has doubled in UK incidence over 10 years [4] to a 2012 incidence of 7,300 and 48% five-year mortality [5]. Time to treatment of three months or more increases the probability of late stage OSCC by 4.5 times [6]. 20-30% of patients first consult HCPs more than three months after detecting symptoms [3].

Most cancer cases occur outside monitored populations [8]. Interventions to reduce time to presentation cannot solely be directed toward ‘at risk’ individuals but should target large populations [9]. Theoretically-grounded population interventions can facilitate presentation of cancer symptoms in populations [10]. The common-sense model (CSM) [11] has been extensively and successfully used to understand events during symptom appraisal and decisions about help-seeking. We argue that conceptual problems exist in the application CSM, and aim to resolve these.

**Theoretical Background**

The CSM posits that individuals recognize specific illnesses because they perceive symmetry between symptoms and their implicit and explicit mental representations of those illnesses [11]. Representations are underpinned by prototypes; long-term understandings of normal health states and specific illnesses, that are formed through personal experience and social and cultural understandings. Self-prototypes pertain to physical and psychological attributes associated with normal functioning. Illness prototypes refer to understandings of specific illnesses organized in terms of symptoms, expected duration of the illness, implications for morbidity, cause and likely outcomes of actions to mitigate illness. The detection of symptoms that deviate from self-prototypes stimulates the formation of symptom representations. People access illness prototypes that are similar to observed symptoms, and deductively use prototype information to populate their representations [12]. Symptom presentation is associated representations that are associated with serious illnesses [13].

Studies on presentation time in OSCC [6 14 15] and other cancers [16] conclude that longer presentation times occur because deductive processes fail. Patients do not link OSCC symptoms to cancer because symptoms are inconsistent with cancer prototypes and better resemble minor oral conditions [14]. Presentation later becomes triggered if symptoms persist or deteriorate, making initial attributions untenable. The implication is that interventions should seek to stimulate symptom recognition through the development of illness prototypes [17].

Conceptual and empirical gaps exist in the application of the CSM. First, the CSM is usually applied to patients with diagnosed conditions where illness prototypes are defined and elaborate. There is less understanding of what happens when prototypes are poorly elaborated or multiple prototypes compete to explain symptoms. Studies show that many patients experience uncertainty in attributing OSCC or other cancer symptoms to specific conditions, and consider multiple causes [15]. It is important to understand why patients do not simply consult a HCP as a ‘safe option’. Second, misattributions of OSCC symptoms favor transient conditions. The CSM proposes that symptom persistence should trigger reappraisal, yet, patients frequently maintain misattributions over six to twelve months and it is not clear why [15 18]. Lastly, many patients report not consulting HCPs because they fear cancer or other serious illness [16 19]. This is inconsistent with a symptom misattribution account.

**Current Study**

**In view of the above concerns, our aim was to identify whether and how the CSM can be revised to better explain presentation time or alternative approaches are needed. We interviewed a consecutive sample of OSCC patients to identify the reasons for presentation or non-presentation. In the absence of firm theoretical guidance to address our concerns, we took an inductive approach and used qualitative methods.**

**METHOD**

Patient Sample: Approval was obtained from the UK National Research Ethics Service (North West); Ref 13/NW/0056. From July 2014 to September 2015, we recruited a consecutive series of patients with recently diagnosed OSCC in a large Head and Neck Cancer service. Patients were introduced to the study by their clinical team. Interested patients were referred to JB who provided a written explanation of the study aims, and obtained informed consent to organize a face-to-face interview. Patients consented in writing before the interview.

Procedure: Patients were interviewed by JB after diagnosis but before surgical treatment. Retrospective accounts can be inaccurate or have omissions [20 21 22]. Patients may forget or inadvertently construct interpretations in the light of subsequent events [23], particularly for subtle and complex appraisals [24]. Cognitive interviewing [25] uses three techniques to improve recall of complex and emotionally distressing events. 1) Focused meditation combines relaxation with an induced attentional focus on current experience [26]. 2) Context reinstatement creates contextual overlap between encoding and retrieval by asking interviewees to reconstruct event-relevant contextual, emotional, physical, and cognitive states [27]. 3) ‘Report everything’ reduces self-editing by asking patients to report all event-relevant thoughts and feelings [25]. Interview recordings were reviewed by a cognitive interviewing practitioner.

