FACTORS AFFECTING TIME TAKEN BY PATIENTS TO PRESENT ORAL SQUAMOUS CELL CANCER SYMPTOMS TO HEALTH CARE PROFESSIONALS

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Thesis Overview

Patient delays in presenting oral squamous cell cancer (OSCC) symptoms to health care providers (HCPs) increases mortality and morbidity. The main aim of the thesis is to gain an understanding of decision-making processes that lead to presentation delay of potential OSCC symptoms.

Chapter 1 of the thesis presents an introduction to the research. It is separated in to three sections. The first section provides a background in to (OSCC) and highlights the importance of reducing patient presentation delay in the disease. The second section explains the various theoretical approaches that are relevant to patient delay, while the third section provides examples of studies that have devised interventions based on the theoretical approaches described in the previous section.

Chapter 2 of the thesis presents a systematic literature review of studies that have analysed reasons for patient delay in head and neck cancer. The review examines quantitative and qualitative studies separately using textual narrative synthesis. The main reasons for patient delay that are consistent across the studies are a lack of knowledge of head and neck cancer, interpreting symptoms as minor conditions that do not require medical attention and failing to attribute symptoms to cancer.

Chapter 3 is the first of the empirical chapters. Previous research provides little information on timescales between patients noticing symptoms and consulting HCPS, or little information about events between these. This chapter is a descriptive study of the length of time that a consecutive sample of 38 patients took from noticing symptoms of OSCC to appraise those decisions, decide to consult a HCP and to do so. It also assesses the number and timings of re-interpretations and revisiting of decisions that patients made if they initially decided not to

see a HCP. A new finding was that 17 patients were not referred on their first visit to a HCP, and that some required multiple visits before referral to a consultant.

Chapter 4 uses the same sample to gain an understanding of appraisal and decision-making processes that lead to presentation delay of potential OSCC symptoms. Patients took part in semi-structured interviews. In a novel innovation, techniques derived from the cognitive interview protocol were used to enhance recall of appraisals and decisions leading to presentation and non-presentation (Wagstaff, Wheatcroft, Caddick, Kirby & Lamont, 2010). These techniques have not been applied in patient delay research before. New findings include a 'sort it' response to symptoms, where patients quickly presented to a HCP to resolve uncertainty about symptoms, and a 'don't want to think about it' response where patients delayed presentation because they attempted to minimise distress by avoiding thoughts about cancer or deliberately misattributing symptoms to minor causes.

Chapter 5 highlights some of the limitations of using retrospective methods. A potentially better methodology that combines a retrospective method with a scenario based 'real time' method is described which was applied to the current research. A sample of community volunteers without oral OSCC engaged in a think-aloud task. Each volunteer was closely matched to a patient from the previous study based on risk factors of OSCC. The volunteers were given a scenario based on their matched patient's symptoms. Volunteers were prompted to interpret the information and to indicate how they would respond in the given situation. Interestingly, the majority of the volunteers responded in similar ways to the 'sort it' patients. This chapter suggests reasons for this finding.

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Declaration

I Juliet Bell, declare that I am the author of this thesis, that unless otherwise stated, all references cited have been consulted by me, that unless otherwise stated, the work of which this thesis is a record has been done by myself and has not been previously accepted for a higher degree.

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Chapter 1: Introduction

1.1 Key facts about oral cancer

Oral cancers are a sub-group of tumours of the head and neck that originate in cell tissue in the oral cavity. They are the 15th most common cancer in the UK (CRUK, 2013). OSCC consists of cancers of the tongue, the floor of the mouth, the hard plate, the buccal mucosa and the upper and lower gingival (Fu, et al., 2013). 90% of oral cancers are squamous cell carcinomas which arise as surface lesions (Ord & Blanchaert, 2000). Like other squamous cell cancers, oral cancer instigates from cells that line surfaces and body tissues, in this case the oral cavity. Oral cancer is mainly detected when it becomes symptomatic or invasive. Early symptoms comprise of oral bleeding, a non-healing ulcer or lump, a red or white patch, swelling, and sudden tooth mobility. Symptoms that occur later include; difficulty moving the jaw, localized pain, abnormal sensations, airway obstruction and chronic earache (Scott, McGurk, & Grunfeld, 2007; OCF, 2013).

Some 6,800 people are diagnosed with an oral cancer each year accounting for 2% of all cancers diagnosed (NHS UK, 2016). The rates of oral cancer have increased by 68% in the UK over the last 20 years. The cancer is on the rise for men and women, young and old, jumping from 8 to 13 cases per 100,000 in the last 2 decades (CRUK, 2016). Incidence rates for oral cancer are predicted to rise by 33% in the UK between the years 2014 and 2035, from 13 cases to 20 cases per 100,000 by 2035 (CRUK, 2016). Cancer Network reported that age standardised rates per 100,000 population was 3.02 between the years 2002 and 2006 (NCIN, 2010). In 2012 the lifetime risk of developing oral cancer was 1 in 75 for men and 1 in 150 for women (CRUK, 2016).

Metastasis occurs when cancer cells from the primary tumour break off and travel to other parts of the body through circulatory systems. The cells then reattach themselves in a new

area. The metastasis tumour that forms in a different area of the body contains oral cancer cells. Symptoms of metastatic oral cancer may include; swelling or lumps in the lymph nodes, intense headaches, unexplained pain in other parts of the body, weight loss or loss of appetite (Cancer Treatment Centers of America, 2017).

1.1.1 Treatment for Oral Cancer

Usually the earlier the stage that the cancer is treated the less intensive the treatment will be and the better the prospect of patient survival (Rogers et al., 2009). Stages 1 and 2 OSCC can often be treated simply and cheaply with a single modality of treatment. Radiotherapy alone has shown to be an effective form of treatment for early stage OSCC. However, radiotherapy can have various complications, so surgery is often the most preferable option. Surgery may be complemented with other forms of treatment. For stages 3 and 4 of oral cancer multi-modality therapy over an extensive period is the common approach. For instance, a patient may receive surgery followed by radiotherapy if the cancer is too big to be removed by surgery. Alternatively, they may receive radiotherapy with chemotherapy; or a combination of surgery, radiotherapy and chemotherapy. Palliative treatment is offered to patients with advanced oral cancer that is unlikely to improve. This treatment aims to control symptoms by reducing the growth of the tumour. Palliative treatment may be surgery combined with radiotherapy, chemotherapy alone or with radiotherapy (CRUK, 2013).

Treatment for oral cancer can have adverse effects on a patient's quality of life because surgery is intensive and often disfiguring, causing functional loss and body image problems. This can trigger anxiety or depression (Foulkes, 2013). The risks and sequelae associated with surgery are primarily based on the extent of the cancer. Sequelae may consist of disfigurement, and difficulties swallowing and speaking. Radiotherapy and chemotherapy

may be toxic to the oral mucosa, leading to pain bleeding and excessive ulceration. Other risk factors linked with these treatments include, oral mucositis, salivary gland dysfunction, dysgeusia, nutritional complications and immune dysfunction (Oral Cancer Foundation, 2017).

1.1.2 Risk Factors for Oral Cancer

Oral cancer is more commonly associated with older people, although a rise in incidence has been reported among adults under the age of 40 (Warnakulasuriya, 2009). Patterns in incidence by age are different for men and women. For men age specific incidence rates rise steeply from around the ages of 40 to 44 and peak between the ages of 65 to 69, before dropping steadily. In contrast for women, age specific incidence rates increase gradually from around the ages of 40 and 44 and peak in the over 80's age group (CRUK, 2016).

Ninety-one percent (93% in males and 85% in females) of oral cancers each year in the UK are linked to tobacco and alcohol consumption (CRUK, 2016). Some 90% of OSCC patients are smokers. People who smoke have six times the risk of developing malignancy than non-smokers. Cigarette smoking causes mutation of the p53 suppressor gene which can lead to tumorigenesis. The risk of developing oral cancer due to smoking is both dosage and duration dependent. Smoking cessation reduces risk, although a study by Bosetti et al. (2008) revealed it takes at least 20 years for the risk to decrease to that of never smokers. Second hand smoke has also been suggested to increase the risk of oral cancer (Bosetti et al., 2008), as Lee et al (2009) found a 63% increased risk in never smokers exposed to second hand smoke at home or work (Lee et al., 2009).

Alcohol consumption is another risk factor in the development of oral cancer (Ord & Blanchaert, 2000). A study in Italy and Switzerland revealed that non-smokers who consumed at least five drinks a day had a five-fold increased risk of developing oral cancer compared to non-drinkers, suggesting that alcohol can independently cause oral cancer. It is suggested that the relative risk for oral cancer reduces only after 15 to 20 years of abstinence. Alcohol (ethanol) itself is not carcinogenic, but animal studies have shown that Acetaldehyde, a break down product of ethanol in the body causes damage to an organism's DNA. This consequently contributes to the development of cancer. Combined usage of alcohol and tobacco has shown to have multiplicative effects on the risk of developing oral cancer (Pelucchi, Gallus, Garavello, Bosetti, & LaVecchia, 2006) and individuals who drink heavily and smoke are at 300 times greater risk of developing oral and pharyngeal cancer than those neither drank nor smoked (Zheng, Boyle, & Zhang, 2004).

The principal cause of the very high incidence of oral cancer in South Asia is known to be the pervasive habit of chewing on betel quid and associated usage of areca nut. Although the risk of developing oral cancer is higher for usage of betel quid containing tobacco, areca nut is carcinogenic to humans and is a risk of oral cancer when used without tobacco (CRUK, 2013).

One contributor to the rise in rates of oral cancer over recent years may be the human papillomavirus. There are over a hundred different strains of the virus and most clear by themselves. However, some infections with strains on the human papillomavirus persevere which can cause cell changes leading to the development of cancer. One of these high-risk strains is HPV-16 (CRUK, 2012). Parkin (2011) proposed that 8% of cancers of the oral cavity are linked to HPV infection (Parkin, 2011).

Oral cancer tends to disproportionally affect those from disadvantaged and low-income sections of society, most likely because they are generally more exposed to preventable risk factors, such as infectious agents, tobacco and alcohol use (Foulkes, 2013).

A relationship has been found between oral cancer and diet. A diet rich in fruit and vegetables can prevent the development of the disease. Cereal and olive oil have also been suggested to have protective effects (Foulkes, 2013). In 2010 over half of oral and pharyngeal cancers in the UK were linked with people eating less than five portions of fruit and vegetables a day (CRUK, 2013). This finding is interpreted in terms of research by Abdulla & Gruber, (2000) showing that vitamins, antioxidant molecules and trace elements found within fruit and vegetables have cancer fighting properties (Abdulla & Gruber, 2000). There is also potentially a link between oral hygiene or poor dental care, but this remains unclear (Mangalath, et al., 2014). Causal pathways for these variables are yet to be shown, so it is possible that some may represent spurious relationships as unhealthy behaviours, such as smoking, alcohol use and diet, tend to be correlated.

1.1.3 The Importance of Early Treatment

Treatment for early stage oral cancer has higher success rates and has fewer and less severe side-effects. In contrast, oral cancer treated at a later stage is more likely to involve multi-modality therapy over an extensive period. The patient is more exposed to the risks and sequela associated with treatment that can have negative effects on quality of life. Early help-seeking for oral symptoms is vital in reducing those risks. Treatment for patients with advanced oral cancer is frequently palliative. Early diagnosis and referral of oral cancer is important in increasing survival and enhancing quality of life. It is also important in reducing morbidity, disfigurement, duration of treatment and hospital costs (Scott et al., 2007). Studies

have found that greater patient delay in oral cancer is associated with advanced disease stage (Sargeran, Murtomma, Safavi, & Teronen, 2009; Kumar et al., 2001). Disease stage has shown to be an independent predictor of survival in oral cancer (Warnakulasuriya, Mak, & Moller, 2007). For oral cancer related to lesions on the floor of the mouth, the 5-year disease specific survival rates by stage are as follows; I: 90%, II: 80%, III: 70%, IVa: 40-50%, and IVb (Inoperable): 20% (Oral Cancer Foundation, 2013). Around 4 out of 10 patients with oral cancer are diagnosed with advanced disease (stage 3 or 4) when presenting their symptoms to health professionals (Rogers et al, 2009). Treatment delay can be subdivided into patient delay, the delay between the appearance of a symptom and presenting to a HCP, and professional delay, the time between presentation and treatment commencement.

The urgent two-week referral system was introduced as a way of reducing professional delay so that any patient who presents to a GP or dentist with symptoms that may reveal cancer can be seen by a specialist as soon as possible. A third of new cancer cases in the United Kingdom are handled as urgent referrals (Lyon, Knowles, Slater, & Kennedy, 2009). A GP or dentist will follow national guidelines in order to make a decision as to whether it is suitable to refer the patient for an urgent hospital appointment within two weeks (Mcllrath, 2013). Since these guidelines have been introduced there has been significant reductions in diagnostic delays in head and neck cancers, mean reduction=21.2 days (Neal et al, 2014). The remaining two thirds of cancer cases are diagnosed through non-urgent referrals, out-patient hospital appointments, mass-screening screening or patients presenting as emergencies to hospitals (Lyon et al, 2009).

However, the main cause for the delay in diagnosis is believed to be the time taken for patients to present their symptoms to a HCP, rather than referral, diagnostic or treatment delay (Rogers et al., 2007; Hollows, McAndrew, & Perini, 2000). Rogers, et al's (2007) study found that health professionals usually deal with oral cancer symptoms promptly. For

instance, in 78% of referral cases a referral letter is sent to an oral and maxillofacial unit on the same day as the first presentation to the primary health care professional. This implies an awareness of oral cancer risk amongst the dental practitioners and the general medical practitioners. Additionally, on average there are three weeks from referral to definitive diagnosis and approximately another three weeks before having surgery (Rogers et al., 2007).

Studies have shown that some individuals postpone seeking medical attention regarding their symptoms for several months. Between 20 and 30% of oral cancer patients delay seeking help for more than three months (Amir, Kwan, Landes, Feber, & Williams 1999; Rogers et al., 2009; Kerdpon & Sriplung, 2001). Additionally, 12% delay their symptoms for more than six months (Kerdpon & Sriplung, 2001). This may partly explain why the 5-year relative survival rate for oral cancer is only 56% in the UK (NCIN, 2010). It is important that people are encouraged to present their oral symptoms to health professionals at an early stage (OCF, 2017).

1.2 Theoretical Approaches

Overview of Theories

Symptom appraisal theories encompass how an individual interprets symptoms. They provide an understanding of the ways in which people subjectively experience their symptoms, and the emotions generated from them. Conversely, deliberation theories explain the processes by which an individual weighs up different alternatives in order to make a decision, such as deciding to consult a HCP regarding symptoms or to not make a decision. Finally, information seeking theories describe the factors leading to information seeking and the

barriers inhibiting action that allow an individual to clarify their symptoms and conditions which in this context will be information regarding oral symptoms and OSCC as an illness.

1.2.1 Symptom Appraisal Theories

1.2.1.1 The Self-Regulatory Model of Illness Representations and Behaviour

OSCC presentation delay research employs a number of theoretical perspectives, all of which describe processes of symptom detection, appraisal and decision-making (Whitaker, Scott & Wardle, 2015). Probably, the most influential is the self-regulation model [SRM] (Leventhal, Leventhal & Contrada, 1998). The *self-regulatory model of illness representations and behaviour* was introduced by Leventhal (1970) to explain how people interpret and cope with illness. The model takes in to account the individual's perceptions of the environment, symptoms, what they know about illness and themselves. This model is also known as a 'common sense' model to emphasise the informal and sometimes objectively incorrect ways in which people interpret symptoms, illness and treatment. These representations are the primary determinants of coping procedures (cognitive and behavioural actions to manage health threats). Representations are activated and explained on the basis of a change in somatic activity (a visible or sensed difference in the body). When this becomes a problem for the individual (i.e. a health threat); problem solving commences which leads to the formation of goals and action plans (Leventhal et al., 1998).

Representations have two sets of properties; content and organisation. The content of the representations is grouped in to six key areas that define the nature of health threat. The first is the *identity* of the health problem, which refers to the label of the threat (e.g. cancer, gum disease or flu) and attributes of the symptom (e.g. a lump in the mouth, bleeding from the

mouth, difficulty swallowing). The second area is *consequences* which consist of long-terms consequences and activity disruption. Consequences tend to relate to the severity of the symptom (e.g. disfigurement, loss of work time or death). The third area is *timeline*, which refers to the time for the development of the illness, its duration and whether symptoms are cyclical or monotonic. The fourth area is *causes* which are perceived triggers of the health problem (e.g. tobacco and alcohol intake, poor diet or stress). The fifth area is expectations of *controllability*. This refers to the degree of which the disease can be prevented or cured (Leventhal et al., 1998). A sixth area that has later been added to the model is *coherence*. This refers to the extent that the representation is coherent or useful in providing an understanding of the disease (Moss-Morris, et al., 2002). These attributes define the health problem, thus establishing the direction for action and goal setting (Leventhal et al., 1998).

Representations are also organised inductively or deductively (Leventhal et al., 1998). Deductions about the meanings of symptoms can be made in a 'top down' way where symptoms are matched to existing representations based on current understanding of illness; for example, the symptom is a solid lump that has persisted and is therefore consistent with cancer. Individuals who make top-down deductions fail to perceive their symptoms as serious when the characteristics of their symptoms are incompatible with their ideas of how serious illnesses such as cancer should manifest. Inductive approaches are 'bottom-up', driven by perceptions of symptom characteristics for example, a symptom is serious because it is abnormal or unusual. Individuals who make bottom up deductions do not make their interpretations of symptoms based on their understanding of specific illnesses.

The second part of the SRM concerns coping procedures. They are the cognitive and behavioural actions taken or not taken to improve health and prevent or treat (i.e. control or cure) illness. Coping involves responding to symptoms in order to either address the cause of symptoms or to relieve negative emotion associated with them. The selection of coping

procedures is influenced by the representation of the health threat. Additionally, the representation is influenced by the appraisal and performance of coping procedures (Leventhal, et al., 1998).

Coping Procedures are embedded in if-then rules for disease management. The 'IF' part of the rule is the characteristics of a disease threat that defines the suitability and determines the outcomes expected for specific actions. The 'THEN' part is what an individual does given the problem definition. In a deductive if-then sequence the 'IF' is derived from understanding of illness, e.g. 'IF the symptom is consistent with cancer THEN seek help'. Conversely, in an inductive sequence the 'IF' is derived from thoughts about symptoms, e.g. 'IF I have an ulcer that persists for three weeks THEN seek help'. The individual actively appraises the outcomes of coping procedures and the appraisal may change their interpretation of the illness threat, (e.g. an abscess becomes possible cancer if it has not healed after seeking advice from a pharmacist. Thus, another set of 'IF-THEN rules are formed in which the IF becomes an appraisal of the success of a coping procedure at managing the problem, and the 'THEN' becomes a revised problem representation (Leventhal et al., 1998).

Representations of a disease threat can overlap with representations of the self. It is often difficult to enhance health-promoting and disease preventing behaviours among healthy (i.e., asymptomatic) individuals as illness threats raised in this context may be considered as irrelevant as they are external to the self, i.e. not expected to affect them. Behaviour responses to disease threats are linked to perceived vulnerability to disease. This perceived vulnerability is generated by aspects of the self. For oral cancer one of these factors could be young age as older people are more likely to be affected by this disease (Leventhal et al., 1998).

The SRM operates in a cultural and social context. It shapes behavioural outputs to achieve goals defined by its representation of the context. Culture defines illness representations and the self. Such cultural influences can include, the way in which healthcare services are organised, specific cultural beliefs and the language used to describe particular illnesses and social circles. An individual actively appraises the utility of cultural and social information. For instance, a person discussing symptoms with family or friends decides whether the information given to them is reliable or not (Leventhal et al., 1998).

1.2.2 Deliberation Theories

Deliberation theories examine the decision processes that lead to prompt or delayed presentation. These are largely distinguished by how people respond to negative emotion generated by symptom detection or decision conflict, and all describe maladaptive ways of dealing with that emotion. In examining the role of negative emotion, all make an implicit statement that people are disturbed by symptoms, possibly because those symptoms are suspected of being serious illness.

1.2.2.1 Defensive thinking component of the Self-Regulation model

SRM theory proposes that, under some circumstances, people may not implement active IF-THEN rules to reduce threat, but instead may delay presentation because they use a defensive coping response to avoid acknowledgement of potentially distressing implications of their symptoms. Thus, they deal with symptoms by avoiding or denying symptoms or their implications (Leventhal, Leventhal, & Cameron, 2001). Support for these ideas comes from studies of presentation delay in other areas of cancer, where patients attribute delay to their

fears of death or the painful and disfiguring effects of treatment (Burgess, Hunter, &

Ramirez, 2001; Lam & Fielding, 2002). Studies have shown that habitual tendencies to cope

with threat-induced distress by avoidance or denial are associated with delay in oral (Tromp,

Brouha, De Leuw, Hordijk, & Winnubst, 2004) and other cancers (Pedersen, Olesen, Hansen,

Zachariae, & Vedsted, 2013; Ruiter, de Nooijer, van Breukelen, Ockhuysen-Vermey, & de

Vries, 2008). However, no research of which are known explicitly shows how patients might

respond defensively to symptoms or how this influences presentation delay.