Interview content: **A request to ‘report everything’ was made at the start of the interview, and prompts to do so given within interviews. Context reinstatement was used throughout the interview by asking for contextual details of key events. The first objective was to develop a timeline of key events during presentation time, defined as the interval between initial symptom detection and first presentation to a HCP.** These were discovering symptoms, changes or persistence of the symptoms, reappraisals of symptoms, decisions to present or not present to HCPs, and when patients presented. We encouraged patients to remember details such as day of the week, activities on that day and temporal proximity to holidays, birthdays or other events that they could accurately date.

The second objective was to gain a detailed understanding of patient’s thoughts and emotions. **Before interviewing patients about symptoms we gave a brief pre-scripted focused meditation exercise, if they consented to it.** Open-ended interview questions were generally used. The interviewer reflected, prompted, summarized, and probed where necessary. Questions explored the nature of symptoms, perceptions and interpretations of symptoms, courses of action considered, how and why courses of action were chosen, and why they were or were not followed. Where patients had not considered cancer, they were asked why not. Patients were asked about past or current oral conditions and how they felt HCPs would respond if they reported trivial symptoms. Interviews lasted a median time of about 40 minutes.

Data Analysis: We used framework analysis [28] to examine themes across and within individuals, and how themes were associated with presentation time. Whilst alert to CRM processes, we wanted to capture and understand unexpected phenomena. Thus, whilst focusing on symptom appraisals, we did not explicitly use the model to frame the analysis. Each interview was read by two of the analysis team. JB used open coding to create initial codes and she and SLB created an analytic framework from descriptive summaries of initial cases. From this a theoretical analysis was developed and agreed by the group and recorded using a Microsoft Excel spreadsheet for codes and a Word document to record case summaries and development of the interpretation. The analysis was continually tested and refined through constant comparison with new data and cycling back to previous cases. Recognizing the potential for justifications and rationalizations, as well as unmotivated inaccuracies, we particularly focused the theoretical analysis on inconsistencies or contradictions within and between transcripts.

Themes were refined by searching for confirming and disconfirming evidence. Standards by which the analysis was assessed included theoretical and catalytic validity [29], by which we mean that findings should have the potential to add to existing theory and inform practice. Key findings are illustrated by italicized quotes, with ellipses (…) indicating omitted text and explanatory comments in square brackets.

**RESULTS**

**Description of sample**

All 66 patients given OSCC diagnoses during data collection were approached. **19 refused, with the main reason that the interview may contribute to trauma or fatigue. Four could not participate for medical reasons. Consequently, less severely ill patients probably participated in this study, and they may have had shorter presentation times.** Five patients were eliminated because patients did not notice symptoms; detection occurred during routine dental examination. Final sample was 38, with a mean age 60.00 (SD=11.5) and 17 females. Patient age, gender, cancer stage and site and presentation time are in Table 1. Longest presentation times were 20 weeks, the shortest one day and the median 3-4 weeks.

**Subjective descriptions of initial symptoms featured discolorations (11), ulcerations blisters (17), lumps or indentations (14), displacement of teeth (2), textural changes (8), localized mild soreness (11), pain (5), and eating difficulties (3).** Initially, few experienced serious problems in talking, chewing or swallowing. Most patients had heard about OSCC, but none knew of specific symptoms.

**Overview**

We found three patient responses to symptom detection. Table 2 shows how these were inferred from analytic themes. Typical cases are described in case studies 1-3. A new finding was what we termed an ‘Uncertainty Resolution’ response, characterized by inductive thinking; patients saw symptoms as unusual and presented within a week to resolve uncertainty about them. A second group, ‘Initial Misattribution’ tried to deduce the meanings of their symptoms but failed to recognize cancer. Presentation time was about 3-4 weeks, after symptom persistence induced reappraisal. Longer times were associated with ‘Defensiveness’. These patients tried to reduce distress by avoiding thinking about symptoms they suspected may be cancer.

Comparing symptom responses provided insights into presentation decisions. *Uncertainty Resolution* patients’ inductive approaches were associated with pre-symptomatic perceptions of vulnerability to serious illness due to age or smoking, and that early intervention might mitigate illness. In contrast, *Symptom Misattributors*, felt less vulnerable to serious illness. They did not consider serious illness and wrongly deduced causes as minor conditions. However, perceptions of vulnerability could also inhibit presentation, as *Defensiveness* patients frequently experienced vulnerability as intense fears of cancer and pessimism about prognosis. Fear caused them to avoid thinking about symptoms, which inhibited presentation. We concluded that presentation was influenced by the existence and nature of pre-symptomatic conceptions of personal vulnerability and the consequences of treatment.