1.2.2.2 Ruminative Response Styles Theory

The ruminative response styles theory was proposed to explain how negatively biased

thinking can lead to delayed decision making (Nolen-Hoeksema & Morrow, 1991; Nolen-

Hoeksema, Wisco, & Lyubimirsky, 2008). Rumination involves a narrow and repetitive

cognitive response to the negative emotion that frequently accompanies symptom detection.

A ruminative response style is a negative thinking style, in which the focus lays continuously

on the causes, meanings and consequences of one's distress. Self-focused rumination

combined with a negative or depressed mood can cause vicious cycles between mood,

thinking and problem-solving, thus leading to greater distress (Lyubomirsky, Kasri, Chang, &

Chung, 2006). It is well appreciated that pessimism and helplessness can lead to depressed

affect, but rumination theory posits a cycle whereby mood and cognition are related

reciprocally. When experiencing negative affect, some people brood about the problems at

the root of their distress, causing them to feel helpless or pessimistic. Although such thoughts

may naturally arise for anyone who experiences a depressed mood, some people persist in

ruminating without taking action to address their situation or to distract themselves

(Lyubomirsky & Tkach, 2004). Papageorgiou and Wells (2001) claimed that rumination is

caused by underlying metacognitive beliefs. They proposed that positive beliefs about

rumination, such as regarding it as being a useful coping strategy, instigate rumination. Also, negative beliefs about rumination, linked to the uncontrollability and harm of rumination facilitates the relationship between rumination and depression (Papageorgiou & Wells, 2001).

As a result, this can cause an individual to delay presenting their symptoms to health professionals. 67% of breast cancer patients who delayed their symptoms by at least 30 days were found to be ruminators. Lyubomirsky et al. (2006) found that individuals who ruminate frequently do not take action to solve problems. For instance, an individual with a ruminative response style who discovers a cancer symptom is likely to have biased thoughts about the self. Therefore, they may interpret the symptom as being something they deserve, eliciting guilt or shame. This may cause a symptomatic individual to believe they have little control over their health, so they feel helpless and less motivated to find effective solutions to their problems (Lyubomirsky, et al., 2006).

Research has indicated that rumination in the presence of a dysphoric mood reduces people's motivation and commitment to resolve their problems (Lyubomirsky & Tkach, 2004). Ruminators are focused on their distress, which may cause individuals who feel sad and anxious to believe that they lack the ability to take action, despite being aware that taking such action is crucial. This means an individual who detects an oral symptom knows what step to take next, but they may believe they lack the energy or skill to do so. All things considered, when self-detecting an oral symptom, a ruminator may experience high negative affect and low positive affect which often creates a vicious cycle comprising various emotional and cognitive deficits. These deficits, along with the ruminator's distress ultimately lead to a delay in help-seeking. In contrast, a non-ruminator who feels anxious or low-spirited when detecting an oral symptom will not go through such a vicious cycle. Therefore, they won't be as likely to delay seeking help. Similarly, a ruminator who is not

experiencing distress is also predicted to be less likely to delay symptom presentation (Lyubomirsky, et al., 2006).

1.2.2.3 Rational-Emotional Model of Decision Avoidance

The prospect that an individual may have cancer can often produce negative emotions such as fear and anxiety. They may consider not taking action in order to deal with their symptoms as they anticipate greater negative emotions towards seeking help from health care professionals than doing nothing. This is likely because they believe seeking help and being diagnosed with cancer will lead to negative consequences, thus negative emotions.

The rational-emotional model illustrates that decision avoidance is driven by the need to regulate negative emotions (see figure 1.1). These negative emotions are either *anticipatory,* currently experienced emotions such as fear and worry, or *anticipated* expected emotions predicated on making incorrect decisions such as guilt or regret. It is proposed that negative emotions can be controlled by decision avoidance or deferring making a decision. An individual generally experiences negative anticipatory emotions when they have *selection difficulty* i.e. they experience conflict deciding which of the options best meets their needs. If the options all have both negative and positive qualities or if all attributes are negative, then choosing between them can lead to distress. Postponing decision making, or decision avoidance is applied in the hope that other solutions will emergence. Anticipated regret occurs when an individual perceives that making a decision will cause them to be responsible for negative consequences, especially when the outcome cannot be changed. Overall, people often anticipate greater regret towards decisions involving action rather than no action (Anderson, 2003).
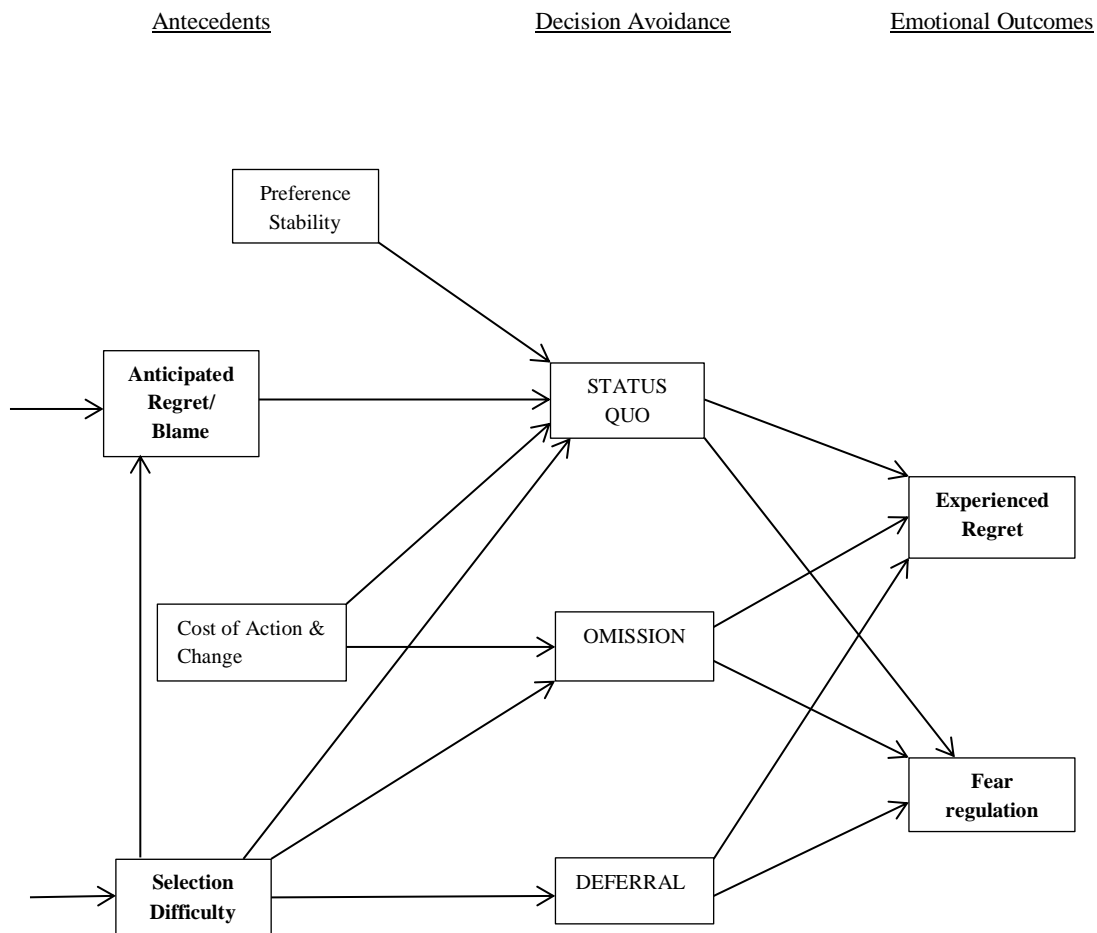
Figure 1.1. **A Rational-Emotional Model of Decision Avoidance (Anderson, 2003)**

N.B. The forms of decision avoidance are presented in capital letters. The emotional influences are shown in bold text and have thin arrows to indicate that other processes and situational factors in turn affect these emotions

Selection difficulty is experienced when individuals find it challenging to select a particular course of action because either could lead to loss. The general hypothesis is that increases in selection difficulty increase decision-avoidance options because it increases the potential costs, and therefore regret, of decisions. Selection difficulty can be influenced by a number of factors. *Time limitation,* puts restrictions on the strategies for selection a decision maker can use. The decision maker decreases their preference for a deferral or avoidant option when the

decision process is speeded up (Anderson, 2003). Individuals with advanced oral cancer symptoms may believe they have limited time to seek medical help in order to avoid detrimental consequences.

Individuals who anticipate regret aim to reduce potential regret over decisions by choosing an avoidant option. These options include *omission choices, status quo choices* and *choice deferral* (Anderson, 2003). However, other research has shown that *anticipated regret* does not always lead to *decision avoidance.* The desire to avoid the negative feeling of regret can encourage people to convert their positive intentions into actions.

The four decision avoidance effects (*status quo bias, omission bias, choice deferral and inaction inertia*) give insight into human behaviour. The first is *the status quo bias*, which refers to an individual's preference to maintain the existing state of affairs, and to avoid options that cause changes in the state of the world. Closely linked to this is the *omission bias,* described as an increased preference for options where action is not needed. These two biases are described as being independent of each other but share the same underlying causes. The concept behind the *omission bias* is that individuals may prefer not to intervene in a process because the consequences of intervention are seen as more detrimental than non-intervention. These two biases are linked to the assumption of loss aversion which implies that people are more afraid to encounter a loss than they are keen to obtain an equal gain, so they generally behave in a risk aversive manner to prevent such losses (Ackerson & Preston, 2009). For instance, it has been revealed that one of the reasons why women did not attend a mammography screening was because it would challenge their 'current health' status quo. They feared that their results would reveal cancer so they preferred not to know (Carter, Park, Moadel, Cleary & Morgan, 2002).

Choice deferral describes a situation where an individual decides to postpone making a choice. This may be due to the individual either choosing not to acquire any of the available options, taking time to search for other options, or avoiding complete responsibility for the decision. An individual is more likely to postpone making a decision when they experience conflict between choices, thus making selection difficult. This implies that a person who notices oral symptoms may postpone deciding to seek professional help as they experience conflict between taking action to resolve their symptoms and doing nothing.

Finally, *inaction inertia* refers to the tendency of an individual to refrain from taking action, when they have already rejected a similar, more appealing opportunity to act. For instance, an individual may wish that they sought a diagnosis earlier, when their symptoms were less severe. This is a form of upward counterfactual thinking. Upward counterfactuals are linked with regret, as individuals are aware that they should have taken the earlier opportunity. This means they do not consider the value of present opportunities, independent of past choices (Anderson, 2003).

The *decision avoidance* effects are influenced by common antecedents. These include *preference stability,* meaning the consistency of people's values over time, which influences their consecutive decisions. An individual selects the status quo option when preferences change less. When c*osts* of making changes are perceived as lower than the costs of selecting the status quo an individual is likely to deviate from the status quo. *Action costs* can cause an individual to opt for inaction. Additionally, when the costs needed to take an action (action costs) increase, selection of the omission option should increase. Similarly, there are also costs for delay. An individual must therefore determine when to decide by comparing the gains that could be formed through further contemplation with the losses that could be experienced by postponing the choice (Anderson, 2003). These ideas are supported by findings that breast cancer patients who delayed seeking a diagnosis from their general

practitioner justified their decisions by providing more arguments for delaying than seeking a diagnosis (Facione & Facione, 2006).

One of the consequences of *decision avoidance* is *experienced regret.* This occurs when individuals mentally recreate past events, adapting their actions and decisions, and view imagined outcomes. The comparison of the counterfactual outcome to the actual outcome brings awareness to the decision maker that they could have achieved a better outcome, and negative emotions are induced through this (Anderson, 2003). Individuals with oral cancer may regret their decision to postpone seeking a diagnosis for their symptoms earlier, particularly as early diagnosis and referral of oral cancer is key in increasing survival and enhancing quality of life (OCF, 2017). The other consequence of *decision avoidance* is *fear regulation.* This form of emotional outcome manages the regulation of emotions such as anxiety that were arsing before decision selection (Anderson, 2003). Individuals with cancer symptoms may be controlling their fears of the medical establishment, medical investigations or the diagnosis by avoiding seeking medical attention (Ackerson & Preston, 2009).

Anderson's model is essentially a balance model, whereby fears of making a decision are stronger than those of not making it. The researcher suggests that when symptoms worsen or do not improve after taking self-medication, fear of the symptoms means that they may feel that they have no other option but to decide to consult a HCP.

1.2.3 Theories of Information Seeking

 'Top down' appraisals depend upon accurate understandings of illnesses and symptomology for people to recognise that symptoms may be cancer. This is why Scott et al. (2007) recommend that people be taught to recognise symptoms as cancer. 'Bottom-up' processes

also depend upon information; people will need to recognise when oral symptoms deviate from normal. For example, people will need to be able to recognise when a symptom is abnormal and not an ulcer or abrasion. With the ready accessibility of medical information over the internet, information-seeking becomes important, and disruptions of information seeking could possibly lengthen delay.

The Comprehensive Model of Information Seeking (CMIS) by Johnson (1993) and A *Model of 'Information Behaviour'* by Wilson (1996) both overtly address the issue of information avoidance. The two models tackle various aspects of empirical findings on health-related information, particularly Johnson's model which was produced with cancer seeking in mind. Both models enable a conscious or unconscious decision to avoid information, and both include anxiety and self-efficacy as motivating or inhibiting factors. In Wilson's model anxiety is the activating mechanism for information avoidance. Anxiety is conceptualised in terms of stress and coping theory. In Johnson's model emotions such as anxiety and fear, as well as actions such as ignoring are included in the 'personal relevance' factor's. In Wilson's model the self-efficacy notion is explicit, while in Johnson's model it is found under salience of information (Case, Andrews, Johnson & Allard, 2005).

Anxiety is linked to beliefs in the efficacy of health care procedures related to cancer. People who believe that a cancer diagnosis leads to certain death and uncontrollable pain are likely to feel powerless in regard to cancer. Feelings of powerlessness lead to less information seeking. Therefore, avoidance behaviour may be a more attractive option in response to the health threat. Studies indicate that people with cancer symptoms may be less inclined to seek information, even though their situation requires more information (Degner & Slogan, 1992). A tendency towards avoidance and fatalism can prevent any form of information seeking (Case et al., 2005).

1.2.3.1 The model of 'Information Behaviour'

This model by Wilson (1996) pictures the cycle of information from the emergence of the information need to the stage when information is being applied (see figure 1.2). The rise of an information need is generated by the context, which can be the individual them self, the environment or the role the individual plays in society. The model stipulates various significant determinants of information seeking behaviour. Like the factors prompting the occurrence of the information need they can be categorised as being environmental, role-related or personal. Between what Wilson calls the 'person in context' and the decision to seek information, is a concept known as activating mechanism. This refers to the psychological processes that motivate information seeking. Wilson proposes that one of the activating mechanisms can be explained by stress and coping theory. Risk/ reward theory and the perception of self-efficacy described by social learning theory also explain why in some situations people are motivated to seek information.

The next phase of the model describes the ways in which information is acquired. Wilson distinguishes between the different ways information is acquired. Passive attention occurs when information is gained from the environment without an intention to seek it. If the information gained this way is relevant it is known as passive search. Active search occurs when information is actively sought for, while ongoing search refers to the continuation of a search to gain more information. Once the information is gained it becomes an item of knowledge and the individual searches for new information (Niedzwiedzka, 2003).
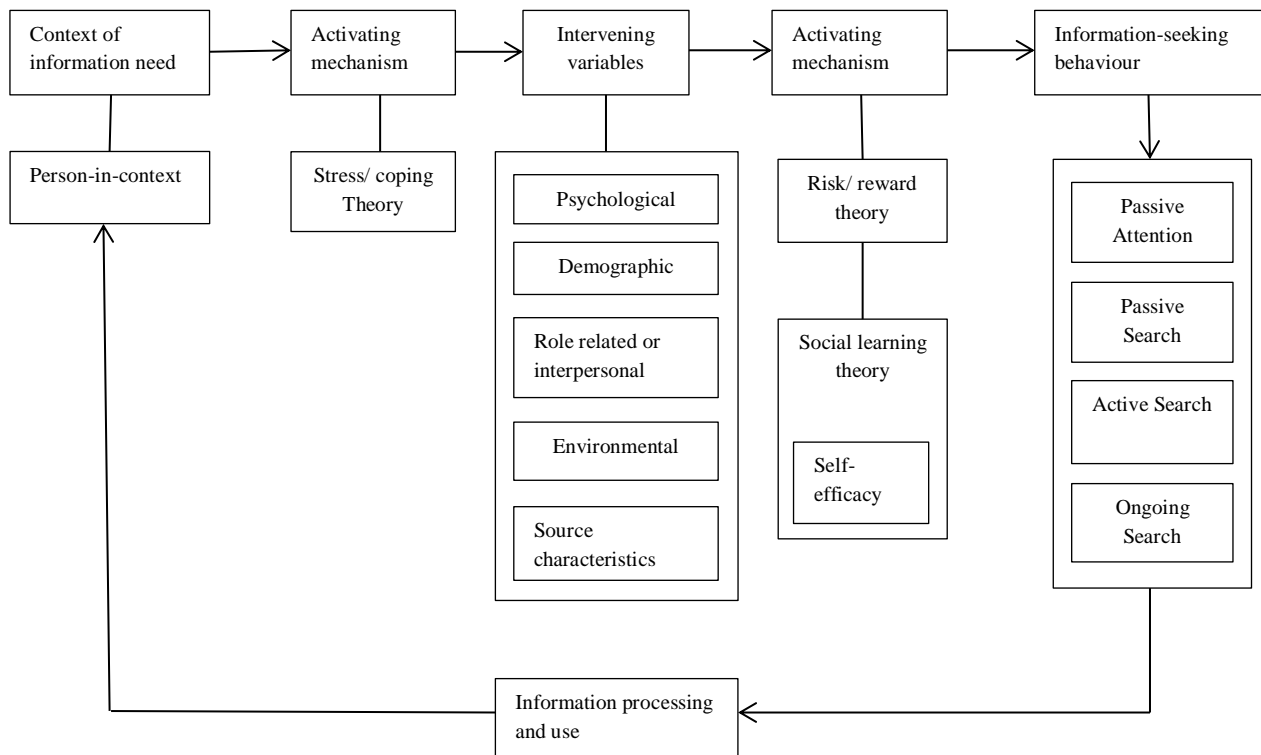
Figure 1.2: Model of 'Information Behaviour' (Wilson & Walsh, 1996)

The activating mechanisms motivate information searching, such as seeking information from a health care professional regarding an oral symptom. They are influenced by five *'intervening mechanisms'* (i) Psychological predispositions, including the inclination to be curious or averse to risks, (ii) Demographic background, which covers age and socio-economic status, (iii) Aspects related to one's social role, such as family and occupation. (iv) Environmental variables, comprising available resources, (v) Characteristics of the source, covering accessibility and credibility (Case et al., 2005).

The significance of this model is that it recognises that the typical *'intervening variables'*, being psychological, demographic, role related, environmental or source characteristics may not come into play if the need or the information required to deal with it is too threatening or stressful. A later 'activating mechanism' also involves self-efficacy, as represented by Bandura's social learning theory. Perceptions of self-efficacy are linked to avoidant behaviours.