**Uncertainty resolution**

Patients immediately felt that symptoms were unusual and could be serious. Some mentioned cancer, whilst others were less specific: ‘*Because I knew in my own mind it was more than an ulcer. What it was I didn’t know but I knew. Something told me that’s not right*.’ (P26). Wanting to, in their words, ‘*sort it*’[[1]](#footnote-1), they decided to present to HCPs (Theme 2.1). Patients made appointments immediately or set timeframes of three or four days to see if symptoms spontaneously remitted.

Patients did not try to deduce causes of symptoms. Most were aware of their elevated risk for diseases such as cancer (Theme 2.3) and some had previous experience of cancer in family and friends. Several mentioned smoking and older age. Importantly, about half of these patients believed that, should illness be serious, early intervention would promote better outcomes (Theme 2.4)*.* For some, beliefs formed explicit IF-THEN sequences; IF patients experienced unusual symptoms THEN they would seek HCP advice. Patient 9 remembered reading a magazine article before experiencing symptoms. She followed the article; *‘if you have it* [an ulcer] *more than ten days, it’s better to go and see a doctor.’*

**Initial Misattribution**

Although describing symptoms as ‘*irritable’*, ‘*painful*’ and ‘*unusual*’, no patient suspected serious illness (Table 1, Theme 1.1). All attributed symptoms to ulcers, minor infections or dental conditions, consequently ignoring the symptom or using over the counter medications. Patients gave two reasons for their attributions. First, symptoms seemed mild or painless (see Case Study 2), which was incompatible with assumptions that cancer symptoms should be severe (Theme 1.2).

Secondly, salient unrelated health problems (Theme 1.3) diverted patients’ attention from OSCC symptoms, took priority over them, or were severe enough to render OSCC symptoms comparatively mild (Case Study 2). P23 was simultaneously diagnosed with a skin cancer, and attributed pain in her jaw to stress: ‘*I assumed because I’ve never had a mouth ulcer that I’d been y’know the way you bite your gum, because I clenched my jaw. I was conscious that my jaw was clenched weeks because I was just waiting, waiting for these results* (of the skin cancer test)*’*.

No patient felt that misattribution constituted symptom avoidance. All but one presented to a HCP to resolve the uncertainty caused when symptom persistence or deterioration rendered initial attributions unconvincing (Theme 1.4). Thus, few showed intervals of greater than six weeks, with the median being 3-4 weeks. Case Study 1 is the only patient who did not reappraise the initial attribution; he developed further benign attributions for symptom changes.

**Defensiveness**

Uniting these accounts were unwillingness to think about serious illness (Theme 3.1) and subsequent suppression of thoughts about symptoms to reduce fear (Theme 3.2). Another strategy was to misattribute symptoms to minor conditions to avoid the inference of cancer (Case Study 3) (Sub-theme 3.3). Participants did not explicitly compare their symptoms to cancer prototypes, possibly because they avoided thoughts of cancer. Instead, patients described their suspicions of cancer as being intuitive as either a ‘*sixth sense*’ (P6), a ‘*feeling*’ (P5) or ‘*something in the back of my mind*’ (P36).

Defensive patients spoke emotionally about their fears of cancer (Theme 3.4). P42 found cancer *‘frightening’*, because *‘cancer seems to be the front runner of death’.* Further, unlike ‘sort it’ patients who anticipated benefit from treatment, these patients spoke of disability; ‘*My sister, she said, ‘I’ve heard friends who’ve had mouth cancer n that’ and then she said ‘they had to have their jaw cut out and stuff like that’ and that scared me a bit’* (P5).

Unlike other groups, several consulted HCPs only when prompted to do so by relatives or partners (Theme 3.4).

Two patients misattributed symptoms to dental problems, and feared dental treatment rather than cancer (Theme 3.5). Although their symptoms eventually interfered with eating and drinking, neither considered the possibility of serious illness. Presentation times were 20 (P4) and 12 (P24) weeks.

**DISCUSSION**

Findings are consistent with existing CSM explanations of why people do not report cancer symptoms. First, symptom misattribution occurred because deductive processes failed (14). In trying to deduce the causes of symptoms from their understandings of oral illnesses, participants perceived symmetries between symptoms and their mental prototypes of minor oral conditions, but felt that symptoms did not match expectations of cancer symptoms. In particular, where patients had unrelated health problems or previous experience of minor oral conditions, symptoms could appear either minor in comparison or other conditions presented alternative explanatory frameworks. This is consistent with the CSM precept that people make symptom interpretations in the context of perceptions of ‘normal’ functioning (12).