1.2.3.2 The Comprehensive Model of Information Seeking (CMIS)

This quasi-causal process model by Johnson (1993) flows from left to right, starting with four *'antecedent' factors* that provide underlying imperatives to seek information. They encompass an individual's background factors (demographics and experience), as well as an individual's personal views of the relevance of the information (salience and beliefs). Characteristics of the information source contribute to the value an individual places on the information for achieving their goals. This value along with the characteristics of the information source drive an individual to take action in order to seek information.
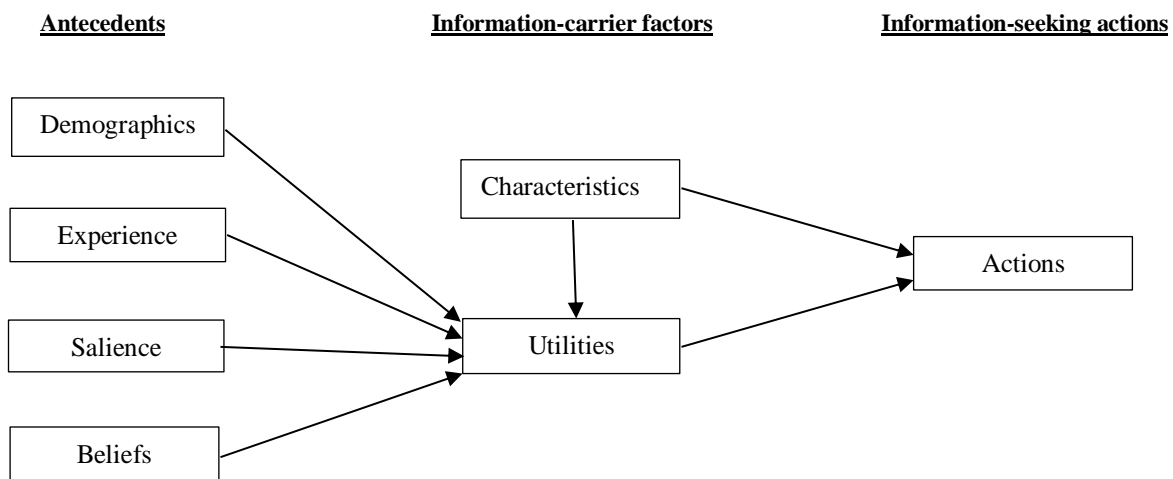
Figure 1.3: Comprehensive Model of Information Seeking (Johnson, 1993)

The first *'antecedent'* factor that leads to information seeking is 'demographics'. Like Wilson's model a number of demographic factors have important consequences, including one's gender, age, along with socioeconomic variables like occupation, wealth and education. For instance, older or more educated people may have a natural disposition to seek information from the internet or other people regarding symptoms. Another background factor is one's personal experience linked to the domain of interest. An individual generally holds some knowledge on the area of interest, as well as the ways one can gain information about it. Social network is an element related to experience that is important to the person

22

seeking information. Cancer information has a great amount of social significance, as the incidence of cancer in one family often encourages other family members to seek information regarding the disease (Case et al., 2005).

The final two 'antecedent' factors fall under the category of 'personal relevance'. These are 'beliefs' about the topic raised and the salience of the information about it. Both are influenced either by an individual's extent of knowledge or their state of ignorance about the topic. They also both indirectly raise the issue of information avoidance. Ignoring takes place when an individual is aware that there is a problem, but they decide not to confront it. The concept of salience infers the personal significance of health information including perceptions of risk to one's health which are likely to motivate information seeking. An individual's beliefs about the outcome of information seeking are also key, as they inhibit the individuals thinking and motivation concerning information seeking. Questions individuals pose themselves here include, 'Is there a problem?' and 'Is there a solution?'. Beliefs depend on people's amount of control over the events, their self-efficacy. People are not likely to seek information if they do not believe that knowing more about the matter will enable them to change their situation.

The second column of Johnson's model *'information-carrier factors'* determines the nature of the information search. The CMIS suggests relationships between two information carrier factors, 'characteristics' and 'utility', and 'information seeking actions'. Credibility and trustworthiness have shown to be important source characteristics (Johnson, 2003). Utility is summarised as the value for meeting one's objectives (Case et al., 2005). The final components of the model are 'information seeking actions'. Searches for information consist of conscious decisions among sources and channels but also include feelings, processes and various other cognitive and behavioural elements (Case et al., 2005).

1.3 Interventions

Most OSCC cases occur outside monitored populations, such as patients with oral dysplasia or other precancerous conditions (Petersen, 2009). Thus, interventions to facilitate prompt presentation cannot be targeted toward specific 'at risk' individuals, and should focus on the general population (Petti, 2009). Mass-reach communications are necessary as they are used to target a wider audience that would not otherwise actively choose to seek information. Such communications have potential to facilitate earlier cancer symptom presentation but are likely to be maximally effective when message development is grounded in theory (Austoker, et al., 2009). Several studies have used the above theories to devise interventions to improve presentation times in cancer.

One study by Mansson, Marklund, Bengtsson, & Fridlund (1998) assessed the effects of an educational programme for early detection of cancer (EPEDC) in primary healthcare in terms of decreasing the patient's delay. 32,627 participants were served by six health centres on the Swedish west coast and were aged 40 years and over. They received an information letter about the signs or symptoms of the five most common cancers. Participants were also given a letter inviting them to visit their health centre if they experienced any of the cancer related symptoms described in the letter. Information about the EPEDC was also in articles and advertisements in the local newspaper. Fifteen previously unknown cancers were detected through this intervention (one pulmonary cancer, seven prostate cancers, six malignant skin disease and one urinary bladder cancer, which was outside of the target cancers. It was revealed that most of the participants with detected cancers had not presented their symptoms to a general practitioner (GP) before the study. It is therefore likely that the study prompted earlier diagnosis by reducing the patient's delay of symptom presentation. The majority participants who responded to the letter indicated that the EPEDC did not cause them anxiety. This intervention suggests that increasing anxiety does not promote help-seeking (Mansson

et al., 1998). A limitation of the study is that the authors do not state that is based on any theories.

Another study by Campbell, et al. (2016) assessed the effectiveness of a psycho-educational intervention conducted in 18 general practices across Northamptonshire, UK which was designed to encourage early presentation of breast cancer in older women. The intervention consisted of a script based one-to-one communication along with a booklet and was delivered by a trainee practice nurse. The first part of the booklet explained the relative and absolute risk of developing breast cancer. The second part discussed the 11 breast cancer symptoms and how to detect them, while the following part covered barriers to help-seeking, including fears and concerns. The next part encouraged action planning when a patient discovers a breast symptom. Finally, there was a section encouraging the patients to await positive feelings from seeking help. The communication with the nurse aimed to reinforce and clarify the messages in the booklet in a style that is empathic and motivational. The nurse presented women with images of early symptoms of breast cancer to improve their knowledge of symptoms; and encouraging women to respond to a series of positively focused statements about seeking help for breast changes, giving them the chance to rehearse what they would do. The intervention was associated with greater awareness of less known breast cancer symptoms and reported breast-check frequency. Only 5% of the women were 'breast cancer aware' at baseline rising to 20% at one year (Campbell, et al, 2016). A limitation of the study is that the authors do not state that it is based on any theories.

An intervention was trialled to encourage early presentation of oral cancer in people at high risk of developing the disease (Scott, Khwaja, Low, Weinman, & Grunfeld 2012). Participants were randomly assigned to a leaflet group, a one-to-one group or a control group. Participants in the leaflet group read a theory-based leaflet based on the SRM (Leventhal, et al, 1998), that explained how to spot oral cancer early. Participants in the one to one group

received an interactional discussion providing key messages regarding early detection of oral cancer, and were then asked to read the leaflet. Participants in the control group did not receive any information about oral cancer. Participants in all groups then completed a questionnaire. The findings revealed that both the leaflet and one-to one group showed less anticipated delay in presenting oral symptoms, greater knowledge of oral cancer, greater understanding of mouth self-examination, as well as greater confidence and likelihood in performing self-examination. Also, neither intervention was found to increase anxiety (Scott et al., 2012). However, an issue with this intervention is that the response rate was low when recruiting participants. This means that the target group may be difficult to reach, and the results may not be generalizable.

Campaigns in America designed to increase oral and pharyngeal screening intentions have shown some positive outcomes. In one campaign, radio and print advertisements, along with free hotlines were used to promote free oral cancer screening within Detroit, Michigan (Jedele & Ismail, 2010). In another, bus wraps and billboards were used to raise awareness of both oral and pharyngeal cancer screenings in Florida (Watson, Tomar, Dodd, Logan, & Choi, 2009). An issue with both these campaigns is that they lacked measures of the mechanisms that were responsible for their success. Therefore, Logan et al. (2013) formed a similar media campaign to determine whether knowledge or concern about oral and pharyngeal cancer influenced oral and pharyngeal screening intentions. Logan et al. (2013) state that concern is a common mechanism in many health and persuasion theories. For instance, in the Extended Parallel Processing Model (Witte, 1992) concern is conceptualised in terms of perceived threat. Also, the Elaboration Likelihood Model (Petty & Cacioppo, 1981) proposes that people process information more deeply when they view it as important to them.

Logan's campaign consisted of posters, brochures, car magnets and hand-held fans. Facts and images were used that were tailored towards rural black residents, as they are often not considered in health promotion campaigns. The campaign was found to successfully increase conditional screening intentions. This was partly due to raising oral and pharyngeal cancer concerns, providing support that people need to be concerned about a health event before they take health relevant action. Knowledge of oral and pharyngeal cancer alone was not found to increase screening intentions (Logan, et al., 2013).

1.4 Conclusion

Most researchers have concluded that patient delay in oral cancer is caused by failing to interpret symptoms as harmful (Grant, Silver, Bauld, Day, & Warnakulasuriya, 2010; Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2007; Scott, Grunfeld, Auyeung, & McGurk, 2009). This is supported by the limited success of interventions that have claimed to encourage early presentation by educating people how to recognise symptoms of various cancers, including oral cancer. However, these interventions have been multimodal, employing information about symptoms, but also other encouragements to report symptoms. Further, due to low participation rates in some interventions the findings may not be representative. Less is known about why people choose not to take part in health interventions. The researcher suggests that patient delay in oral cancer may be caused by deeper issues than failing to interpret symptoms as harmful. Theories have shown that experiencing negative emotion generated by symptom detection or decision conflict can cause people to avoid taking action. Indeed, interventions have claimed to be successful by not inducing negative emotions such as anxiety. The researcher suggests that more research needs to be done to gain a deeper understanding in to how people respond emotionally to symptoms of oral cancer so that health promotion messages can be structured accordingly.

Chapter 2: A systematic review analysing reasons for patient delay in head and neck cancer

2.1 Introduction

The need to identify factors that lead to patient presentation delay in head and neck (H&N) cancer was highlighted in Chapter 1. The aim of this chapter is to explore whether such factors can be reliably identified from the literature. Over the last 10-15 years a substantial body of research has looked at patient presentation delay in other forms of cancer, with breast cancer being one of the most researched. Noonan (2014) conducted an integrative literature review that investigated socio-demographic, health-related behaviours and psycho-social reasons for patient delay in oral cancer. Noonan found only a small number of explicitly psychological studies for OSCC up until the year 2010, many of which derived from the same set of research studies (e.g. Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2007; Scott, McGurk, & Grunfeld, 2008; Scott et al., 2009).

A larger literature is available for H&N cancer (Brouha, Tromp, Leeuw, Hordijk, & Winnubst, 2005; Vaisanen et al., 2014). Indeed, OSCC is a subset of H&N cancers. In addition to similarity of anatomical region, non OSCC H&N cancer symptoms are similar to OSCC in that they commonly come to patients' attention because they cause disfigurement and functional difficulties, such as vocalisation, swallowing, salivary or nose and throat problems. There has not been an explicitly H&N review into psychological factors that delay presentation. Thus, it was considered feasible and appropriate to review the H&N literature to apply insights to OSCC.

The researcher decided to review both quantitative and qualitative studies as both these methods have different advantages and disadvantages in analysing reasons for patient delay. Qualitative research does not require prior expectations about phenomena, and provides rich

and detailed accounts of people's thoughts, emotions and behaviour. However, findings cannot be generalised to the general population of people who detect symptoms, thus the prevalence of different factors and their relation to delay cannot be established. On the other hand, quantitative data requires testable hypotheses, allows large amounts of data to be easily summarised, and findings can potentially be generalised provided that individual study sampling, measurement and analytic methods are sufficiently robust. It was considered important to analyse quantitative and qualitative studies separately, as both methods produce very different data that is difficult to compare with each other (Bourbour & Barbour, 2003).

The aim of this review was to identify factors that contribute to patient delay in reporting symptoms that may be indicative of H&N cancer.

2.2 Method

2.2.1 Inclusion & Exclusion Criteria

Both qualitative and quantitative peer-reviewed studies that examined reasons for patient delay in H&N cancer in patients over 18 years old were included. Case studies were excluded. Patient delay was defined as: 'the period in time from first noticing a symptom of head and neck cancer to attending health provider consultation for the first time'. Studies that only assessed medical delay (the delay caused by the health professionals in seeking treatment) or could not distinguish between patient and medical delay were excluded. Head and neck cancer was defined in accordance with the definition given by the National Institute of Health (NIH) and categorised by the area of the head or neck in which they began, although this is not necessarily where the initial symptoms appeared. These areas include the oral cavity, the pharynx (nasopharynx, oropharynx, and hypopharynx), the larynx, paranasal sinuses, nasal cavity and salivary glands. Studies that included Oesophageal cancer, thyroid

cancer, brain tumours and eye cancer were excluded as NIH does not classify them as H&N cancer (NIH, 2017).

Only articles in the full English language were included and a date restriction was applied so that articles that were not published between the years 2000 and 2017 were removed. Scott, Grunfeld & McGurk (2006) did a systematic review of studies that analysed factors associated with patient delay in oral cancer. The review included eight studies that were published between the years 1975 and 2005. Little research assessing reasons for patient delay in other areas of H&N cancer has been done before the year 2000.

2.2.2 Search Strategy

The literature search used the EBSCO database which searches across five different medical, nursing and psychological databases including: Medline full text, Psychinfo, PsychARTICLES, CINAHL plus, AHMED. The search combined the terms *'patient'* and *'delay'* with terms related to cancer (including *cancer* or *carcinoma* or *tumour* or *neoplasm*), as well as terms related to areas of H&N cancer *(nasopharyngeal* or *hypopharyngeal* or *sinonasal* or *laryngeal* or *oral* or *head and neck* or *mouth* or *throat* or *pharynx* or *larynx* or *nasal* or *sinus* or *salivary gland*).

Searches were combined, and duplicates removed before study selection. Hand searches were also conducted of the reference lists of the included articles.

2.2.3 Study Selection

Using the electronic databases, search terms were identified from titles, abstracts and keywords. Following the search identified studies were examined for inclusion. The

researcher screened all identified titles and then the abstracts of selected titles for inclusion. Then all papers identified as potentially relevant were read by the researcher who examined whether they met the inclusion criteria. A sample of the papers was cross-checked with another researcher. When it was not clear whether a paper was relevant or not a joint decision was made between the researcher and the supervisor. Figure 2.1 describes the process of study selection, and table 2.1 illustrates the reasons for exclusion of studies based by stage of selection.

2.2.4 Data Extraction

Data was extracted for each of the papers included in the review, and the information was summarised in to separate spreadsheets for the qualitative and quantitative data. Extracted data consisted of the author(s) of the paper, the date the paper was published, the sample size of the study, the location, i.e. the country that the research took place in, the focus of the research, the study design, method of analysis, the factors found to be associated with delay and or the factors found not to be associated with delay. This data is summarised in Tables 2.2 to 2.5.

Figure 2.1: Flow diagram of study selection

```
┌─────────────────────────────┐
│  Records identified through  │
│  database searching (n=255)  │
└─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐
│   Records after duplicates   │            ┌──────────────────────────────┐
│     removed (n=201)          │───────────▶│ Records excluded from title  │
└─────────────────────────────┘            │         (n= 132)             │
              │                             │                              │
              │                             │    Records excluded from     │
              ▼                             │       abstract (n=30)        │
┌─────────────────────────────┐            └──────────────────────────────┘
│   Full text articles assessed│
│   for eligibility (n=39)     │───────────▶┌──────────────────────────────┐
└─────────────────────────────┘            │  Records excluded from full  │
              │                             │        text (n=16)           │
              │                             └──────────────────────────────┘
              ▼
┌─────────────────────────────┐            ┌──────────────────────────────┐
│    Studies included in       │◀───────────│    Additional records        │
│    synthesis (n=25)          │            │  identified through hand     │
└─────────────────────────────┘            │     searching (n=2)          │
                                            └──────────────────────────────┘
```
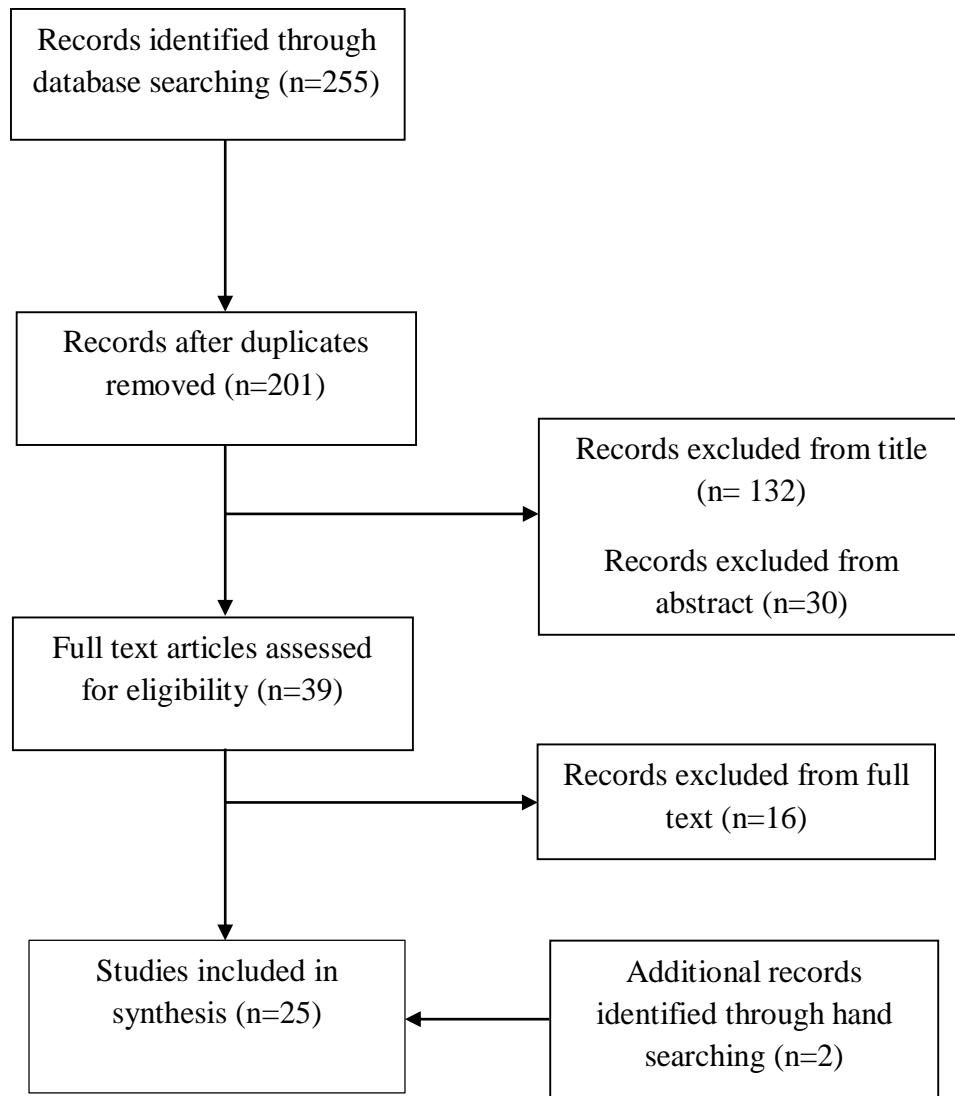
Table 2.1: Reasons for exclusion of studies by stage of selection

Reasons for Exclusion	Title Screening	Abstract Screening	Full Text Screening
Topic (e.g. not about presentation delay or h&n cancer)	118	4	0
Studies addressed the length of delay, not explanations of delay	0	6	7
Medical delay only/ Not about patient delay	1	12	2
Not primary data (e.g. review or commentary)	6	3	1
Intervention Study	3	0	0
Sample (e.g. children)	3	0	0
Case study only	0	2	0
Duplicate not previously identified	1	3	6

2.2.5 Data Synthesis

Textual narrative synthesis was used to analyse the data. This approach typically divides studies in to homogeneous groups making it beneficial for synthesising different types of research evidence such as qualitative and quantitative studies. Lucas, Baird, Arai, Law, & Roberts (2007) claimed that textual narrative synthesis makes transparent heterogeneity between studies as it clarifies the diversity in study designs and analysis. This allows similar studies to be compared and their quality to be assessed relative to similar study designs. It also shows where evidence is absent and evaluates the strength of evidence across different methods. Where differing methodologies show similar findings, this provides a degree of confidence in those findings. Lucas et al. (2007) further commented that the textual narrative synthesis is convenient for reviews that aim to describe the existing body of research, identify what has been found, the strength of evidence present, and gaps that need to be filled.

The utility of the approach has been shown in various reviews by the Evidence for Policy and Practice Information and Co-ordinating Care (EPPI-Centre) (Shepherd et al., 2002; Harden et al., 2004; Oliver et al., 2005). These include reviews of communication between health care professionals and professionals about prescribing (Stevenson, Cox, Britton, & Dundar, 2004), and reviews of women's views of ultrasound in pregnancy (Garcia et al., 2002). Generally, in a textual narrative synthesis the study characteristics, quality, context and findings are reported on following a standard format. The similarities and differences between this information is then compared across studies.

The synthesis in this chapter is divided into quantitative and qualitative studies. The synthesis starts with a descriptive analysis of the data from reviewed studies including the research aims, descriptions of the sample, aspects related to patient delay and aspects unrelated to patient delay from the authors analysis. It then progresses to theoretical analysis. The key method of the analysis is constant comparison within and across studies to detect convergences and resolve inconsistencies. A constant comparative approach is used that converts data in to systematic categories in order to identify themes, patterns, relationships and variations. The method involves reducing data into subgroups, displaying data in visual form, comparing patterns and themes within a data set, and conclusion drawing and verification. The synthesis is at the level of reported findings rather than the authors' interpretations, and the researcher sometimes drew different theoretical conclusions from the authors in the context of the developing analysis.

Conclusions of reviews that use the textual narrative synthesis approach are generally displayed in tables or diagrammatic form. The results aim to capture the depth and breadth of the research area and contribute to a new understanding of the area of interest, as well as present implications for research and practice. Additionally, all methodological limitations of the review are stated.

2.3 Results

The literature search yielded 25 studies, 21 of which were quantitative and four qualitative. Nine were conducted in the UK, two in Finland, three in the Netherlands, one in Iran, four in India, one in France, one in Thailand, one in Japan, one in China, one in Canada, and one in Greece. The sample of participants in each of the quantitative studies ranged from 53 to 559 The sample of participants in each of the qualitative studies ranged from 15 to 57.

Table 2.2: Summary of study characteristics from included quantitative studies

Author& Date	Country	Sample Size & Cancer Location	Focus	Design	Analysis
Joshi et al (2014)	India	n=201 Oral (GBC or tongue)	To find out the causes of delay in seeking specialised care in advanced oral cancer	Questionnaire	Not stated
Kerdpon & Striplung (2001)	Thailand	n=161 Lip or Oral	To investigate the factors related to patient & professional delay in diagnosis of oral cancer	Structured Questionnaire	Multiple logistic regression
Kumar et al (2001)	India	n=79 Oral	To analyse the psychosocial factors related to delay in presentation of oral cancer patients	Questionnaire	Univariate & Multivariate logistic regression
Onizawa et al (2003)	Japan	n=152 Oral	To analyse factors contributing to delay in the diagnosis of oral cancer	Retrospective Case Study Analysis	Logistic regression
Rogers et al (2007)	UK	n=559 Oral & Oropharynx	Exploring the relationship between deprivation and patient delay in presentation and treatment of oral cancer	Retrospective case note review	Fisher's Exact Test, X2 test

Gao & Guo (2009)	China	n=102 Oral	To analyse the possible factors involved in patient delay in oral squamous cell cancer	Questionnaire	Multiple logistic regression
Agrawal, M et al (2016)	India	n=226 Oral	To assess help-seeking behaviour and factors predictive of delayed approach to HCPs after appraisal for oral cancer	Structured questionnaire	Logistic regression
Akram et al (2014)	India	n=259 Oral & Oropharynx	To analyse the impact of sociodemographic & psychosocial factors on the delayed reporting to HCP in oral & oropharyngeal cancer patients	Cross sectional (structured questionnaire)	Logistic regression
Sargeran et al (2009)	Iran	n=100 Oral	To investigate diagnostic delay and its determinants among oral cancer patients	Structured questionnaire/ interviews	ANOVA, logistic regression
Hollows et al (2000)	UK	n=100 Lip, Oral, Oropharynx. Hypopharynx	To investigate the delays in referral and treatment in patients with oral cancer	Case note analysis	Statistical correlation
Vaisanen et al (2014)	Finland	n=85 Oral, Oropharynx, Hypopharynx. Nasopharynx, Sinonasal, & Larynx	To explore the effects of health behaviour & patient characteristics on seeking medical advice in head & neck cancer patients	Cross sectional (Questionnaire)	Logistic regression
Yu et al (2008)	Canada	n=102 Oral & Pharynx	To define patient, professional and total delay, and to define factors that may increase them	Quantitative Interview/ case note review	Not stated
Pitiphat et al (2002)	Greece	n=105 Oral & Pharynx	To identify factors associated with delay in the diagnosis of oral cancer	Structured Questionnaire	Logistic & Linear Regression

Crossman et al (2016)	UK	n=161 Oral	To explore symptomology in patients with oral cancer and the role of the GP in diagnosis	Semi-structured questionnaire	Chi square test
Llewellyn et al (2004)	UK	n=53 Lip, Oral, Oropharynx	To investigate factors predictive of patient delay among younger patients with oral cancer	Interview	Multiple regression
Tromp et al (2004)	Netherlands	n=277 Pharynx, Larynx, Oral	To investigate the association between patient delay & the psychological factors in patients with h&n cancer	Mixed methods Questionnaire Interview	One-way ANOVA, Multiple Regression
Rozniatowski et al (2005)	France	n=100 Oral, Oropharynx	To examine the psychosocial factors involved in delayed consultation by patients with h&n cancer	Mixed methods (semi-structured interview, questionnaire)	ANOVA, students t test
Scott et al (2008)	UK	n=80 Oral	Factors associated with patient delay for potentially malignant oral symptoms	Cross-sectional questionnaire	Logistic regression
Brouha, Tromp, Leeuw, Hordijk, & Winnubst (2005)	Netherlands	n=117 Larynx	To determine the length of stages of patient delay in patients with laryngeal cancer and to find out whether these delays were related to the stage of disease at diagnosis	Semi-structured interview/ questionnaire	Chi square test, Kruskal-Walis test
Brouha, Tromp, Hordijk, Winnubst & Leeuw (2005)	Netherlands	n=189 oropharynx & oral	To examine which factors are related to patient delay in patients with pharyngeal and oral cancer	Retrospective, mixed methods. Interview & Questionnaire	Logistic regression
Rogers et al (2011)	UK	n=71 (41 interviewed) Oral & Oropharynx	Exploring the reasons for delayed presentation in oral & oropharyngeal cancer from the patients perspective	Cross-sectional mixed methods (short survey & telephone interview)	Not stated

Table 2.3: Summary of factors found to be associated with patient delay from included quantitative studies

Author& Date	Factors associated with patient delay	Factors not associated with patient delay
Joshi et al (2014)	Lack of awareness, absence of pain	No significant association between delay and employment & primary education
Kerdpon & Striplung (2001)	Prolonged delay linked to use of traditional herbal medicine	No significant association between other variables investigated (sex, age, marital status, religion, area of residence
Kumar et al (2001)	View that cancer is a curse/ ill fated to have cancer. Non-availability of transport. Interpreting symptoms as trivial. Socioeconomic status	
Onizawa et al (2003)		No significant association between delay & gender, age, past history of disease, no of family members in household, cigarette, alcohol use, employment, medication
Rogers et al (2007)	Low alcohol consumption, non-smokers	Primary health professional, patient age, gender, marital status & deprivation
Gao & Guo (2009)		Gender & Age
Agrawal, M et al (2016)	Lack of knowledge on oral cancer symptoms	
Akram et al (2014)	Older age, lower socioeconomic status, rural residence, insufficient knowledge of head & neck cancer, attributing symptoms as minor, lack of fear, alternative therapy	
Sargeran et al (2009)	Marital status, tumour stage	

Hollows et al (2000)		No correlation between patient delay and cigarette usage. No correlation between patient delay and alcohol usage
Vaisanen et al (2014)	Main symptom not pain, not suspecting cancer, general fear of physicians	
Yu et al (2008)	No annual dental check-ups	
Pitiphat (2002)	Non-smokers/ former smokers	No correlation between quantity of cigarettes consumed, alcohol use, age, gender & education
Crossman et al (2016)	Didn't realise the problem or symptom was serious	
Llewellyn et al (2004)	No further education, significant stress in the period prior to diagnosis, lower social class, lower amounts of tobacco smoked	
Tromp et al (2004)	Aged >65, living alone, avoidance coping excessive drinking. Negatively related to optimism, health hardiness, overall defensive functioning	
Rozniatowski et al (2005)	Living alone	
Scott et al (2008)	Minor condition, lack of knowledge, socio-economic status, competing life events, higher levels of deprivation	
Brouha, Tromp, Leeuw, Hordijk, & Winnubst (2005)	Interpreting symptom as innocuous, benign. Thought symptoms not serious enough to warrant going to a doctor	
Brouha, Tromp, Hordijk, Winnubst &Leeuw (2005)	Thought symptom was harmless, didn't bother them. Ignored symptom. Anxious about visiting GP. Pain with no visible lesion (OC only)	Smoking more than 20 cigarettes a day and consuming more than 4 alcoholic drinks a day. Marital status. Education
Rogers et al (2011)	Mis-interpreting symptoms as minor, trivial. Low awareness (little thought as to whether it could be cancer	

Table 2.4: Summary of study characteristics from included qualitative studies

Author & Date	Country	Sample Size & Cancer Location	Focus	Design	Analysis
Scott, Grunfeld, Main & McGurk (2006)	UK	n=17 Oral	To explore patients' initial experiences & reactions to developing symptoms of oral cancer	Qualitative exploratory study (semi-structured interview)	Framework Analysis
Scott et al (2007)	UK	n=57 Oral	To produce a theory guided investigation of the specific cognitive and emotional reactions to discovery of potentially malignant oral symptoms	Qualitative exploratory study (semi-structured interview)	Framework Analysis
Scott et al (2009)	UK	n=57 Oral	Exploring the reasons for patient delay in seeking treatment following self-discovery of potentially malignant symptoms	Qualitative exploratory study (semi-structured interview)	Framework Analysis
Grant et al (2010)	Finland	n=15 (<45 years old) Oral Oropharynx	Explores the reasons for patient delay in younger patients seeking treatment from a GP or a dentist	Qualitative exploratory study (semi-structured interview)	Framework Analysis

Table 2.5: Summary of factors found to be associated with patient delay from included quantitative studies

Author & Date	Factors Associated with Patient Delay
Scott et al (2006)	Psychosocial variables, unconcerned about symptoms, lack of knowledge of OC, not attributing symptoms to cancer, social responsibilities
Scott et al (2007)	Attributing symptoms to minor conditions that don't cause emotional distress. Symptom beliefs. Emotional responses (lack of concern)
Scott et al (2009)	Interpreting symptom as minor self-correcting symptom. Competing responsibilities
Grant et al (2010)	Low awareness, self-treatment, watchful waiting, interpretation of symptoms (minor, no pain, didn't bother them)

2.3.1 Presentation time results

The findings of recent studies carried out in the UK that examine the length of patient delay in histological diagnosed oral cancer are varied.

In Crossman et al's (2016) study involving patients who were treated for oral cancer at one of the 158 National Health Service Hospitals (NHS) in England, the majority reported presenting their symptoms to HCP's within four weeks, while the remaining 15% reported delaying presentation for more than three months (Crossman et al., 2016).

Llewellyn, Johnson & Warnakulasuriya's (2004) study consisting of patients from hospitals in the South-East of England revealed that 62% reported delaying consultation for more than twenty-one days and 28% reported delaying for at least 14 days (Llewellyn, et al., 2004). As the age range of the sample in this study does not match that of typical oral cancer patients it is difficult to compare the findings to studies that included older patients in their sample.

Scott, Grunfeld, Main, & McGurk (2006) studied patients at a hospital in London. Patient delay was found to range from 1-48 weeks (mean=11 weeks; SD=14.3 weeks; median=3 weeks). 53% of patients presented their symptoms to HCP's after one month or less and 24% presented after three months (Scott, Grunfeld, Main, & McGurk, 2006). However, as the sample size of this study is small it is again difficult to compare the findings to other studies.

Rogers, et al's (2007) study consisted of patients at a hospital in Liverpool. 22% consulted HCP's less than a month after noticing oral symptoms, 40% consulted between one and two months, 22% consulted between three and five months and 16% consulted after six months or more (Rogers et al., 2007). A later study by Rogers et al. (2011) was carried out at the same hospital assessing the length of patient delay in 39 oral cancer patients. Nineteen patients (48.72%) contacted a HCP within a week of noticing symptoms, 10 patients (25.64%)

contacted a HCP between a week and a month of noticing symptoms and another 10 patients contacted a HCP after a month (Rogers et al., 2011).

2.3.2 Qualitative Results

Four studies analysed patient delay in H&N cancer using qualitative methods. Two of the studies involved patients with a confirmed diagnosis of H&N cancer, and two of the studies involved patients with potential H&N cancer. Individuals who presented to health care professionals with symptoms of oral cancer were included in all the four qualitative studies, while individuals who presented with oropharyngeal cancer were included in one of the studies. Studies addressed four themes that illustrate potential reasons for patient delay in H&N cancer: pre-symptom knowledge and understanding of cancer healthcare; initial symptom interpretations and attributions; symptom re-interpretations; and, access to HCP's.

2.3.2.1 Pre-symptom knowledge and understanding of cancer and health care

In all the papers, the majority of patients claimed to have limited awareness of H&N cancer. One oral cancer study in people under 48 years of age found that some spoke of being unaware that oral cancer existed before their own oral symptoms developed (Grant, et al., 2010). Others knew that it existed but knew little else about the disease (Grant et al., 2010; Scott, Grunfeld, Main, & McGurk, 2006). Grant et al. (2010) reported that a few patients acquired knowledge about oral cancer through knowing people who had the disease, some of whom died from it. However, the authors do not describe how those experiences effected their perceptions of oral cancer, and whether those experiences influenced the time they took to presentation. The potential importance of knowledge is emphasised with some patients

who felt prompted to seek professional help for their symptoms early because they remembered seeing a television campaign on oral cancer; for instance, one patient reported seeing an advert on television featuring a person who delayed seeking help for their oral symptoms and was experiencing difficulties speaking. The advert also featured others who sought help promptly and had no impairments (Grant et al, 2010). This suggests those patients' linked their symptoms to cancer and recognised the importance of seeking help early thus experienced less delay.

Studies found that, where patients were aware of links between smoking and cancer generally, they did not link smoking to oral cancer. Grant et al (2010) found that although most patients knew that smoking and alcohol could cause oral cancer smoking was not prominent in their accounts of why they developed the disease. Additionally, Scott, Grunfeld, Main, and McGurk (2006) found that patients were aware of the connection between smoking and cancer, not specifically oral cancer. Scott's participants also claimed that they were not aware of the link between alcohol and oral cancer. However, Scott, Grunfeld, Main, and McGurk (2006) did not state whether the patients who expressed these views were smokers or heavy drinkers.

Patients sometimes reported negative attitudes towards their HCPs. These attitudes tended to manifest from previous unpleasant experiences of seeing HCPs or the belief that HCPs would not be able to resolve their health issues. Other patients mentioned that they believed in seeking help at the appropriate time or circumstance. They stressed that one must not seek attention at the first sign of illness or waste the HCPs time by presenting with minor ailments (Scott et al., 2009). However, it is not clear from the latter view why the patients would be inhibited from seeking help as symptoms develop and worsen.

2.3.2.2 Initial symptom interpretations and attributions

All the papers suggest that the majority of their samples initially believed that they had minor conditions that did not warrant seeing a HCP. These included ulcers, allergic reactions, thrush, minor dental problems or trauma such as accidental biting or rubbing of dentures (Scott et al., 2007). Patients frequently had previous experiences of similar symptoms that turned out not to be cancer (Scott, Grunfeld, Main, & McGurk, 2006).

As they thought symptoms were of minor illnesses, most patients expected a natural recovery, or they felt that they should deal with the symptoms themselves using self-medication (Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2009). Further, patients expected a HCP to give a simple diagnosis and basic treatment that they could administer themselves (Scott, Grunfeld, Main, & McGurk, 2006). A number of different types of self-medication were reported including using mouthwashes, taking iron tablets, repeatedly brushing teeth or applying pain relief gel (Scott, Grunfeld, Main, & McGurk, 2006; Grant et al., 2010).

Conversely, other patients who sought help early did not report having clear ideas about the causes of their symptoms, but they wanted to consult HCPs to resolve their uncertainty over their symptoms (Scott et al., 2009). These patients did not necessarily suspect cancer, and only a minority said that they did. Instead they reported being generally unsure of the origin of their symptoms and wanted to receive a diagnosis that would give them understanding and clarity. Thus, worry and concern acted as a trigger to help-seeking. Some patients reported seeking help early as they were worried or concerned about their symptoms. They believed that early help-seeking would not only ease their symptoms but also their worry (Scott et al., 2009).

2.3.2.3 Symptom reinterpretations

Only a minority of patients persisted with their misattributions (Scott et al., 2007). More commonly patients reviewed symptoms and reappraised their interpretations. Those patients formed new interpretations, with the result that many changed their minds to become more uncertain about their initial attributions. All papers saw this uncertainty as important in driving help seeking (Scott et al., 2007; Scott et al., 2009). Factors that induced reinterpretation were the persistence of symptoms or the deterioration of symptoms, which convinced patients that their initial attributions to time-limited conditions, such as ulcers, were false. Symptom interpretations were also reappraised when symptoms did not improve after self-medication (Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2007; Grant et al., 2010), or when symptoms caused pain or problems with eating and speech (Scott, Grunfeld, Main, & McGurk, 2006). Scott et al. (2007) found that when patient's interpretations of their symptoms changed their emotional responses changed. This led some patients to become worried about their symptoms.

Additionally, new information that highlighted alternative explanations for their symptoms led patients to reconsider the identity of their symptoms. This information was acquired via the media, medical literature or other people (Scott et al., 2007). One patient changed his mind about his symptom after information he had seen on television about identifying symptoms of cancer (Scott et al., 2007).

Some patients reinterpreted their symptoms after significant others (e.g. partners, friends and family) expressed concern and gave suggestions of the possible causes of their symptoms. Those who spoke to a significant other about their symptoms sought professional help soon after the development of their symptoms. Meanwhile, those who did not initially discuss their symptoms with significant others tended to delay seeking professional help (Scott, Grunfeld,

Main, & McGurk, 2006). This indicates that advice given from significant others, prompts help-seeking and prevents delay.

2.3.2.4 Accessing HCPs

Some patients felt that access to their dentist or GP surgeries was a perceived or actual barrier to seeking help for their symptoms. Those patients reported having difficulties getting appointments with HCPs at convenient times or having to travel long distances to visit health care providers (Scott et al., 2009; Scott, Grunfeld, Main, & McGurk, 2006).

A few patients explained that their social circumstances or other responsibilities made it difficult for them to find a convenient time to see a HCP. They mentioned that they prioritised other tasks such as those related to family life, work commitment, holidays, comorbidities etc. over their symptoms (Scott et al., 2009; Scott, Grunfeld, Main, & McGurk, 2006).

Other patients reported that they delayed presentation because they decided to mention their H&N symptoms to their HCPs during appointments for other conditions. They felt that that was more convenient for the HCPs rather than making two separate appointments regarding different conditions and 'wasting two doctors time' (Grant et al., 2010). Scott et al. (2009) commented that regular medical appointments or check-ups can either reduce or increase patient delay. They provide the opportunity for patients to present symptoms to the HCPs attention when they wouldn't normally, but they can also lead people to wait until their next pre-booked appointment to present their symptoms.

2.3.3 Quantitative Results

Nineteen of the studies involved patients with a confirmed diagnosis of H&N cancer, and two of the studies involved patients with potential H&N cancer not yet confirmed. Studies employed samples with differing H&N cancers. Individuals who presented with symptoms of oral (including lip) cancer took part in 20 of the studies. Individuals who presented with symptoms of pharyngeal cancer took part in 11 of the studies. Individuals who presented with symptoms of laryngeal cancer took part in three of the studies. Individuals presenting with symptoms of sinonasal cancer took part in just one of the studies. Studies addressed four potential predictors of delay; sociodemographic factors, disease factors, risk factors and behavioural factors.

2.3.3.1 Socio-demographic Factors

Gender was not associated with patient delay in any study (Kerdpon & Striplung, 2001; Onizawa et al., 2003; Rogers et al., 2007; Gao & Guo, 2009, Pitiphat et al., 2002). The studies reported mixed findings for age. Three studies found no association between age and patient delay (Kerdpon & Striplung, 2001; Onizawa et al., 2003; Pitiphat et al., 2002). However, Akram, Siddiqui, and Karimi (2014) found longer patient delays in people over the age of 50 than under 50. Similarly Tromp et al. (2004) found that patients over the age of 65 were more likely to delay seeking help for their symptoms than those under the age of 65.

The studies provide a mixed view of the impact that marital status had on delay. Some studies found that being single, which was defined as not living with a partner, was linked to greater patient delay than being married (Tromp et al., 2004; Rozniatowski et al., 2005; Sargeran et al., 2009). Other studies found no connection between relationship status and patient delay

(Rogers, et al., 2007; & Kerpdon & Striplung, 2001; Brouha, Tromp, Hordijk, Winnubst & Leeuw, 2005).

Two studies assessed the link between area of residence and patient delay. Akram et al. (2014) discovered that those in rural residence in India were more likely to delay seeking help for their symptoms than those in urban residence. While in Thailand, Kerdpon and Striplung (2001), found no difference in patient delay between those who lived in urban and rural residences.