Second, defensiveness was triggered because some participants’ understandings of cancer were populated by negative and fear-provoking memories of illness and treatment in family and friends (16). This may explain why patients frequently report fear of cancer as a reason for not presenting (19). Patients also strategically misattributed symptoms to minor causes, which may explain enduring attributions to minor conditions previously observed (14). **The CRM is a dual process theory of cognitive and emotional responses to illness. People use defensive techniques to manage distress associated with illness representations of negative consequences and low control of illnesses [30].** Although associated with longer presentation times in this study, defensiveness has been largely neglected in empirical work. Previous research links scores on defensive coping scales to slower presentation in OSCC [31] and other cancers [32 33]. Our findings emphasize the importance of defensiveness.

However, a deductive account fails to explain why participants actively reported symptoms. Uncertainty resolution and initial misattribution participants (the latter after symptom persistence rendered misattributions untenable) reported symptoms because they could not explain them. These patients did not possess elaborate prototypes of cancer or other serious illnesses, and none spoke of trying to deduce symptom cause by comparison to cancer prototypes. Instead, they largely thought inductively - perceiving symptom unusualness as sufficiently threatening to consult a HCP. In essence, presentation was guided by perceptions of the symptom itself. Inductive thinking was underpinned by pre-symptomatic perceptions of risk and benefit. **Participants attributed presentation to an awareness of their vulnerability to cancer or other serious lifestyle-related diseases, which they expressed in both cognitive and emotional terms.** Further, many also believed that early medical intervention could mitigate illness. These findings are consistent with breast cancer research showing that people who feel susceptible to cancer and believe it treatable are more likely to seek diagnoses [34] and OSCC research that patients cite early intervention as a reason for presentation [18].

Taking our findings as a whole, presentation likelihood appears attributable not to the specifics of how people match symptoms to illness prototypes, but to how patients deal with uncertainty. A risk perception framework [35] can be usefully introduced into the CSM. Risk perception theory [36 37] suggests that people perceive risk in multiple ways, with different behavioral implications for each. Risk can be perceived deliberatively, as the likelihood of serious illness, emotionally, as feelings of dread or fear, or as a template established by previous experiences. The pragmatic estimations of vulnerability made by uncertainty resolution participants represent deliberative risk perception, which has previously been associated with preventive behavior [38]. Distress about cancer in defensive participants represents emotional and experiential perceptions, which, when experienced as aversive, are often associated with avoidance [30].

From a risk perception viewpoint, self-prototypes assume importance. First, the perception of symptom unusualness was activated when symptoms become discrepant with prototypes of normal bodily states [39]. Second, participants’ self-prototypes were infused with pre-symptomatic perceptions of vulnerability to cancer and other serious illnesses, priming patients to regard unusual symptoms as threatening [12]. Illness prototypes are also important. Although lacking sophisticated prototypes of cancer identity, patients’ views on the consequences and control of cancer were critical. Optimistic views about the efficacy of early intervention were associated with presentation to resolve threat, often by employing IF-THEN rules [40], whilst pessimistic views about the consequences of cancer and its treatment were related to a different response; participants attributed symptoms to minor illness or avoided thinking about them [30].

**The CSM and other models [41] posit that appraisal involves symptom interpretation, which precedes and is distinct from decision-making. Decision-making is deciding whether to present or not and is influenced by efficacy and outcome expectancies. The CSM allows recursion between appraisal and decision-making, but our findings suggest greater fluidity. Pessimistic outcome expectancies were associated with defensive symptom appraisals, and optimistic expectancies with consideration of cancer. Thus, expectancies, that are normally thought to be associated with decision-making, actually had profound influences on symptom appraisal**.

Population-level interventions could have two aims; to promote awareness of vulnerability (whilst causing minimal distress) and to offer realistic hope that OSCC is treatable. Messages could inform audiences that prompt presentation increases the likelihood that medical intervention will be both successful and non-invasive, and encourage audiences to make time-specific intentions to seek consultation [42]. An example is the message that Patient 9 remembered from a magazine article; IF an oral symptom persists for more than a set number of days, THEN make an appointment with a HCP.

As the key to intervention is to influence pre-symptomatic self and illness prototypes, future research could focus on the development of these prototypes. In particular, it will be important to understand why some participants thought about vulnerability in pragmatic terms of cancer likelihood and others in terms of vivid emotional experiences. Experiences of cancer in family and friends were not restricted to defensive participants, and it is important to determine the extent to which optimistic and pessimistic views of cancer reflect specific experiences, social conditioning or individual differences in optimism and pessimism [43].