Socio-economic status (SES) was linked to patient delay, with those who were identified as being upper or middle class being less likely to delay seeking help for their symptoms than those who were identified as being lower class (Akram et al., 2014; Kumar et al., 2001; Llewellyn et al., 2004). Scott et al. (2008) reported that those who lived in areas of higher deprivation in the UK were more likely to delay reporting their symptoms, although Rogers et al. (2007) reported no relationship between patient delay and levels of deprivation in the UK. Two studies that assessed the link between employment status and patient delay did not identify a significant correlation (Joshi, Nair, Chaturvedi, Agarwal, & D'Cruz, 2014; Onizwa et al., 2003). Llewellyn et al found a link between level of education and patient delay, with patients who had no further education after secondary school showing greater patient delay. However, Brouha, Tromp, Hordijk, Winnubst, & Leeuw (2005), Pitiphat et al. (2002), and Joshi et al. (2014) found no relationship between education level and patient delay.

2.3.3.2 Disease Factors

Some studies found that patients who were identified as having advanced stage cancer at the time of diagnosis, those who had stage 3 or 4 cancer were more likely to have delayed seeking professional help for their symptoms than those who had stage 1 or 2 cancer

(Sargeran et al., 2009; Kumar et al., 2001). Additionally, two studies reported that those with larger lesions or lesions with larger maximal diameter showed greater patient delay (Rozniatowsi et al., 2005; Gao & Guo, 2009). It is not clear as to whether advanced cancer or larger lesions causes delay because patients are reluctant to report them, or cancers simply deteriorate during delay. Conversely, one study found that individuals who had advanced stage cancer were less likely to delay seeking professional help for their symptoms (Rogers et al., 2007).

Two studies found the site of cancer to be a factor linked to patient delay. Rogers et al (2007) reported that oral and oropharyngeal cancer patients who had tumours in the lower gum or floor of mouth tended to seek help more promptly than those with tumours in other oral locations such as the tongue and buccal mucosa. Gao and Guo (2009) reported that lesions on the tongue were more likely to delay seeking help than those with tumours in other locations. Other studies did not find a link between site of tumour and patient delay (Scott et al, 2008; Sargeran et al., 2009).

Scott et al (2008) analysed the impact of specific symptoms on patient delay. They found the only specific symptom associated with greater patient delay was a sore throat. They also found the extent, or the number of potentially malignant oral symptoms was not associated with patient delay (Scott et al, 2008).

2.3.3.3 Risk Factors for head and neck cancer

The studies provide a mixed picture of the impact risk factors of H&N cancer such as tobacco and alcohol consumption had on patient delay. On one hand, some studies found that smoking is associated with reduced patient delay; non-smokers (Rogers et al., 2007; Pitiphat et al., 2002) or lower rate tobacco users (Lllewellyn et al., 2004) experienced less delay.

However, other studies found no association between patient delay and smoking status (Oniziawa et al., 2003; Hollows et al., 2000), or the quantity of cigarettes consumed (Pitiphat et al., 2002; Brouha, Tromp, Hordijk, Winnubst & Leeuw, 2005; Hollows et al., 2000).

Some studies found no association between patient delay and alcohol consumption (Brouha, Tromp, Hordijk, Winnubst & Leeuw, 2005; Oniziwa et al., 2003; Hollows et al., 2000; Pitiphat et al., 2002). Tromp et al (2004) revealed that heavy drinkers had greater patient delay than light drinkers, but Rogers et al (2007) found that light drinkers had greater patient delay than heavy drinkers.

No other proposed risk factors of H&N cancer were found to be related to patient delay. Pitiphat et al. (2002) found no association between patient delay and the following factors; having history of liver cirrhosis, having family history of cancer, and having history of sexually transmitted disease. Additionally, Oniziwa et al. (2003) found no association between patient delay and past history of malignant diseases. However, these studies did not establish whether patients were aware that these factors increase the likelihood of H&N cancer.

Oral and pharyngeal cancer patients who were not under the regular care and supervision of a dentist, i.e. those who did not attend routine check-ups with a dentist, tended to show greater delay in seeking help (Yu, Wood, & Tenebaum, 2008). However, no other studies have analysed the relationship between patient delay and routine dental check-ups.

2.3.3.4 Behavioural Factors

Various behavioural factors were found to lead to patient delay in H&N cancer in many of the studies. They can be grouped into symptom interpretation, fear, knowledge and understanding of cancer, contextual factors and dispositional factors.

Symptom Interpretation: The literature highlights that patient's failure to appraise symptoms deductively by linking them to illness lead to delays in their presentation. Perceptions of interpreting symptoms as trivial or not attributing symptoms to cancer were two of the main reasons patients reported for not seeking help sooner (Kumar et al., 2001; Akram et al., 2014; Vaisanen et al., 2014; Crossman et al., 2016; Brouha, Tromp, Leeuw, Hordijk, & Winnubst, 2005; Brouha, Tromp, Hordijk, Winnubst & Leeuw, 2005; Rogers et al., 2011).

Akram et al's (2013) study of newly diagnosed patients with cancer of the oral cavity found that of the 156 patients who delayed presenting their symptoms, 131 reported attributing their symptoms as benign, while 25 attributed them to cancer. In contrast, of 103 patients who did not delay reporting symptoms 37 reported attributing their symptoms as benign, while 66 attributed them to cancer. This suggests that identifying symptoms as being indicative of cancer is important in prompt presentation. Similarly, Vaisanen el al's (2014) study involved newly diagnosed patients with cancer of the oral cavity, oropharynx, nasopharynx, hypopharynx, larynx and the nasal cavity and sinuses. A population based cross-sectional design was used and the findings revealed that around half the patient suspected their symptoms could be cancer. Those who reported having no suspicion of cancer tended to have greater patient delay than those who did report having a suspicion.

Brouha, Tromp, Leeuw, Hordijk, & Winnubst's (2005) study involved patients with newly diagnosed cancer of the larynx taking part in an interview. A questionnaire was set for patient's close relatives and GP to verify the answers. The findings revealed that 52% of the patients with glottis carcinoma delayed seeing a HCP because they interpreted their symptoms as benign or assumed their symptoms were not serious enough to warrant seeking professional help. Another study by Brouha and colleagues (Brouha, Tromp, Hordijk, Winnubst, & Leeuw, 2005) consisted of patients with newly diagnosed cancer of oral cavity, oropharynx and hypopharynx taking part in an interview. Again, a questionnaire was set to

the patient's close relatives and GP to verify the answers. The findings revealed that the patients delayed their symptoms because they thought they were harmless. They often attributed their symptoms to minor conditions such as infections or dental problems. Kumar et al's (2001) study of newly diagnosed oral cancer found the view that '*trivial ulcers in the mouth are self-limiting*' (p. 13) to be a significant predictor of patient delay. This finding illustrates that patients thought their symptoms would resolve themselves without the need of treatment from HCPs.

Crossman et al's (2016) study was of 161 participants who had been diagnosed with oral cancer two to three years previously. The findings revealed that, of the participants who reported that something had put them off going to their doctor, 74% (n=77/ 104) of them stated that 'not realising the symptom was serious' was a barrier to them seeking help. Rogers et al's (2011) study involved patients who had been diagnosed with cancer of the oral cavity or the oropharynx within the past two years. All the patients took part in a questionnaire and over half of them were questioned further over a telephone interview. The findings revealed only 13% of the patients thought their symptoms were caused by a potentially serious condition.

Scott et al's (2008) study involved patients who had been newly referred to a H&N cancer service with potentially malignant oral symptoms. They found that patients who initially attributed their oral symptoms to a minor condition were more likely to delay seeking professional help than those who originally attributed their symptoms to a serious condition.

Some studies found that patient delay was associated with an absence of pain from the symptom (Vaisanen et al., 2014; Joshi et al., 2014). Absence of pain is likely to form a cognitive representation that the symptoms do not indicate serious illness and therefore do not warrant professional help.

Pre-symptom Knowledge and Understanding of Cancer: Five of the papers reported a lack of knowledge or awareness of H&N cancer to be associated with patient delay (Scott et al., 2008; Akram et al., 2014; Agrawal et al., 2016; Rogers et al., 2011; Joshi et al., 2014).

Scott et al. (2008), and Akram et al. (2014) both assessed knowledge of the aetiology, the screening process and the symptoms of oral cancer using the 36 item 'knowledge and beliefs about oral cancer questionnaires' (Humphris, Duncalf, Holt, & Field, 1999). Agrawal et al (2016) assessed knowledge of symptoms using a questionnaire with seven closed ended questions. No evidence of the validity or reliability of this questionnaire has been reported.

Rogers et al (2011) used a different approach. They asked patients the hypothetical question if they would have sought help sooner if they had more knowledge on symptoms of oral cancer. Sixty-two percent responded with 'definitely yes' or 'yes', 8% responded with 'not sure', and 31% responded with 'no' or 'definitely no'. However, the patients level of knowledge was not assessed making it difficult to interpret the findings. Joshi et al. (2014) questioned patients about their reasons for their delay in seeking help. Lack of awareness of oral cancer was the most common reason patients gave for not seeking help promptly. However, they did not probe what the term 'lack of awareness meant' and it is unclear whether patients did not know that oral cancer existed or did not know about its symptoms. In a study conducted in India, Kumar et al. (2001) found that patients who believed that cancer is attributable to fate or a curse were more likely to delay presenting symptoms.

Fear: Four quantitative studies analysed the effects that fear had on patient presentation delay (Vaisanen et al., 2014; Agrawal et al., 2016; Akram et al., 2013; Joshi et al., 2014). Vaisanen et al. (2014) found that 31% of patients in their study claimed that a general fear of physicians led to their delay. This is much larger than the number of patients who claimed fear to be a cause of their delay in other studies.

Agrawal et al. (2016) revealed that only 8% of patients reported fear defined as 'apprehension regarding consultation' as being a barrier to seeking professional help for symptoms. The low percentage is this study may be due to the method. Respondents were asked in a close-ended question what they thought was a barrier for them seeking help for their oral symptoms. They were required to select one answer out of five options (cost/ fear/ difficult to access/ lack of time/ don't think important). Thus, it was not taken in to account that respondents may have perceived multiple barriers to help-seeking. Joshi et al. (2014) found that 4% of patients reported that denial of disease or fear of going to hospital lead to their delay in help-seeking. However, descriptions of questionnaire items were not provided, so it is not clear how those factors were assessed. Conversely, Akram et al. (2013) found fear to be linked to earlier presentation rather than delay. Patients who endorsed an item entitled 'absence of fear' to be significantly associated with patient delay. However, it is not clear how 'absence of fear' was interpreted by patients.

Contextual Factors: Various contextual factors that were unrelated to the symptoms were found to influence patient delay. Scott et al. (2008) used a life event questionnaire to assess the frequency and valence of different life events that occurred before or co-incident with symptom detection. The average severity of life events in the patient delay period was an independent predictor of greater duration of patient delay. Llewellyn et al. (2004) showed that perceptions of stress prior to diagnosis independently predicted greater patient delay. Typical examples patients gave were the long-term stress of marriage breakdown, bereavement or losing one's job. Llewllyn et al. (2004) claimed that this may be due to other commitments preventing an individual from being more attentive over their symptoms or making time to visit a HCP.

Studies conducted in developing countries suggest that people may try to treat symptoms with alternative therapies. In a Thai study, Kerdpon & Striplung (2001) found that treating

symptoms with traditional herbal medicine before seeking help from a medical professional was linked to greater patient delay. In India, Akram et al. (2014) also found a positive relationship between patient delay and the use of alternative therapy. However, it is not known why participants used alternative therapies; whether those individuals used alternative therapies as a substitute for medical treatment or whether medical treatment was not easily available to them.

Dispositional Factors: Dispositional factors have also been linked to patient delay. Tromp et al. (2004) examined links between dispositional variables, coping style, lack of optimism, low health hardiness and greater overall defensive functioning, and delay in a sample of diagnosed OSCC patients. Avoidance coping is defined as behavioural or cognitive strategies employed to avoid stimuli, thoughts or feelings. Active coping is defined as coping strategies that are directed to modifying or removing the threat, such as presenting to a HCP for diagnosis and treatment. Tromp et al. (2004) reported that patients who delayed presenting their symptoms for more than three months engaged less in active coping. Optimism is characterised by a global expectation that one will experience good outcomes. Patients who were high in optimism were less likely to delay presenting symptoms. Health hardiness is the extent to which an individual is committed to looking after their health and the extent that they perceive control over their health. Patients who were high in health hardiness showed less patient delay.

2.4 Discussion

Twenty-five studies were reviewed, examining a range of different reasons why patients delayed presenting symptoms to medical professionals. They consisted of four qualitative studies and 21 quantitative studies.

The main finding reported across the qualitative studies is that patient delay is largely due to patients attributing their symptoms to minor ailments that do not warrant seeing a HCP. The qualitative studies suggest that lack of awareness of oral cancer leads to delay, and that knowledge of oral cancer gained from the media can lead to earlier presentation. The studies also reported that patients' reinterpretations of symptoms due to the worsening or persistence of symptoms led to presentation. In addition, issues related to accessing HCP surgeries were noted as factors that contributed to delay in presentation. Although it is understandable that the above factors influence patient delay it is surprising that emotional factors such as fears of cancer were not reported as contributing to delay as they have done in other studies (Smith, Pope, & Botha, 2005; Fish, Prichard, Ettridge, Grunfeld, & Wilson, 2015).

As for the quantitative studies, there was mixed evidence for relationships between patient delay and socio-economic factors because the findings were mixed and diverse. The only common finding that was assessed across many studies is that there is no link between gender and patient delay. Like the qualitative studies, interpreting symptoms as trivial and not attributing symptoms to cancer, as well as a lack of knowledge of H&N cancer were associated with patient delay. Studies showed support for contextual factors (perceptions of stress, severity of life events and alternative therapies) as well as dispositional factors (less active coping, less optimism and less health hardiness) as contributors of patient delay. However, only a small number of studies assessed contextual or dispositional factors, meaning that the findings are tentative.

2.4.1 Sociodemographic factors

Some of the quantitative studies that analysed socio-demographic factors found older age (Akram et al., 2014; Tromp et al., 2004), lower socio-economic status (Akram et al., 2014;

Kumar et al., 2001; Llewellyn et al., 2004), rural residence (Akram et al., 2014) and being single (Tromp et al., 2004; Rozniatowski et al., 2005; & Sargeran et al., 2009) to be predictors of patient delay. However, these findings are inconclusive as other studies did not find a significant relationship between patient delay and those factors. Scott et al. (2008) suggested that socio-economic aspects may influence patient delay via other factors. These include perceived susceptibility to illness, real or perceived ability to access health services and circumstances that take priority over current health problems. Gender was not found to be associated with patient delay. This is inconsistent with findings from studies that have analysed patient delay in other areas of cancer concluding that men are likely to delay seeking help for symptoms because they viewed help-seeking as un-masculine or a sign of weakness (Gascoigne, Mason, & Roberts, 1999).

2.4.2 Symptom interpretation and reinterpretation

The prominent finding from the qualitative studies is that patient's appraisals of their symptoms are important. Patients who initially attributed their symptoms to minor, self-correcting conditions were found to be more likely to delay reporting their symptoms. Quantitative studies also lent support to this view, finding that poor knowledge of cancer was associated with delay and that participants frequently cited symptom misattribution as a reason for delay. These findings are in line with the SRM (chapter 1, section 2.1) inferring that cognitive representations guide responses to health threats (Brouha, Tromp, Hordijk, Winnubst, & Leeuw, 2005; Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2007). These researchers argue that delay occurs because top-down processes fail. Patients do not link OSCC symptoms to cancer or other serious illnesses. Instead they attribute symptoms to minor conditions, such as ulcers or dental problems, because symptoms are either similar to those associated with these conditions (Scott et al., 2007). The policy implication of this

research is that people should be taught to better recognise and understand symptoms of OSCC (Scott et al., 2012).

The qualitative studies showed that most patients made fresh appraisals as symptoms persisted or worsened. These frequently led to reinterpretations of those symptoms, which caused concern amongst patients, many of whom reported those symptoms to a HCP. The clinical implications of symptom misattribution will depend upon the timescale of patients' symptom reappraisals. This is currently unknown. However, Scott et al. (2009) found median presentation times of three weeks in their study.

The qualitative studies also show that patients' attributions of OSCC symptoms to minor symptoms are frequently uncertain, some patients even consider cancer a possible cause (Scott et al., 2007). Thus, it is important to understand why patients choose to attribute uncertain symptoms to benign rather than serious conditions, and do not simply consult a HCP as a 'safe option' to protect against their attributions being mistaken. Further, symptom misattributions usually favour transient conditions (Scott et al., 2007), and should become less convincing over time. Yet, patients frequently maintain misattributions over six to twelve months (Scott, Grunfeld, Main, & McGurk, 2006), and the reasons that they hold to long-term misattributions are yet to be described.

2.4.3 Risk factors

The qualitative studies suggest that some patients were unaware of the risk factors of oral cancer (Scott, Grunfeld, Main, & McGurk, 2006; Grant et al., 2010). Most patients were aware of the connection between tobacco and cancer but not necessarily oral cancer. The patients also indicated a lack of awareness of the association between alcohol and oral cancer.

A lack of awareness of the risk factors of oral cancer could mean that some people who consume tobacco and alcohol regularly do not perceive themselves as vulnerable to oral cancer, so they are more likely to misattribute their symptoms to other causes. This could lead them to delay seeking help. Alternatively, regular tobacco and alcohol consumers who have more awareness of smoking and drinking as risk factors of oral cancer may view themselves as being more vulnerable to H&N cancer than people who don't smoke or drink alcohol regularly. Thus, they may be more likely to interpret their symptoms as cancer causing them to seek help promptly.

Differences in the awareness of risk factors of H&N cancer may explain why the quantitative studies that analysed the link between tobacco and alcohol consumption and patient delay in H&N cancer revealed conflicting findings, i.e., some studies found a relationship between patient delay and those factors while others did not. An alternative explanation for why longer delays occurred in smokers and drinkers may be that those people avoided linking their habits to an increased risk of H&N cancer due to a fear of cancer. Thus, they avoided seeking help for their symptoms.

Yu et al. (2008) found that regular dental check-ups are associated with more prompt presentation. The study did not suggest any reasons for this finding. However, it may be attributable to patients perceiving dental appointments as important due to the risk of developing oral conditions, feeling more comfortable in seeking dentists' help, or more general factors such as being less prone to dental fear or health anxiety.

2.4.4 Disease factors

Most of the studies that assessed disease factors showed advanced stage cancer or larger lesions to be associated with greater patient delay (Sargeran et al., 2009; Kumar et al., 2001;

Rozniatowsi et al., 2005; Gao & Guo., 2009). Obviously, delay can cause disease progression, but it is also plausible that more advanced symptoms may prolong delay because they cause patients to fear presentation (Smith et al., 2005) or because patients have less faith that medical intervention can help them.

Only two studies revealed links between cancer site and patient delay (Gao & Guo, 2009; Rogers et al., 2007). Gao and Guo (2009) found lesions on the tongue to be associated with greater patient delay. Rogers et al. (2007) found tongue and buccal mucosa (lining of the cheek) lesions to be associated with more delay than lesions on the floor of mouth or lower gum. No specific reasons were suggested by the authors why this must be. It is surprising that lesions on the tongue have been associated with greater delay, particularly as it is the most common symptom site of oral cancer (AHNS, 2016). Therefore, it is assumed to be a site that people are more likely to associate with cancer. The tongue is also a more visible area of the mouth, so symptoms are easier for people who experience them to detect compared to other areas such as the roof of the mouth. Additionally, symptoms in this area can often be felt easily, particularly when eating and speaking. Thus, they are likely to cause inconvenience for the people experiencing them, which assumingly would prompt them to seek help sooner.

2.4.5 Dispositional Factors

Only one study examined the effects of dispositional factors on patient delay (Tromp et al., 2004). They found patients who delayed presenting their symptoms to HCP's engaged in lower active coping and showed lower optimism and lower health hardiness. Dispositional factors have been found to reduce patient delay in studies involving breast cancer patients, including optimism (Lauver & Tak, 1995) and active coping (Facione, Miaskowski, Dodd, &

Paul, 2002). A relationship between denial and patient delay has been confirmed in some studies but not for others (Katz, Weiner, Gallagher, & Hellman, 1970; Mitchell, Macdonald, Campbell, Weller, & Macleod, 2008; Watson, Greer, Blake, & Shrapnell, 1984). No other studies are known to have examined the effects of dispositional factors on patient delay in H&N cancer, meaning the findings from this study are novel.

2.4.6 Fear

The qualitative studies did not find that fear of symptoms caused patients to delay reporting symptoms, thus challenging the findings from help-seeking studies in other areas of cancer that claim fears related to cancer, treatment and investigation contribute to delay (Smith et al., 2005; Fish et al., 2015). Scott et al. (2007) claimed that the patients were not fearful of their symptoms as most of them attributed their symptoms to minor, transient conditions that required no need for emotional distress. A few of the quantitative studies (Vaisanen et al., 2014; Agrawal et al., 2016; Joshi et al., 2014) suggested that some patients fear towards help-seeking lead to them delaying help-seeking although with exception of Vaisanen et al's (2014) study that showed only a small minority of patients gave fear as a reason for not seeking help sooner, meaning the support for this is not particularly strong. Conversely one study found absence of fear leads to patient delay (Akram et al., 2014).