**Limitations**

This study appears to be comparable to others, with presentation time similar to the median 39 days reported by Scott, et al [15]. has several limitations. First, we sampled patients with OSCC. By definition, presentation is the correct response and attribution to minor conditions mistaken. Yet, the latter attribution is accurate for most oral symptoms, and advice to consult HCPs could result in a majority of false alarms that might deter future visits. Second, although we have used cognitive interviewing techniques, it would be unwise to assume that we have eliminated recall problems. A third limitation is that we are unable to rule out the possibility that differences in patients’ presentation times are caused by objective features of the symptoms. Uncertainty resolvers’ symptoms may have been more severe than those of misattributors. This interpretation is partly mitigated because the site and stage were approximately evenly distributed across response types (see Table1). **Table 1 shows that presentation time was not always related to stage, demonstrating that reducing the patient interval will not necessarily reduce morbidity and mortality. Thus, messages promoting the benefits of early intervention should be nuanced.**

**Conclusion**

The key research outcome of this research is a reformulation of the CSM to emphasize the central role of pre-symptomatic perceptions of vulnerability to serious illnesses how that vulnerability is perceived, and perceptions the efficacy and effects of treatments.

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Table 1. Demographic and clinical details of the 43 participants

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| ID | Cancer Stage | Cancer Site | Age | Gender | Relationship  | Education  | Employment  | Smoking  | Alcohol units/week | Patient Interval |
| 1 | T1N0M0 | FOM | 47 | Male | Married | Degree | Unemployed | Current | 21+ | 1 day |
| 2 | T2N1M0 | FOM | 67 | Male | Divorc/Sep | No qual. | Retired | Former | 21+ | 2-3 days |
| 3 | T1N0M0 | Tongue | 69 | Female | Married | Diploma | Retired | Never | 14+ | 8 weeks |
| 4 | T1N0M0 | Tongue | 51 | Male | Cohabiting | Diploma | Employed | Current | 21+ | 20 weeks |
| 5 | T4aN2cM0 | Tongue | 44 | Male | Single | No qual. | Unemployed | Current | 21+ | 16 weeks |
| 6 | T2N2bM0 | Retromolar | 45 | Male | Married | GCSE's | Employed | Current | ≤ 21 | 16 weeks |
| 7 | T2N2bM0 | Retromolar | 52 | Male | Single | GCSE's | Unemployed | Current | 21+ | 1 week |
| 8 | T1N0M0 | Tongue | 68 | Male | Married | No qual. | Retired | Former | ≤ 21 | 6 weeks |
| 9 | T1N0M0 | Tongue | 59 | Female | Married | No qual. | Unemployed | Current | ≤ 14 | 2 weeks |
| 11 | T2N0M0 | FOM | 62 | Male | Divorc/Sep | No qual. | Unemployed | Current | 21+ | 2 days |