2.4.7 Situational (Context/ Access Factors)

The qualitative studies view access to HCPs as important to help-seeking. The patients often spoke of presenting their symptoms to GP's or dentists when they had check-ups or appointments regarding other conditions (Grant et al., 2010; Scott et al., 2009). The qualitative studies highlight other barriers to help-seeking relating to access to HCPs. They include, difficulty getting appointments, distance to HCPs and prioritising other

responsibilities over help-seeking (Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2009).

The quantitative studies also show that there are situational factors, unrelated to symptoms that lead to patient delay. They include greater significant life events occurring before or co-incident symptom detection (Scott et al., 2008) and a greater perception of stress (Llewellyn et al., 2004). Llewellyn et al (2004) suggested that the findings may be partly due to patients engaging in avoidance coping. This occurs when an individual is faced with a stressor and they try to distract themselves in some way. This may have caused feelings of stress which lead to patient delay.

Comparison of Asian and Western countries suggest interesting cultural differences. A study conducted in Thailand and another in India claimed the use of alternative therapy to be a cause of patient delay (Kerdpon & Striplung, 2001; Akram et al., 2014). Additionally, a study conducted in India found the view that cancer is attributed to fate or curse as being related to patient delay. These findings seem to emphasise the cultural determinants of delay.

2.4.8 Limitations

This review has some limitations. As is always the case in presentation delay research, studies relied on the patient's self-report as they required the participants to recall events that occurred before they sought help. These include the duration of their symptoms, appearance of their symptoms, sensations induced by their symptoms, the thoughts and emotions they felt towards their symptoms, and specific life events that occurred. However, all studies that rely on respondent's self-report are subject to recall errors (Van den Brink, Bandell-Hoekstra &

Abu-Saad, 2001). There are various factors that lead to recall errors. One of these is interference, for instance when the quantity of events a person experiences increases the probability of them recalling a specific event decreases. Another factor is the significance of the event and the respondent's psychological state, such as their mood. The interval between when the event takes place and when it is recalled is also important. These factors can result in an inaccurate recall of past experiences, such as in the form of loss of information due to a failure to recall the experience, or remembering events as taking place earlier or later than they actually did. Thus, causing an experience to be under-reported or over-reported. Other factors contributing to recall errors may include personal variables (age, gender, socio-economic status), interviewing technique, social desirability and motivation of the respondent (Coughlin, 1990).

Recall errors can affect the validity of the results. Other areas of health research have shown that studies that rely on respondent's self-report are prone to errors in recall of frequency and intensity of symptoms (Van den Brink et al., 2001), as well as the responses to those symptoms (Andersen & Mikkelsen, 2008).

Some studies attempted to avoid issues that can lead to recall errors (Brouha, Tromp, Leeuw, Hordijk, & Winnubst (2005); Brouha, Tromp, Hordijk, Winnubst, & Leeuw, 2005; Gao & Guo, 2009). The data obtained from the patients was compared with that from the patients' GPs and the relative. When the length of the total patient delay stated by the relative surpassed that reported by the patient by one month, and the relative confirmed that the patient had delayed seeking medical attention, the data from the relative was used. The date of first medical contact was derived from information given by the GP. However, a problem with widespread use of this methodology is that the relative's data may not be more accurate than the patient's.

Some of the self-report studies involved the patients taking part before their treatment had commenced (Scott et al., 2007; Brouha, Tromp, Leeuw, Hordijk, & Winnubst, 2005). Not all the studies were clear about when the patients participated. In one study patients were interviewed two to three years after diagnosis (Crossman et al., 2016). However, the sooner that patients recall the events that occurred between first noticing symptoms and seeking professional help the less likely are the chances of recall errors occurring.

Scott et al. (2007) interviewed patients who had been referred with potentially malignant oral symptoms before their first consultation with a health professional. The patient's responses may have been influenced by the fact that the interviews took place after a provisional diagnosis was given. Therefore, they may not have reported certain information because they did not view it as significant, as they were yet to receive a formal diagnosis of cancer. Nonetheless, Nosarti et al. (2000) claimed that people's motives for delaying a consultation with a GP are the same for those who develop cancer and those who do not.

2.4.9 Conclusion and recommendations for research

Findings across the studies showed either support for or refutation of hypothesised relationships. It is concluded that there is inconsistent evidence to support that socio-demographic factors, disease factors or risk factors of H&N cancer contribute to patient delay. Both the qualitative and quantitative studies establish that a lack of knowledge of oral cancer, interpreting symptoms as trivial and not attributing symptoms to cancer contribute to patient delay in H&N cancer. However, it is still not clear why some patients persisted with their interpretations when symptoms progressed. Fears regarding consultation and fears of disease have not shown to be important factors related to patient delay, except in one study.

This review raises questions as to how fear was assessed in some of those studies. One study assessed the effects of dispositional factors on patient delay. They found less active coping, less optimism and less health hardiness to be associated with delay. More research should be done to support this finding and provide a greater understanding of how people cope when they notice symptoms of H&N cancer. This may help to address the hesitations the researcher has about patient delay in H&N cancer being mainly caused by the misattribution of symptoms.

Future research involving the use of self-reports should consider ways of reducing factors that can lead to recall errors in order to increase the validity of the studies. Understanding more about the causes of patient presentation delay will lead to more effective interventions to be produced that aim to prevent people with symptoms of H&N cancer from delaying seeking professional help.

Chapter 3: Timeline analysis

3.1 Introduction

Although several studies have attempted to assess the time taken from noticing symptoms to reporting them, none that the researcher is aware of have analysed in detail the length of time it takes people to make specific interpretations and decisions before consulting a HCP and being referred to a specialist, as well as the number of interpretations and decisions people make before consulting.

Timelines are not necessarily linear. Studies have shown that for some patients their initial interpretation is the only one they make before consulting with a HCP. However, others do not always decide to consult a HCP after an initial interpretation. Decisions people make other than seeking help from a HCP include treating their symptoms with self-medication, making changes to how they eat, focusing on family or work commitments, waiting for check-ups or other appointments waiting to see how a symptom develops etc (Grant et al., 2010; Scott et al., 2008; Scott et al., 2009). These decisions are usually, but not always, preceded by appraisals of symptoms as being not threatening. Typically, people who decide not to present to a HCP reappraise their symptoms when symptoms persist or deteriorate, or new information comes to light (Scott, Grunfeld, Main, & McGurk et al., 2006; Scott et al., 2007; Scott et al., 2008; Scott et al., 2009). Thus, patients may cycle between several interpretations and reinterpretations before they report to a HCP.

Another reason that patients may not experience a linear timeline is that a HCP may not always make a referral. HCPs may misdiagnose conditions or opt to monitor symptom development, requiring that patients return to the HCP. Crossman, et al. (2010) showed that, out of a sample of 109 oral cancer patients, 13% were treated for another condition and 5% were told to come back if the symptom continued (Crossman et al., 2010). It is valuable to

understand how the professional's opinion effects the patient's interpretation of symptoms, and in particular how long it will take for the patient to return to a HCP., i.e., whether they accept the HCP's opinion or form their own ideas about the symptoms, as well as how the patient comes to a decision that leads them to return to the same HCP or a different HCP to consult.

The current chapter will discuss the time taken for patients to report their symptoms to a HCP after first noticing them. Accurate calculation of time taken is likely to be degraded by memory processes and potentially by inadvertent or deliberate biases (Van den Brink, et al., 2001; Andersen & Mikkelsen, 2008). Perusal of published papers does not lead to a clear identification of how this issue is dealt with and the methodological literature does not recommend standard procedures. The empirical study described in this thesis uses cognitive interviewing techniques to deal with the broader problems of memory failure and biased reconstruction of events (Wagstaff, et al., 2010). Further, specific attempts were made to establish accurate timelines by requesting that patients provide information in relation to key dates such as birthdays, public holidays or days of the week. This provides a structured and empirically-supported method of improving recall accuracy (Martyn & Belli, 2002), and this chapter will provide an accurate description of the events (initial and reinterpretations and decisions) that precede presentation to a HCP and the time taken for patients to navigate these events.

This chapter aims to construct a timeline of events that occur between noticing symptoms and attending an appointment with a health professional. These events include the initial appearance of symptoms, when patients make interpretations about these symptoms, whether they reinterpret these symptoms, when they decide to present symptoms and when they actually do. In the light of Crossman et al. (2010), it is also relevant to understand timelines

between HCPs misdiagnoses or advice to patients to return if symptoms persist or worsen, and when patients actually return to HCPs.

3.2 Method

Data for this chapter were taken from a consecutive sample of patients diagnosed with OSCC. The patients took part in a single interview for the purpose of the current chapter as well as the next chapter (chapter 4). The next chapter provides a qualitative examination of the reasons why presentations were delayed or not. For efficiency, the sampling and data collection methods that were used to inform the results of both chapters are described here. Chapter 4 will refer back to this chapter in its method section.

3.2.1 Participants

Forty-three patients with a recent histological diagnosis of OSCC were recruited from the Liverpool Head and Neck Cancer Service to take part in a recorded interview in person with the researcher. The interview concerned the experiences that led them to present their symptoms to a HCP. Thirty-eight of those patients reported detecting symptoms before consulting a HCP. The remaining five patients reported that their symptoms were detected accidentally by a HCP, i.e. at a routine check-up or appointment regarding other symptoms, thus they were excluded from the analysis.

Inclusion criteria for the study were: (i) Patients who were referred to the Liverpool head and neck cancer service and had been diagnosed with squamous cell carcinoma of the oral cavity for the first time, (ii) Patients who were over the age of eighteen, (iii) Patients who had not

yet undergone surgical treatment for their symptoms, (iiii) Patients who are currently not on any surveillance programmes for oral cancer.

Exclusion criteria for the study were: (i) Patients who have had a previous diagnosis of carcinoma of the head or neck, (ii) Patients aged under the age of eighteen, (iii) Patients who have been on surveillance programmes for oral cancer, and (iiii) Patients whose consultants or other members of the treatment team consider participation to be unwise for medical or psychological reasons.

3.2.2 Recruitment process

Patients were recruited at Aintree University Hospital. Eligible patients were recognised by the clinical team from the records of new patients referred to the unit. Patients were introduced to the study by members of the clinical team who told patients of the existence of the study and that patients could join the study subject to inclusion and exclusion criteria. They referred interested patients the researcher who was present at the clinic. The researcher explained the study to the patients in private. Patients were also provided with a printed summary of the study which they could take away with them. The summary stated the study's aims, methods, issues of confidentiality and rights of refusal, as well as the researchers contacted details if patients wished for further information. Written consent from the patients was obtained in two parts. First, written consent was taken after patients had read and understood the printed summary. This was for the researcher to approach the patients by telephone to request an interview. If patients agreed (gave verbal consent) a time and date was arranged for the interview. Second, patients were asked to consent in writing again immediately before the interview.

3.2.3 Study procedure

Patients were interviewed in a private and secure area at home or in the hospital as per patient preference. The researcher followed a lone worker policy to ensure that her safety was not put at risk. This involved reporting to a trusted person at The University of Liverpool when at the interview location and again when they had left the location.

Upon meeting the patients for the interview, the researcher reminded them of the purpose of the study and explained that a digital recording and written notes were to be made during the interview. The patients were then given the opportunity to ask any questions regarding the study. To provide a context for the sample, each patient was given a short demographic questionnaire to fill in which asked them to specify their age, gender, ethnicity, postcode, marital status, highest level of education achieved, employment status, most recent occupation, smoking and drinking behaviour, and whether they are dependent on others for care, or whether others are dependent on them for care. Once the interview had ended the researcher thanked the patients for their time and asked if they had any questions or concerns about the study. Finally, the researcher then gave the patient a printed debrief sheet to read.

The recordings of the interviews were transcribed verbatim by the researcher. Transcripts were anonymised by removing all identifiable information including names of people and places, birthdates, addresses and personally unique information. The researcher created the following transcription guidelines that were applied consistently across each of the interview transcripts;

- Abbreviations identified who said what, e.g. JB= Interviewer, P=Patient
- The length of notable pauses was displayed in brackets, e.g. [5 second pause]
- Identifiable information was described in brackets, e.g. [name of patient's partner]

- Inaudible content was presented as dots, e.g. . . .

- Non-speech was explained in brackets, e.g. [dog barking]

All patients were given an ID number. These were used on the transcripts and questionnaires in order for the investigatory team to identify the patients. Information such as gender, age group, smoking and alcohol use and some clinical information were attached to the transcripts. The transcripts and interview recordings were saved to a computer database that could only be accessed by the researcher and chief investigator.

3.2.4 Interview schedule

A semi-structured approach was taken. The style was conversational and, except for opening and closing exchanges, the interview was led by the participant. Questions and prompts were guided by the structure below. Issues that were seen as important by the participant were also pursued.

- The initial nature of symptoms, their thoughts and feelings about the symptom, interpretations of symptom meaning, courses of action considered (seek help, discuss with friends/family, wait and see, ignore etc.).

- The persistence or progression of symptoms and participant responses to them. Participants also described the points at which their interpretations of symptoms changed if they did change and why. They were also asked to describe the points at which they considered presenting and the reasons that they did or did not do so.

- If patients had considered cancer as a possible cause, they were asked about why they made that interpretation, their confidence in it, and the role that it played in decisions to present or not.

Interviews were conducted with the aid of an interview guide. The style was conversational and, except for opening and closing exchanges where the researcher introduced and finished the interview, interview content was generally determined by the patient. Prior to the research being carried out, the interviewing procedure was piloted with a small group of volunteers to ensure that the questions were appropriate and that they assisted in gaining specific information from respondents. Participants were interviewed individually by the researcher. They were people who have been treated for H&N cancer and attend a patient research forum at a hospital in Liverpool.

The first objective of the interviews was to develop a timeline of key events. This was instrumental in the formation of this chapter. Key events included first noticing symptoms, noticing changes or persistence of the symptoms, reappraisals of symptoms, courses of action considered, most importantly when patients decided to present symptoms to HCPs and did so. The researcher then recited the events from the timeline and when they occurred so that the patients could confirm if the details had been noted by the researcher correctly. During establishment of the timeline the researcher asked several direct questions to establish the sequencing and timing of events.

The timeline consisted of the first and subsequent appearances of their symptomology, including physical descriptions and sensations induced by the symptom, as well as their interpretations and responses to their symptoms. Patients were also asked to estimate the time between events. If a patient stated that the HCP they initially presented to did not refer them to a specialist after their first consultation, he or she was asked to estimate the time between when they first presented their symptom to a HCP and when they presented their symptom to a HCP for a second and in some cases a third or fourth time before they were referred.

3.2.5 Reducing recall failure or bias

In estimating time taken, patients were probed about specific dates and asked to remember when events occurred in relation to known dates such as Christmas, Easter, birthdays, work or family commitments, public holidays, significant community or sporting events.

An adapted version of the Liverpool Interview Protocol (Wheatcroft & Wagstaff, 2014) was used to enhance the information recalled by the participant. This protocol is extensively used in forensic psychology to encourage witness recall and precise reporting of events (Geiselman et al., 1984). Studies have shown that this technique enhances the amount of information recalled by the witnesses whilst sustaining reliability (Paulo, Albuquerque, & Bull, 2013).

The cognitive interview protocol rests upon two mnemonic components: Context reinstatement and *'report everything'* (Wagstaff et al., 2010). Memory trace retrieval is often improved when there is an overlap between the encoding and retrieval environments. Therefore, the aim of context reinstatement is to achieve this overlap. Patients were asked to mentally recreate the moment from when they first noticed their symptom, up until when they went to a medical professional to seek help; including their emotional, physiological, and cognitive states at the time (Holliday, Humphries, Brainerd, & Reyna, 2011). Research has demonstrated that memories that have been coded during a high emotionally aroused state may only be accessed if the same affect is created during retrieval. Like witnesses of a crime, people who notice symptoms of cancer may find their experiences induce highly emotional states (Geiselman et al., 1984). This therefore provides support that cognitive interviewing techniques are appropriate for this study. Before the context reinstatement mnemonic, the patients were asked to close their eyes. This technique has been suggested to encourage

cognitive retrieval by facilitating the production of visual and auditory images, and diminish any distractions (Wagstaff et al., 2010).

Context reinstatement has been found to be more effective at facilitating memory for an emotional event when it is combined with *focused meditation*, a technique derived from hypnotic investigative interviewing (Wagstaff, Cole, & Wheatcroft, 2007). Hypnotic induction techniques adopt a relaxed, passive mode of thinking. This is initiated by the focusing of attention on neutral targets such as breathing, while refraining from distracting thoughts. These procedures may increase memory by facilitating a more 'holistic' mode of information processing (Wagstaff, 1998). The focused meditation mnemonic shares the aspects of hypnotic induction techniques, without the 'hypnosis' label that can trigger false positive errors generally associated with hypnosis (Wagstaff et al., 2007). The patients were repeatedly prompted to focus on their natural breathing pattern for around a minute.

Interviewees generally choose to only report information that they think is important or relevant to what is being investigated. The 'report everything' mnemonic was used to encourage the patients to talk freely about what happened by instructing them to report everything they can remember, no matter how trivial it seems. This is an effective technique because details viewed as irrelevant by the patients may be valuable to the research. Recalled memories, whether irrelevant or not, may also activate more relevant recall (Paulo et al., 2013).

All three components context reinstatement, 'report everything' and focused meditation were included in the interview. They were used after the timeline of events had been established and before the patient was asked questions regarding details of the first symptom.

3.2.6 Ethics

The study was approved by the NHS Research Ethics Committee, North West (reference 13/NW/0056).

Although the possibility that patients could have sought help earlier was never raised in the interviews the researcher was aware that some may already have suspected this which may have caused them to reveal existing regret or distress while being interviewed. The researcher was trained by her supervisors to recognise and respond to distress appropriately in the study population. Responses consisted of advice to the patient about sources of help for problems that do not require specialist help through to immediate referral to the patient's GP or other local authorities in response to being aware of risk or serious harm. Participants were reminded that they did not have to continue discussing any area that they didn't wish to, and they could terminate the interview at any point.

3.2.7 Data analysis

The interviews were transcribed verbatim and then key information was summarised in a time line highlighting the events that occurred up until referral. The moment the participant first noticed a symptom was depicted as day zero and the events that occurred after that were depicted in days and weeks. Other events recorded, and times included: patients' interpretations about these symptoms, when they reinterpreted these symptoms, when they made decisions to present or not to present symptoms and when they actually did present. Where HCPs misdiagnosed symptoms or asked patients to return if symptoms persisted or worsened, this was recorded.

The interview summaries enabled the researcher to identify the interpretations and decisions the participants made that led to them being referred by a HCP. They also allowed the researcher to determine the time between those interpretations and decisions. The interpretations and decisions that each participant made were then mapped onto a diagram (Figure 3.1) illustrating the pathways each participant took that led them to consult. The mean, standard deviation, median and interquartile range of participants who took each pathway was calculated allowing for summaries of time elapsed between each. A second figure (Figure 3.2) was developed to account for participants who were not referred to a specialist service. The primary feature of Figure 3.2 was the time taken to return to the HCP, and the number of iterations experienced by patients.

3.3 Results

Table 3.1 shows patients' estimates of times from symptom appearance to first presentation to a HCP, as well as demographic information, and risk information (smoking and drinking history). The longest time patients took to present symptoms was 20 weeks, the shortest was less than one day and the median 3-4 weeks. The median is similar to that of three weeks reported by Scott et al. (2009). Table 3.2 shows patients' estimates of times from symptom appearance to first presentation to a HCP, along with the pathway in which they were referred, and clinical characteristics (the cancer stage, the cancer site and the symptoms. A glossary of medical terms to describe terms used in the table is described below.

Table 3.1: Delay times, demographic & risk information of the patient sample

ID No	Length of Patient Delay	Age	Gender	Relationship Status	Highest Education Level	Most Recent Occupation	Employment Status	Ethnicity	Dependency	No of alcohol units per week	Smoking Status	No of cigarettes per day	No of years smoked for
1	1 day	47	Male	Married	Undergrad Degree	Shop keeper	Unemployed	Caucasian	N/A	Previously 22+	Former Smoker	10	26
2	2-3 days	67	Male	Divorced/ Separated	No Qualifications	Engineer	Unemployed	Caucasian	N/A	20-30	Current Smoker	1	20+
3	8 weeks	69	Female	Married	Diploma	Radiographer	Unemployed	Caucasian	N/A	25	Never Smoked	N/A	0
4	20 weeks	51	Male	Cohabiting	Diploma	Carer	Employed	Caucasian	N/A	32	Current Smoker	10	33
5	17 weeks	44	Male	Single	No Qualifications	Pub Landlord	Unemployed	Caucasian	N/A	28	Current Smoker	30	32
6	16 weeks	45	Male	Married	GCSE's	Paint Sprayer	Employed	Caucasian	Living with dependent children	5	Former Smoker	20	20
7	1 week	52	Male	Single	GCSE's	Driver	Unemployed	Caucasian	Living with dependent adult	50	Current Smoker	15	35
8	6 weeks	68	Male	Married	No Qualifications	Sales Rep	Unemployed	Caucasian	N/A	14	Former Smoker	15-20	54
9	2.5 weeks	59	Female	Married	No Qualifications	Carer	Unemployed	Caucasian	N/A	6	Current Smoker	15	43
11	2 days	62	Male	Divorced/ Separated	No Qualifications	Labourer	Unemployed	Caucasian	N/A	100	Current Smoker	30-40	51
13	6 weeks	52	Male	Divorced/ Separated	Diploma	Window Fitter	Employed	Caucasian	Living with dependent adult	56	Former Smoker	20	41
14	4 weeks	78	Male	Married	No Qualifications	Labourer	Unemployed	Caucasian	N/A	20	Former Smoker	25	50
15	2 weeks	60	Male	Married	No Qualifications	Car Prod Operator	Unemployed	Caucasian	N/A	50	Former Smoker	25	20
18	<1day	78	Male	Widowed	No Qualifications	Unknown	Unemployed	Caucasian	Living with a dependent adult	30	Former Smoker	15	44
19	12 weeks	64	Male	Married	A Levels	Company Director	Employed	Caucasian	N/A	44	Never Smoked	N/A	0
20	2 days	52	Male	Married	GCSE's	Admin	Unemployed	Caucasian	N/A	14	Former Smoker	20	20
21	4 weeks	73	Female	Married	GCSE's	Bank Cashier	Unemployed	Caucasian	N/A	56	Former Smoker	20+	56
22	2 days	53	Female	Married	Unknown	Admin	Employed	Caucasian	N/A	10	Never Smoked	N/A	0
23	6-8 weeks	42	Female	Single	A Levels	Recruitment Consultant	Employed	Caucasian	N/A	18	Former Smoker	20-30	24
24	8-10 weeks	56	Male	In relationship	No Qualifications	HGV Driver	Employed	Caucasian	N/A	15-20	Never Smoked	N/A	0
25	12 weeks	69	Female	Married	No Qualifications	Hairdresser	Unemployed	Caucasian	Living with dependent adult	0	Former Smoker	10	20
26	1 week	57	Female	Divorced/ Separated	No Qualifications	Cleaner	Employed	Caucasian	N/A	0	Former Smoker	15	37
27	1 week	63	Male	Married	No Qualifications	Steel Erecter	Unemployed	Caucasian	N/A	50	Former Smoker	10-15	41
28	1 day	70	Female	Single	Diploma	Teacher	Unemployed	Caucasian	N/A	22	Former Smoker	30	48
29	4 weeks	72	Female	Widowed	No Qualifications	Cleaner	Unemployed	Caucasian	N/A	6	Current Smoker	5	49
30	1 week	48	Male	Widowed	Diploma	Musician	Unemployed	Caucasian	N/A	14	Former Smoker	20	32
31	4 weeks	61	Male	Cohabiting	No Qualifications	Social Services	Unemployed	Caucasian	N/A	50	Former Smoker	10-15	10
32	1 week	83	Female	Married	GCSE's	Housewife	Unemployed	Caucasian	N/A	0	Never Smoked	N/A	0
33	2 weeks	53	Female	Single	GCSE's	Holiday Rep Manager	Unemployed	Caucasian	Living with a Career	56	Current Smoker	5-10	47
34	2 weeks	63	Female	Married	No Qualifications	Health Care Assistant	Unemployed	Caucasian	Living with dependent adult	8	Former Smoker	15	46
36	4-6 weeks	70	Female	Divorced/ Separated	GCSE's	Wages Officer	Unemployed	Caucasian	N/A	28	Current Smoker	20	33
37	8 weeks	59	Female	Married	GCSE's	Catering Assistant	Unemployed	Caucasian	N/A	0	Never Smoked	N/A	0
38	8-10 weeks	41	Female	Cohabiting	Diploma	Manager	Employed	Caucasian	N/A	0-8	Former Smoker	15-20	20
39	3 weeks	77	Female	Widowed	GCSE's	Chef	Unemployed	Caucasian	N/A	0	Never Smoked	N/A	0
40	4 weeks	63	Male	Married	No Qualifications	Electrition	Unemployed	Caucasian	N/A	21	Never Smoked	N/A	0
41	3-4 weeks	39	Female	Married	Diploma	Care home Coordinator	Employed	Caucasian	Living with dependent adult	0-1	Former Smoker	15-20	6
42	12 weeks	77	Male	Married	No Qualifications	HGV Driver	Unemployed	Caucasian	N/A	22	Former Smoker	2-5	13
43	4 days	44	Male	Single	No Qualifications	Delivery Driver	Unemployed	Caucasian	Living with dependent children	Previously 22+	Current Smoker	8	25

Table 3.2: Clinical characteristics, referral pathway and delay times of the patient sample

ID No	Cancer Stage	Cancer Site	Referral Pathway	Symptoms	Length of Patient Delay
1	T1N0M0	FOM	Dentist	Abrasive skin flap under tongue	1 day
2	T2N1M0	FOM	Dentist	Ulcer under tongue/ Pain when eating	2-3 days
3	T1N0M0	Tongue	Dentist	Pain when eating	8 weeks
4	T1N0M0	Tongue	Dentist	Small painful bumps on tongue	20 weeks
5	T4aN2cM0	Tongue	Dentist	Tingling under tongue/ Pain around jaw & side of head	17 weeks
6	T2N2bM0	Retromolar	Dentist	Dull ache in neck/ tooth ache/ split gum	16 weeks
7	T2N2bM0	Retromolar	OOH Hospital	Feelings of an ulcer at back of mouth/ difficulty eating	1 week
8	T1N0M0	Tongue	Doctor	Brown patch on tongue	6 weeks
9	T1N0M0	Tongue	Doctor	Stinging tongue/ lesion (red inside & white outside	2.5 weeks
11	T2N0M0	FOM	Dentist	Small lump on gum/ swelling	2 days
13	T1N0M0	FOM	Doctor	Feelings of a lump under tongue	6 weeks
14	T1N0M0	Tongue	Dentist	Cluster of tiny blisters on tongue	4 weeks
15	T4aN0M0	Mandible	Dentist	Abscess on side of tongue	2 weeks
18	T2N1M0	FOM	Doctor	Sore, red throat/ Difficulty swallowing	<1day
19	T1N0M0	Buccal Mucosa	Dentist	Rough edge on inside of cheek	12 weeks
20	T1N0M0	Tongue	Dentist	Small white spot on side of tongue	2 days
21	T4aN2bM0	Tongue	Doctor	Sore throat when eating/ Feelings of ulcer under tongue	4 weeks
22	T1N0M0	Tongue	Doctor	Solid lump under tongue (red inside, white outside)	2 days
23	T1N0M0	Retromolar	Doctor	Crater-like ulcer in roof area of gum	6-8 weeks
24	T4aN1M0	Mandible	Dentist	Ache & swelling on side of face/ lump/ discharge/ bleeding	8-10 weeks

25	T3N1M0	Tongue	Doctor	Small white ulcers on one side/ Problems eating & talking	12 weeks
26	T2N2cM0	FOM	Doctor	Ulcer 'split in to two', changed from white to pink	1 week
27	T4aN0M0	Mandible	Dentist	White ulcers under tongue/ Stinging when eating	1 week
28	T4aN2bM0	Mandible	Doctor	Loose molar, blisters on gum, difficulty biting	1 day
29	T1N0M0	Maxilla	Dentist	Soft dent in back of gum	4 weeks
30	T2N1M0	Tongue	Doctor	Feeling of skin peeling off tongue, pea-sized lesion	1 week
31	T4aN0M0	Mandible	Dentist	Rough texture on right side of mouth	4 weeks
32	T1N0M0	Maxilla	Dentist	Toothache/ Roof of mouth was white & felt raw	1 week
33	T2N0M0	FOM	Doctor	Ulcer that changed from pink to white	2 weeks
34	T4aN2cM0	Mandible	Dentist	Loose teeth/ Red, swelling bottom gum	2 weeks
36	T2N2bM0	Buccal Mucosa	Dentist	Ulcer on left cheek	4-6 weeks
37	T1N0M0	Maxilla	Dentist	Two small white lesions on lower gum	8 weeks
38	T1N0M0	Tongue	Dentist	Tongue felt sore achy/ A red & white ulcer	8-10 weeks
39	T4aN2bM0	Mandible	Doctor	Sore mouth/ Cluster of four or five small yellow ulcers	3 weeks
40	T2N0M0	Tongue	Doctor	Pain from ear to throat	4 weeks
41	T2N0M0	Tongue	Dentist	White patch under tongue/ discomfort/ earache	3-4 weeks
42	T3N2aM0	Buccal Mucosa	Dentist	Moveable lump where jaw bone hinges	12 weeks
43	T2N0M0	Tongue	Dentist	Small yellow spot under tongue	4 days

Glossary of medical terms: Buccal Mucosa= Lining of the Cheeks; FOM= Floor of Mouth; Mandible= Lower jaw bone; Maxilla= Upper jaw bone; OOH Hospital= Out of hours hospital; Retromolar= Area behind wisdom teeth; TNM= Cancer staging system; T= Size of primary tumour; N= The extent to which the cancer has spread to lymph nodes; M= Weather the cancer has spread to different parts of the body

Fifteen patients were not referred to GPs on their first visit. This occurred for a number of reasons, including HCPs making a misdiagnosis or HCPs merely advising a short period of time to elapse in case symptoms remitted spontaneously. To reduce complexity in the results presentation, the analysis is split up to describe events before the first presentation to a HCP, and a second section describing events for the 15 participants requiring multiple HCP visits before referral.

3.3.1 Paths and timelines to the first presentation to a HCP

The various paths that the different patients took from noticing an oral symptom to consulting a HCP who referred them to a specialist are shown in Figure 3.1. The diagram starts at when the patient first notices a symptom and ends at presentation to a HCP. Figure 3.1 shows a modified decision tree, whereby patients interpret symptoms and make decisions. First patients may notice symptoms. This leads to an initial interpretation which guides decisions to present to a HCP or to not present. Path A refers to patients who decided that they would present to a HCP. The diagram shows that over a quarter (10/38) of the patients decided that they would consult a HCP after first appraising the symptom, and did so. Some 28/38 patients decided not to present. These included patients who did not perceive a threat, for example they did not believe that symptoms were serious, and patients who wanted to 'wait and see'. At this point, three patients who decided not to see a HCP subsequently did so without

undergoing any symptom reinterpretation (Path B). This occurred for two reasons, patients were forced to attend by relatives or their cancer was discovered during a visit to a HCP for another reason.

The remainder of patients (25/38) made a second appraisal, or reinterpretation, of their symptoms because symptoms persisted; they gained new information, or the symptom became worse. They then decided to either consult a HCP or not. The majority of them (21/28) decided to consult a HCP after appraising their symptoms a second time. These represent Path C. Others who did not, repeated the process of either being forced to attend a HCP (Path D) or making a third appraisal (path E). After a third reappraisal, all attended a HCP.

The diagram shows that over a quarter (10/38) of the patients decided that they would consult a HCP after first appraising the symptom (Path A). A minority (3/28) of the patients were forced to consult a HCP after appraising their symptoms once, while the majority of them (21/28) decided to consult a HCP after appraising their symptoms a second time. Only four patients appraised their symptoms a third time, and three of four decided to consult a HCP. The remaining patient decided not to consult but ended up seeing a HCP for other reasons.

Figure 3.1: Diagram of the various pathways the participants took which lead them to consult HPC's
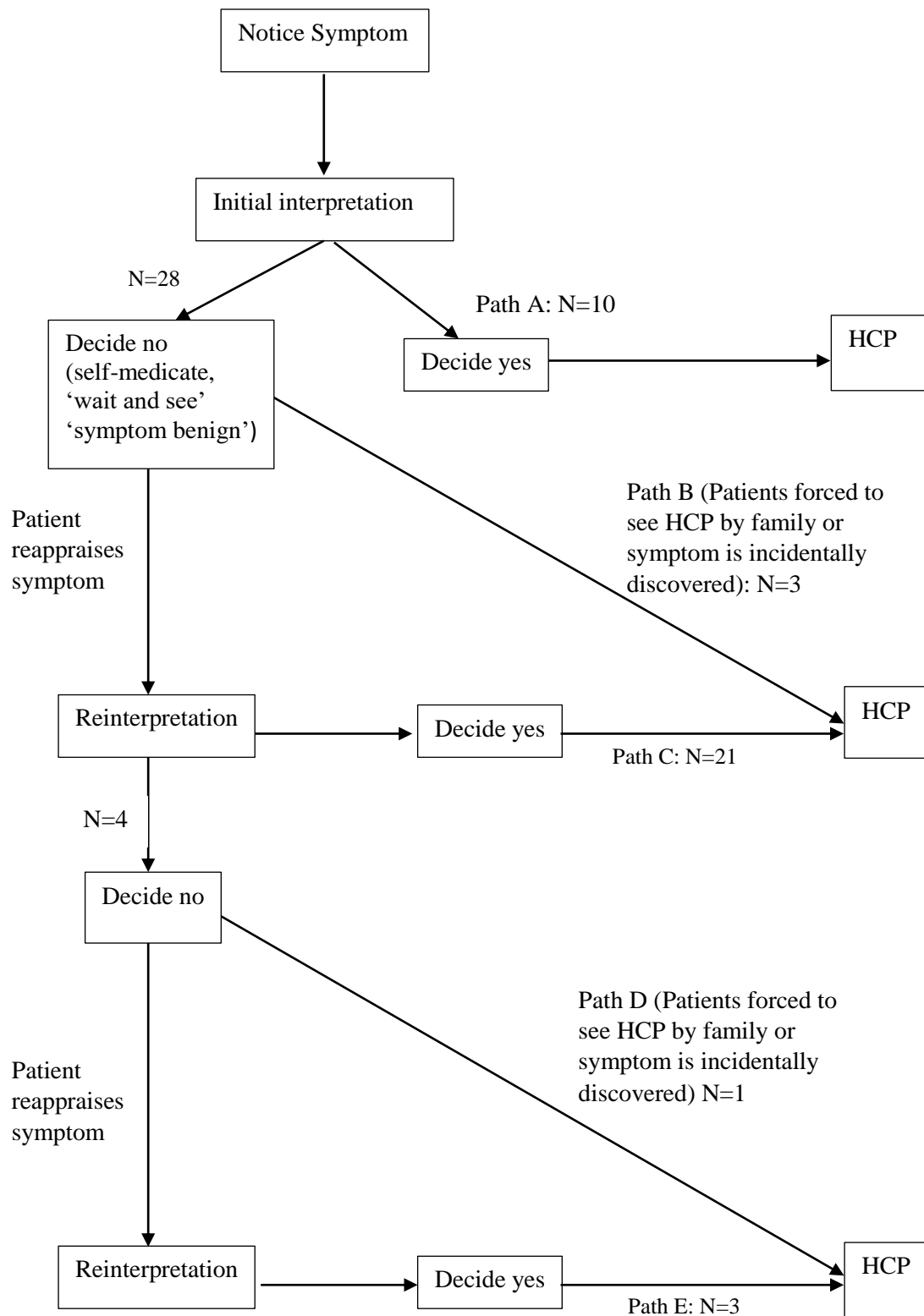
The mean, standard deviation, median, interquartile range, first quartile and third quartile calculations of the times it took the participants to follow various paths are displayed in table 3.3. Times indicate the cumulative time (in weeks) from symptom detection to presentation.

Table 3.3: Calculations of the times it took participants to follow each of the paths to consultation after they first noticed symptoms

	Number	Mean	Median	SD	First Quartile	Third Quartile
Path A – straight to HCP	10	2.1	0.29	3.71	0	3.5
Path B – patient does not decide to attend HCP consultation but later attends without making a reappraisal	3	9.76	9	9.88		
Path C – patient attends after one reappraisal	21	4.88	4	4.49	1	7
Path D - patient does not decide to attend HCP consultation but later attends without making a reappraisal	1	16	16			
Path E – patient attends a HCP after the second reappraisal	3	6.83	6	4.81		

Table 3.3 presents timelines for each path. The table shows two distinct features. First is the central role of reappraisal in presentation. Patients who made a first reappraisal delayed presentation by a median of four weeks and those who made a second appraisal delayed presentation by six weeks. Conversely, those who did not make reappraisals, and thus did not decide themselves to attend a consultation with a HCP, showed median presentation times of nine weeks. Thus, symptom reappraisal appears to be a crucial point at which patients seek help. The second feature, is that delay was minimised when patients saw a HCP after their first appraisal. Although the patients who did not decide to consult were forced to see a HCP at a median of nine weeks, they took shorter on average than the patient who was forced to consult after making a reappraisal.

3.3.2 Timeline for patients who required multiple HCP presentations before referral

The various pathways that the patients took after a HCP did not refer them on the first visit are shown in the diagram below (figure 3.2). The diagram starts at the initial non-referral to a specialist. From here the patient can choose to accept it or challenge the HCP's decision by returning to the same or a different HCP. This process continues until the patient is referred. Similar to figure 3.1, figure 3.2 shows a modified decision tree. To begin with, HCP's did not refer 17 patients on the first consultation. Path A refers to two patients who did not accept the HCP's non-referral, thus they returned promptly to a HCP and insisted that they were referred to a specialist for tests. Both patients were then referred to a specialist. Fifteen other patients initially accepted the HCP's decision. Path B represents one patient who did not choose to challenge the HCP's decision but was forced by others to return and challenge the HCP's decision by his partner. Path C represents nine patients who returned to a HCP for a second opinion and then referred. They normally returned because symptoms persisted or worsened.

Five patients were not referred to a specialist when they consulted a HCP for a second time regarding their symptoms. They later returned for a third time. One patient was forced by family members to return to consult a HCP, resulting in the patient being referred (path D). Four patients returned to consult a HCP for third time, and three were referred (path E). The remaining patient made the decision to consult a HCP for the fourth time. She was then referred (path F).

Figure 3.2: **Diagram of the various pathways the patients took which lead them to revisit a HCP after a HCP did not refer them on the first visit**
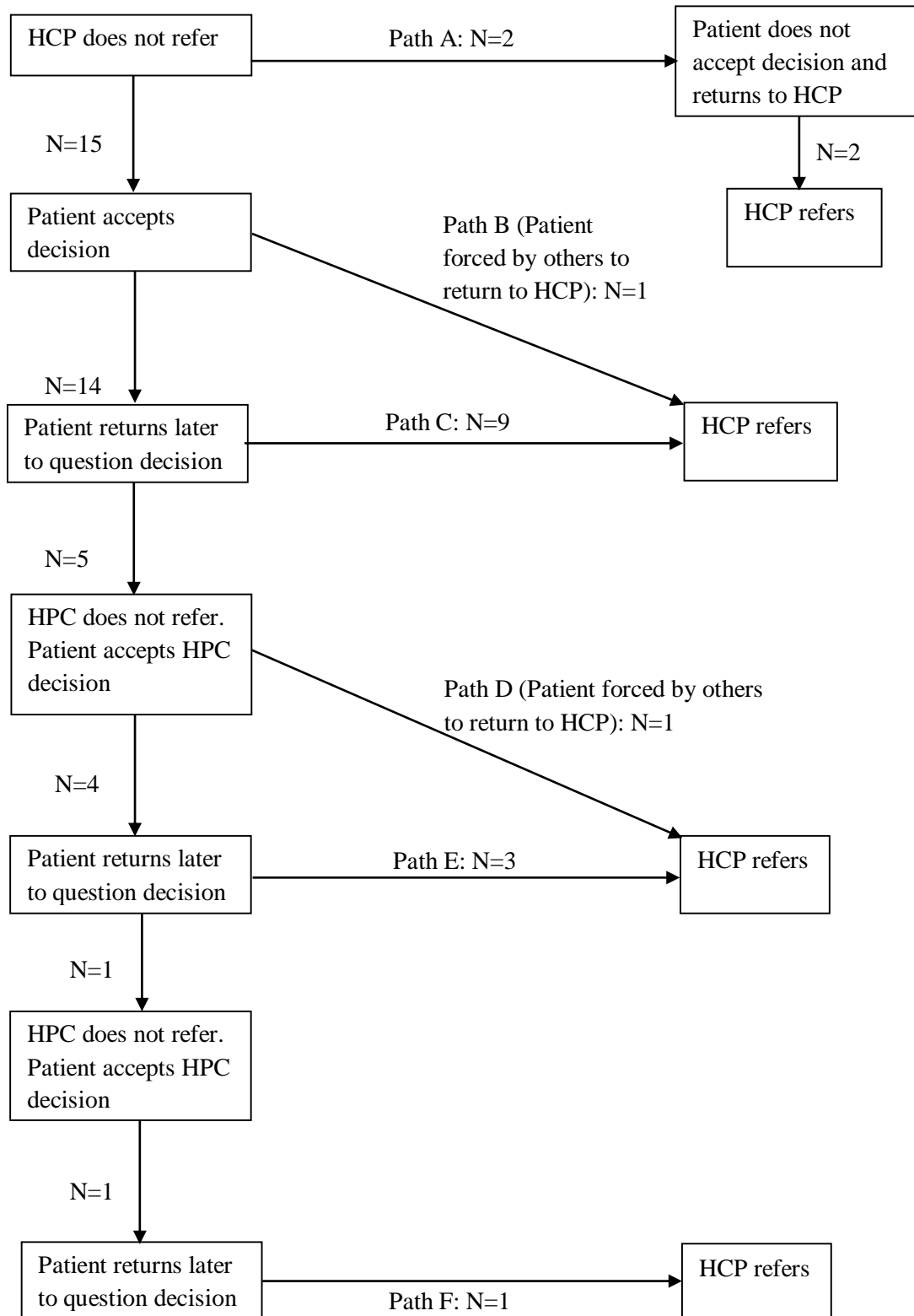
The mean, standard deviation, median, interquartile range, first quartile and third quartile calculations of the times it took the participants to follow various paths are displayed in table 3.4. Times indicate the cumulative time (in weeks) from first being sent away by a HCP without referral to a HCP referring them on consultation.