| 13 | T1N0M0 | FOM | 52 | Male | Divorc/Sep | Diploma | Employed | Current | 21+ | 6 weeks |
| 14 | T1N0M0 | Tongue | 78 | Male | Married | No qual. | Retired | Former | ≤ 21 | 4 weeks |
| 15 | T4aN0M0 | Mandible | 60 | Male | Married | No qual. | Unemployed | Former | 21+ | 2 weeks |
| 18 | T2N1M0 | FOM | 78 | Male | Widowed | No qual. | Retired | Former | 21+ | 1 week |
| 19 | T1N0M0 | Bucal Mucosa | 64 | Male | Married | A Levels | Employed | Never | 21+ | 12 weeks |
| 20 | T1N0M0 | Tongue | 52 | Male | Married | GCSE's | Unemployed | Current | ≤ 21 | 2 days |
| 21 | T4aN2bM0 | Tongue | 73 | Female | Married | GCSE's | Retired | Current | 14+ | 4 weeks |
| 22 | T1N0M0 | Tongue | 53 | Female | Married | Unknown | Employed | Never | ≤ 14  | 2 days |
| 23 | T1N0M0 | Retromolar | 42 | Female | Single | A Levels | Employed | Former | ≤ 14 | 6 weeks |
| 24 | T4aN1M0 | Mandible | 56 | Male | Cohabiting | No qual. | Employed | Never | ≤ 21  | 12 weeks |
| 25 | T3N1M0 | Tongue | 69 | Female | Married | No qual. | Retired | Former | ≤ 14 | 9 weeks |
| 26 | T2N2cM0 | FOM | 57 | Female | Divorc/Sep | No qual. | Employed | Current | ≤ 14 | 1 week |
| 27 | T4aN0M0 | Mandible | 63 | Male | Married | No qual. | Unemployed | Former | 21+ | 1 week |
| 28 | T4aN2bM0 | Mandible | 70 | Female | Single | Diploma | Retired | Former | 14+ | 1 day |
| 29 | T1N0M0 | Maxilla | 72 | Female | Widowed | No qual. | Retired | Current | ≤ 14 | 4 weeks |
| 30 | T2N1M0 | Tongue | 48 | Male | Widowed | Diploma | Unemployed | Current | ≤ 21  | 1 week |
| 31 | T4aN0M0 | Mandible | 61 | Male | Cohabiting | No qual. | Unemployed | Former | 21+ | 4 weeks |
| 32 | T1N0M0 | Maxilla | 83 | Female | Married | GCSE's | Retired | Never | ≤ 14  | 1 week |
| 33 | T2N0M0 | FOM | 53 | Female | Single | GCSE's | Unemployed | Current | 21+ | 2 weeks |
| 34 | T4aN2cM0 | Mandible | 63 | Female | Married | No qual. | Unemployed | Current | ≤ 14  | 2 weeks |
| 36 | T2N2bM0 | Bucal Mucosa | 70 | Female | Divorc/Sep | GCSE's | Retired | Current | 14+ | 4-6 weeks |
| 37 | T1N0M0 | Maxilla | 59 | Female | Married | GCSE's | Unemployed | Never | ≤ 14  | 8 weeks |
| 38 | T1N0M0 | Tongue | 41 | Female | Cohabiting | Diploma | Employed | Former | ≤ 14  | 8 weeks |
| 39 | T4aN2bM0 | Mandible | 77 | Female | Widowed | GCSE's | Retired | Never | ≤ 14 | 3 weeks |
| 40 | T2N0M0 | Tongue | 63 | Male | Married | No qual. | Unemployed | Never | ≤ 21 | 4 weeks |
| 41 | T2N0M0 | Tongue | 39 | Female | Married | Diploma | Employed | Former | ≤ 14 | 3-4 weeks |
| 42 | T3N2aM0 | Buccal Mucosa | 77 | Male | Married | No qual. | Retired | Former | ≤ 21 | 10 weeks |
| 43 | T2N0M0 | Tongue | 44 | Male | Single | No qual. | Unemployed | Current | ≤ 21 | 5 days |

Glossary: FOM= Floor of Mouth

Table 2: Derivation of Distinct Responses to Symptoms from Analytic Themes

|  |  |  |  |
| --- | --- | --- | --- |
| Theme | Description | Example Quote | Patients |
| 1. Uncertainty resolution |
| 1.1 ‘*That’s not right’* | Patients suspected serious illness because symptom was unusual | ‘*I just mean there was something in the back of my head saying ‘that’s not right’. I couldn’t tell you exactly what but it’s just knowing, it’s sort of in your conscious mind you think it’s a mouth ulcer but subconsciously I think you sort of think mmm it doesn’t look quite right’ so it’s worth investigating’*. (P20) | 1,2,9,15,18, 20,22,26,27, 30,33,34 |
| 1.2 ‘*if symptoms don’t clear up get it checked out* | Inductive rule telling patients to seek HCP help if symptoms are unusual.  | ‘*I say any unexpected pains or whatever if they don’t clear up get it checked out. Y’know all the adverts on the telly going on about cancer this and cancer that so as I say get it checked out so’* (P7) | 1,2,7,9,30 |
| 1.3 ‘*I was always aware that I was gonna get cancer one day’* | Patients primed to suspect illness due to beliefs about personal vulnerability | ‘*I have awareness of cancer in my family. So I was always aware that I was gonna get cancer one day but I never suspected it would be somewhere like my jaw. I thought it was gonna be my bowel and maybe my lung*.’ (P15) | 6,7,9,15, 22, 28,30,34 |
| 1.4 ‘*certain things are preventable or curable if caught early enough’* | Patients believe that early intervention can mitigate serious illness | ‘*certain things are preventable or can be preventable or curable if caught early enough which obviously was something that was in my mind when I er found this lump’* (P22)*.*  | 1,15,22 |
| 2. Initial misattribution |
| 2.1 *I never presumed that it was anything that serious* | Patients did not suspect cancer or other serious illness | ‘*I didn’t have no thoughts about the symptom until I came to hospital. But before then I never had no presumptions that it was anything that serious*.’ (P33). | 13,14,19,21,32,33,39,40, 41,43 |
| 2.2 *I didn’t know what any of the symptoms were* | The symptom differs from expectations of serious illness | ‘*I didn’t know what any of the symptoms* (of OSCC) *were. Before this if you asked me to draw a picture of what oral cancer looked like it would be ‘a big black lump sticking out of somebody’s face or something’* (P41)  | 13,19,29,40, 41 |
| 2.3  *It was only very minor compared to…* | Misattribution occurred when unrelated illnesses were salient | *‘No it was just em like I say it was an incidental thing. It was only very minor compared to em, like I say I had gall stones so I was having stomach ache and that was bothering me more than the ulcer.’* (P21) | 6,11,19,21, 23,31 |
| 2.5 *There was no change whatsoever* | Patients questioned misattributions because symptoms did not remit | *‘It wasn’t Bonjela I used but something similar. No change whatsoever. Oh I then had my own suspicions that it could be something a bit pernicious, which of course it proved to be’* (P39) | 13,14,19,21, 32,33,39,40, 41 |
| 3. Defensive coping |
| 3.1 ‘*the last thing you wanna think’* | Patient does not want to think about cancer | *‘Well obviously there’s things in your mind that would say it might be cancer or it might not. You know you don’t know. Nobody wants to go around thinking it is cancer. I suppose that’s the last thing you wanna think*’(P8) | 3,5,6,8,36, 38,42 |
| 3.2 ‘*you just ignore it’* | Patient tries not to think about symptom  | ‘*I started to panic and I thought it’s more than an ulcer, and really deep down I thought there’s something there that could be cancer in the mouth. I didn’t really know but your one of them where you put it off won’t you cause you don’t wanna know, so you just ignore it and ignore it for a bit longer until you’ve got that bad you have to go* [to a HCP].’ (P5).  | 3,5,6,8,38,42 |
| 3.3 ‘*I didn’t want to accept it was anything worse than an ulcer’’* | Patient makes misattribution to avoid deducing serious illness | *‘I suppose if I’m truthful I didn’t really want to accept it was anything worse than an ordinary ulcer’*. (P36) | 24,36,38,42 |
| 3.4 ‘*I wouldn’t wanna go through what ma Dad went through’* | Patients express vulnerability to illness in intensely fearful ways | ‘*I always said if I had cancer I wouldn’t wanna know. I’d just want to carry on with it. I wouldn’t wanna go through what my Dad went through’*. (P5) | 5,6,31,38,42 |
| 3.6 ’*My girlfriend pestered me to go the dentist’* | Patient is pressed to present to a HCP by others | *‘My girlfriend pestered me to go the dentist, otherwise I wouldn’t have bothered really… Because she kept nagging at me to get my, to get my teeth sorted and to find out if there was anything more wrong’* (P4). | 4,24,29,36 |

Case Study 1: Uncertainty Resolution – P1

 **Background**: Male, 47, current smoker, drinks above 21 units per week. No direct or vicarious experience of OSCC. Awareness of the existence of OSCC but little detailed understanding. P1 spoke of his belief that health problems should, in principle, be investigated and treated as soon as possible: ‘*So nip it in the bud now, don’t pretend it will go away. Actually get that biopsy done, find out what’s going on and get it sorted*.’

**From detection to presentation**: P1 noticed symptom that he described as ‘*unusual*’: ‘*I picked up a skin flap. I knew there was something not quite right cause the texture of it and it felt a little bit like sand paper if you like. It was er, it was not fleshy. It was abrasive*.’

Whilst uncertain of the origin of the symptom, P1 explained his response in terms of an explicit principle, whereby he would take action to see a HCP if he felt a symptom was unusual: ‘*So that’s why really. That’s like self awareness y’know when you check yourself and stuff it’s like that shouldn’t be there so get it sorted’*. P1 specifically demanded that the dentist refer him for a biopsy, suggesting that by unusual symptoms he meant potential cancer symptoms ‘*I didn’t sit in a cupboard and hide y’know or anything like that. I acted upon it as soon as thought, I actually thought it’s not right cause as I say, as my dentist said to me it’s something completely different, and I said ‘oh no it’s not’. I went back the next day, came back ‘No it’s not. Can I please go for biopsy please?*’’.

Initially, the dentist diagnosed a salivary gland problem. P1 was sufficiently assertive and confident in his views to refuse to accept his dentists’ misdiagnosis: ‘*I went down to my dentist who tried to fob me off and I have mentioned this before, who tried to fob me off with er ‘it’s actually a salivary gland and I, I spoke to my wife and said ‘no that’s wrong’ so I went back the next day and said that’s a load of bullshit. I need to have a biopsy, and so that was that and that’s when we went from em it pretty much stayed until we went to, to the dental hospital’*.

Case Study 2: Misattribution of symptom to ulcer – P19

P19 initially attributed a ‘*a rough edge on my cheek on the inside of my check,* (felt) *with my tongue’* to a mouth ulcer.He did not at any stage consider cancer or any other serious illness as the cause of the symptom.

**Background:** Male 64 , non smoker drinks above national guidance. Never treated for cancer but is currently receiving treatment for stable angina. Reports a reluctance to consult a GP because: ‘*I do feel sometimes that you can only go in with one problem and you daren’t go in with another problem to the GP cause they’re so busy, erm because I did see the GP about changing my medication and he sent me for some blood tests etc, and when I went in I was tempted to mention this mouth ulcer but I just felt they didn’t have enough time so I didn’t mention it*’

**From detection to presentation:** P19 immediately attributed symptom to a mouth ulcer which he tried to treat with Bonjela (an anti-ulcer gel). Upon persistence of the symptom, P19 tried other anti-ulcer treatments. The symptom became ‘*larger*’, but P19 felt that it responded to his self-administered treatments because it became ‘*flatter and smoother*’.

When asked why he did not present the symptom to a HCP when it persisted during treatment, P19 attributed this persistence to friction between the inside of his cheek and his teeth (Theme 1.2): ‘*Right I began to think basic things like em maybe the teeth is catching the side of my cheek and that was causing it, but I didn’t once think it might be y’know cancer, not once. It didn’t, never, ever entered my head’*.

P19 did not at any time regard the symptom as serious, primarily because he did not experience pain (Theme 1.1); ‘*I really was not concerned or alarmed by what was in my mouth in a naive sort of way, because there was no pain, and I think that was a big issue for me. I think if it was painful I would have gone along to the doctor or dentist before I did’*.

**Reason for presentation:** P19 presented the symptom to his dentist because he wanted treatment for what he interpreted as a dental problem; that his teeth had caused and aggravated the ulcer.

Case Study 3: Defensive response to a symptom– P38

 P38 appraised her symptom in two competing ways; an explicit attribution to an ulcer and an intuition that the symptom may be cancer. We interpreted her attribution to an ulcer partly to serve the purpose of reducing her fears about cancer.

**Background**: Female, 53, never smoked moderate drinker who had been treated for cancer ‘*quite a few years ago’*. P38 is an office manager. Several months previously an employee under her supervision died of Head and Neck cancer. This was deeply upsetting to P38: ‘*it broke my heart, really*’ and was ‘*very much in my head for months*’. P38 did not describe fear of cancer, nor did s/he explicitly link this experience with his/her response to symptoms. Indeed, P38 did not mention the death of the employee until the end of the interview.

**From detection to presentation**: After detection of a ‘*hard lumpy mass*’ on the tongue, P38 described her attribution to an ulcer caused by friction with teeth as helping her to be ‘*positive’* in the face of her fears that the symptom may be serious ‘*It was like a gut instinct, I couldn’t put my finger on it, why I was thinking that way or why I was getting an intuitional message in my head, strange, quite strange really*’.

This tension was evident eight weeks between symptom detection and presentation:’ *Yea it’s in that back of your mind, it’s in the back of your mind definitely, but you’re thinking don’t be stupid it’s just an ulcer. Don’t be silly, y’know it’s the tooth rubbing on it. It can’t be that surely. It might have been niggling in my mind but I had the hope that it wasn’t anyway.*’

Significantly, P38 did not address the symptom as s/he would normally respond to a medical symptom. ‘*I usually go on to Google and start looking at the NHS website but I didn’t funnily enough that time I surprised me. I don’t know if I felt like I was mad busy at work and family life and I had no time to kind of mess about googling, erm I don’t know. Maybe I didn’t do it cause I knew what it was. I don’t know, psychologically did I know deep down what it was? I’m not too sure.*’ Similarly, P38 departed from his/her usual strategy of consulting a HCP: ‘*my method of doing stuff is that if I think I’ve got something wrong with me believe you me I’m at the doctors’*

**Reason for presentation**: P38 eventually consulted his/her dentist. The explicit reason was to treat the cause of the ulcer: ‘*And I felt my tongue and I thought God that’s sharp, erm and to be honest I probably left it too long but I just kept saying each week ‘oh it will go, it will go’ and then I finally thought well it’s not gone I’ll have to make an appointment with the dentist to get this tooth filed right down’*

The dentist referred P38 for investigation of the lump.

1. ‘Sort it’ is a UK slang term meaning to resolve a problem. [↑](#footnote-ref-1)