Table 3.4: Calculations of the times it took participants to follow each of the paths from first being sent away by a HCP without referral to a HCP referring them on consultation.

	Mean	Median	Standard Deviation	First Quartile	Third Quartile
Path A- Patient does not accept decision and returns to HCP n=2	0.27	0.27	0.18		
Path B- Patient initially accepts decision but is forced back to HCP by partner n=1	10-12	10-12			
Path C- Patient referred after second volitional HCP visit n=9	1.53	1	1.13	0.75	2
Path D- Patient initially accepts second non-referral but is forced back to HCP by family n=1	2	2			
Path E- Patient referred after third volitional HCP visit n=3	18	8	21.79		
Path F- Patient referred after fourth volitional HCP visit n=1	9	9			

Table 3.4 shows that an initial non-referral was followed by most patients returning to the HCP within two weeks and being referred. However, patients were more reluctant to return after a second non-referral. Four patients experienced long delays of eight weeks or greater before returning to a HCP for a third or fourth time.

3.4 Discussion

This is the first study to look at patient delay in oral cancer that attempts to quantify patient delay in terms of times taken to make single or multiple symptom appraisals and single or multiple presentations to HCPs. While previous studies acknowledge that some people with oral cancer are not referred on the first consultation, they have not examined how decision-making influences the time it takes people to return to make multiple visits to HCP's until they are referred to a specialist. Another unique quality of the study is that interviewing techniques from the Cognitive Interview Protocol were used with the aim of reducing recall failure or biases that may cause inaccurate or omitted information. These techniques have been used in a health setting before.

The findings reveal that the patients who decided to consult after making an initial appraisal of a newly appeared symptom did so very quickly, within a week. However, it was more common for patients to decide against seeking consultation, and to present after a reappraisal. Although those who decided to consult after a second appraisal took longer to see a HCP than those who decided to consult after making their first appraisal, the median presentation time of four weeks was not unreasonable. The NHS recommends that people should consult a HCP if an oral symptom has been present for three weeks (NHS Choices, 2016). However, those who decided to consult after making a second reappraisal took on average double the time to present that the NHS recommends. Patients who were forced by friends or family to

present their oral symptoms showed longer presentation times. Finally, patients whose HCP did not refer them on the first consultation were relatively quick to seek a second consultation, but those seeking third or fourth consultations showed extended delays.

According to Scott, Grunfeld, Main, & McGurk (2006) patients who decide not to seek HCP assistance after making an initial appraisal may be justified, in that symptoms can easily be mistaken for minor transitory conditions. However, when symptoms do not remit, reappraisal seems to be a logical response to an initial decision not to present to symptoms to a HCP. Empirically this does not greatly increase delay. Thus, a promising strategy for health promotion is to provide messages that encourage prompt reappraisal. For instance, a message could inform people that what they think is a regular ulcer could in fact be something more threatening if it persists for longer than a set number of days. The importance of encouraging patients to make a reappraisal is emphasised by the four patients who did not make reappraisals. These patients were forced to see HCPs by family and friends, and their delays were substantially longer than those patients who made reappraisals.

When patients were not referred by a HCP on the first consultation, most revisited a HCP within two weeks. It is unclear whether HCPs encouraged the patients to return during the first consultation. Importantly, patients do not return promptly for a third consultation if not referred for a second time. The reasons for this are unclear. If a HCP's second opinion is consistent with their first, this consistency may be sufficiently persuasive to convince patients that symptoms are minor. Alternatively, patients may feel that HCPs will not respond positively if challenged with a third visit. This finding does not necessarily mean that HCPs are at fault here, as there are no indications in this study as to whether symptoms objectively warranted referral.

Nonetheless, it appears to be clear that a second failure to refer has profound implications for patients' persistence in presenting to HCPs, as it is associated with lengthened delay. Therefore, health promotion strategies could also be aimed at the HCPs by recommending that they encourage patients to return if the symptom persists. Also, it may be helpful to recommend that HCPs refer patients to a specialist if they present their symptoms a second time, as a precaution, even though symptoms may not seem cancerous to the HCP.

The study is not without limitations. Firstly, we do not have objective accounts as to the severity of symptoms at the times that they were appraised by patients or when HCP consultations took place. Thus, it is not known if all symptoms warranted referral when patients presented them to HCPs. Further, it is important to be aware that, in retrospect, all patients had OSCC. At the times that patients and HCPs observed these symptoms, this was not apparent, and the probability of cancer may have been low. Thus, the key implication to draw from this study is not that patients and HCPs make incorrect appraisals, but that it is important to encourage patients to reappraise symptoms if symptoms persist and deteriorate. Additionally to raise awareness amongst HCPs that patients may be discouraged form presenting persistent symptoms after a second consultation.

Chapter 4: A qualitative analysis of patient delay in those diagnosed with OSCC

4.1 Introduction

The Introductory chapter highlights the reasons why OSCC is an increasing concern for public health (Chapter 1, section 1.1). It also highlights the importance of reducing the time elapsed between patients detecting symptoms and presenting them to a HCP (Chapter 1, section 1.1.3). and the need for interventions to be targeted toward the general population through mass-reach communications (Chapter 1, section 1.3).

4.1.1 Background

As the literature review (Chapter 2) showed, the literature on presentation delay in OSCC (Brouha, Tromp, Hordijk, Winnubst, & Leeuw, 2005; Scott, Grunfeld, Main, & McGurk, 2006; Scott et al., 2007) suggests that delay occurs because top-down appraisals fail. Patients do not link OSCC symptoms to cancer or other serious illnesses. Instead they attribute symptoms to minor conditions, such as ulcers or dental problems, because symptoms are either similar to those associated with these conditions (Scott, Grunfeld, Main, & McGurk, 2006) or inconsistent with patients' expectations of how cancer will manifest (Scott et al., 2007). Presentation becomes triggered only as symptoms persist or deteriorate to the point that initial attributions become untenable.

However, the above studies also show that patients' attributions of OSCC symptoms to minor symptoms are frequently uncertain (Scott et al., 2007). Thus, it is important to understand why patients choose to attribute uncertain symptoms to benign rather than serious conditions and it is unclear why they do not simply consult a HCP as a 'safe option' to

protect against their attributions being mistaken. Indeed, some patients reported that they were not entirely confident in the attributions they made, yet did not consult HCP's (Scott et al., 2007), Further, symptom misattributions usually favour transient conditions (Scott et al., 2007), and should become less convincing over time. Yet, patients frequently maintain misattributions over six to twelve months (Scott, Grunfeld, Main, & McGurk, 2006), and the reasons that they hold on to long-term misattributions are yet to be described.

SRM theory proposes an alternative reason for delay that has, to date, received little attention from OSCC researchers; that patients delay presentation because they use a defensive coping response to avoid acknowledgement of potentially distressing implications of their symptoms. Thus, patients deal with potential distress that symptoms invoke by avoiding or denying symptoms or their implications (Leventhal et al., 2001). Some evidence suggests that this might occur in practice. Studies have shown that presentation delay is associated with habitual tendencies toward a defensive coping style in oral (Tromp et al., 2004) and other cancers (Pedersen et al., 2013; Ruiter et al., 2008). Further, patients have attributed presentation delay in other areas of cancer to their fears of death or of the painful and disfiguring effects of treatment (Burgess et al., 2001; Lam & Fielding, 2002). However, no research of which the researcher is aware explicitly shows how patients might respond defensively to symptoms or how this influences presentation delay.

4.1.2 Current Study

The aim of this study was to resolve the above ambiguities associated with current explanations of presentation delay in OSCC; specifically, to understand why some patients attribute symptoms to minor ailments despite uncertainty over the cause of their symptoms and why they do not consult HCPs as a 'safe' option. Further, the researcher wanted to

explore when or why people use defensive coping and how they do so. To achieve this, a consecutive sample of OSCC patients were interviewed to identify the reasons for their decisions to present or not present. SRM ideas concerning symptom appraisal and defensive coping formed a general framework to guide the investigation, but the researcher wanted to be open to patients own ways of understanding and addressing symptoms. Thus, the research questions are inductive, and a qualitative approach was taken.

4.2 Method

4.2.1 Participants

Details of the sample as well as the inclusion/ exclusion criteria is described in chapter 3, section 3.2.1.

4.2.2 Recruitment process

This is described in chapter 3, section 3.2.2

4.2.3 Study procedure

This is described in chapter 3, section 3.2.3

4.2.4 Interview schedule/ Use of cognitive interviewing techniques

After the timeline described in the previous chapter, the second objective was to document patients' appraisal and decision-making processes. Unlike the focussed questions used in establishing the timeline, open-ended questions were generally used so that the patients' responses were not constrained. For this reason, also, interruptions from the interviewer were kept to a minimum with researcher dialogue limited to reflecting, prompting, summarising,

and probing where necessary. To avoid generalised responses, the patients were encouraged to speak specifically about key events taken from the timeline in the order that they took place. Questions explored the nature of symptoms (e.g. 'What did the symptom look like?'), patients' perceptions and interpretations of symptoms (e.g. 'What did you think caused the symptom?'). Patients then were asked to describe courses of action that they considered (e.g. 'What happened when you noticed this ulcer getting bigger?') and to explain why they chose the course that they did (e.g. 'What was it that made you decide to go to your chemist?').

An adapted version of the Liverpool Interview Protocol (Wheatcroft & Wagstaff, 2014) was used to enhance the information recalled by the participant. The protocol is described in chapter 3, section 3.2.5.

Towards the end of the interview, after patients felt that they had fully answered questions in their own words, more focused questions were asked to gain insight in to the patients' attitudes and beliefs towards seeing a health professional. 'How would you describe the relationship between you and your dentist/ GP?', 'How many times have you been to see a GP in the past year?', 'What kind of things make you see a GP?' and 'How do you think your GP would react if you presented with a symptom that turned out to be harmless?' Participants were also asked if they have routine check-ups with a dentist or GP. Participants were then asked questions to gain an insight in to their perceptions of oral cancer 'Up until you had the symptom, what had you heard about oral cancer?' 'Up until you had the symptom what had you heard about treatments of oral cancer?' Finally, patients were asked whether they had past or current oral conditions, such as ulcers or infections that we thought might influence their perceptions and interpretations of OSCC symptoms. These questions were not included if the participant covered responses to them earlier on in the interview.

4.2.5 Ethics

Described in chapter 3, section 3.2.6

4.2.6 Analysis

The philosophical orientation of the research corresponded to subtle realism and pragmatism. Subtle realism is the view that reality is something that exists independently of those who experience it, but it can only be accessed through the interpretations of others. In the current study the researcher was aware of the importance of the patients own accounts of the reasons that prompted as well as prevented them from presenting their symptoms to a HCP. The researcher believed that varying viewpoints between the patients yielded different types of understanding that captured reality in its depth and understanding. Pragmatism involves selecting the method which appears best suited to the research problem. In the current study, the researcher took a qualitative approach consisting of semi-structured interviews as it was felt that this approach would provide a more detailed analysis of patient delay in oral cancer by allowing participants the freedom to express their views in their own terms (Ritchie, Lewis, Nicholls, & Ormston, 2013).

Analysis took place concurrently with data collection addressing the continued conceptual and procedural evolution of the interview guide. The researcher adopted a comparative approach in which analytic categories were established both descriptively, in terms of what patients said, and theoretically in trying to determine the functions or meanings of speech locally and across the interview as a whole. The interviews carried the risk that pre-decisional processes are mis-recalled and reconstructed after those decisions have been made, or 'altered' in order to fit favoured interpretations. Therefore, interviews were not viewed as providing direct access to participant's experiences and plans, but rather they were

interpreted in the context of the whole interview, field notes and consistency with the other party in the corresponding interview.

The researcher was particularly focused on the tendency of interviews to provide justifications rather than explanations of behaviour. The researcher also considered the possibility that consistencies with and between the interviews were unsuspecting and a product of memory distortion or loss. Each transcript was read by the researcher and at least one other investigator. The whole team often reviewed and tested the developing analysis to provide a broader reference group.

Consensus validity was verified by discussing the analysis within the team. Reflexive validity was revealed by assessing the extent to which conceptual categories developed and changed during the analysis. Validity of the final interpretations was assessed by referring to the literature to examine theoretical coherence with previous literature. The extent of this coherence and any inconsistencies will be reported. Suggestions of catalytic validity also guided the analyses. This means that priority was given to aspects of the analysis that offered theoretical and practical progress.

The data was analysed using a Framework Method, a highly systematic method of categorising and organising large qualitative data sets. It enables data to be compared with ease across participants as well as within individual participants. The method was chosen with the intention of forming a holistic, descriptive overview of the data in the study. As the data covered similar topics and key issues this method was appropriate as it allowed for the data to be contrasted and compared. The framework method has been applied successfully in research over the past 25 years, and in recent years it has become a popular for analysing qualitative health research (Gale, Heath, Cameron, Rashid, & Redwood, 2013).

4.2.7 Analysis Procedure

Although cancer presentation delay research employs a number of theoretical perspectives (Noonan, 2014) the researcher decided to structure the analysis on the most commonly used framework, the self-regulation model. This was chosen as it comprehensively describes the processes of symptom detection, appraisal and decision-making. Although the researcher did not construct pre-formed codes for SRM constructs attention was given to elements of the text pertaining to the model. This included patients' cognitive and emotional responses to symptoms, deductively and inductively derived meanings for symptoms, IF-THEN rules, attributions to conditions other than OSCC and positive and negative coping responses. These were coded as they occurred, and their absence noted if they did not. Unexpected phenomena, such as patients' responses to HCPs' misdiagnoses, were also coded. The researcher also developed codes for unexpected phenomena.

The researcher became familiar with the interview transcripts by re-reading them. The transcripts were also read at least once by another member of the research team. Any analytical notes of thoughts and impressions were jotted down on the margin of the transcripts.

After familiarisation the research team applied codes to the interviews they had read in order to describe what they have interpreted in the interviews as important. In addition to predefining some codes according to self-regulation theory, an 'open-coding' approach also took place; thus, allowing unexpected phenomena to be recorded. Codes referred to substantive things (e.g. as particular behaviours or incidents), the patients' beliefs emotions, as well as methodological/ impressionistic elements (e.g. how the participant was feeling during the interview). The aim of coding was to classify the data so that it could be compared systematically with other parts of the data set. Coding also alerted the researcher to consider aspects that may ordinarily be invisible because it does not 'fit' with the rest of the account.

The researcher independently coded the first few transcripts. Regular meetings with the whole research team took place to discuss the codes so that alternative viewpoints could be offered.

After the first few transcripts were coded the research team met to agree on a set of codes to apply to all the following transcripts. Codes were grouped in to categories to form a working analytical framework. Different versions of the analytical framework were formed before no additional codes emerged. The analytic framework could not be finalised until the last transcript was coded. The working analytical framework was applied by indexing following transcripts using the existing categories and codes. The codes were then abbreviated and written on to the transcripts.

A Microsoft Excel spreadsheet was used to create a matrix and the data was 'charted' into the matrix. Charting consisted of summarising the data by category from each transcript. References to interesting and illustrative quotations that were presented with a capital 'Q', an anonymised transcript number, page and line reference were also noted. The aim of charting was to reduce the data while preserving the original meaning and feel of the participant's words.

The data was then able to be interpreted. Characteristics of and differences between how the participants responded to symptoms were identified from the data to form theoretical concepts. The findings generated through this process went beyond description of particular cases to explanation of reasons for specific responses to symptoms.

4.3 Results

4.3.1 Description of sample

Sixty-six patients were approached. Twenty-three refused or could not participate for medical or psychological reasons. Forty-three consented, but five were eliminated because their interviews revealed that cancer detection was incidental, usually through routine dental examination, and that they had not noticed symptoms. This left a sample of 38. The mean age of the patients was 60, standard deviation of age =11.5, 44% were female. The delay times, demographic and risk information (history of smoking and alcohol usage) for each patient are displayed in table 3.1.

4.3.2 Initial Analysis

Four key categories emerged from the initial analysis of patient's responses to symptoms. These were; (1) 'Sort it', (2) 'It's only minor', (3) 'Put it Off' (4) Avoidance

'Sort it' and 'put it off' categories applied to patients who were uncertain about the nature of their symptoms. Sort it patients responded to uncertainty immediately by seeking professional help straight away. 'Put it off' patients expressed intentions to seek help, but they did not have the same urgency as the 'sort it' patients to seek help quickly. They tended to give reasons for not seeking help promptly; some chose not to let their symptoms interfere with their daily lives, for instance a few mentioned being busy with work and one patient mentioned that she decided to enjoy her holiday abroad before consulting. Other 'put it off' patients described waiting for routine check-ups or other appointments to present symptoms, which often lead to them delaying for weeks or months. Misattributions involved patients being confident that symptoms related to minor conditions such as ulcers, dental problems or

infections. The patients said that they sought help because their symptoms were causing difficulties with daily activities such as eating, drinking or talking. Avoidance involved patients who actively avoided consultation as they feared that their symptoms were cancer.

4.3.3 Redevelopment of Categories

The categories were altered as the researcher felt it made more empirical sense to have 3 main categories indicating main responses which were 'sort it', 'it's only minor' and 'don't want to think about it'. On reflection, patients in the 'put it off' category showed similar characteristics to the 'don't want to think about it' and the 'it's only minor' responses. An example is patient 19 who expressed intentions to consult a HCP but reported being too busy to make an appointment, *'It was a busy time at work at the time and it was also the run-up to Christmas. I did try to book an appointment at the doctors to have a look at it but they couldn't fit me in and asked me to phone again the next day, and I left it then until the New Year when I made an appointment with my dentist'* (P19). This patient later was placed in the 'it's only minor' category as it was felt the patient did not interpret his symptoms as serious enough to disrupt his activities by seeing a HCP, *'I really believe if it was something painful I would have seen a GP before. I would have definitely gone along and seen the GP but the fact that there was no pain I naively thought it was nothing'* (P19).

Similarly, another patient was originally in the 'put it off' category as she used this phrase to describe how she prioritised other life events over seeking help. *'I needed to get time for me to get it sorted instead of just going through life like a hundred mile an hour like I do, that I needed to take time out for me to go the dentist and get it looked at instead of, I kept putting off and putting it off and putting it off cause I felt like I had no time. I was too busy'.* However, she was then placed in the 'don't want to think about it' category as she reported

suppressing thoughts about cancer *'it's [cancer] 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 [cancer] surely. It might have been niggling in my mind but I had the hope that it wasn't anyway'*.

4.3.4 Overview of final analysis

Two sequential patient appraisals were identified that contribute to delay; 1) whether patients initially suspected that their symptoms might portend cancer or serious illness, and 2) how they responded once they thought that their symptom(s) did. Several patients did not consider the possibility of serious illness and attributed symptoms to minor conditions – *'It's only minor'*, but most of those patients presented when their symptoms did not remit. Their delays were generally 3-4 weeks. Patients who suspected serious illness exercised one of two responses. Some elected to '*sort it'* and pursued appointments with HCPs almost immediately. These patients spoke of being aware of increased risks of serious illness attributable to age or smoking, but believed that early medical intervention could mitigate any disease progression. Other patients suspected cancer but expressed reluctance to think about it – *'Don't want to think about it'*. Several of these patients recalled previous traumatic experiences of cancer in family and friends and feared cancer. These patients reported some of the longest delays. Table 4.1 displays the patients' responses arranged in categories, as well as the sub-categories within each category.

Table 4.1: The patients' responses arranged in to categories and sub-categories

Categories	Sub-categories
1. 'It's only minor'	(i) Mismatch between symptoms and perceptions of cancer
	(ii) Other health conditions more salient
	(iii) Persistence or worsening of symptoms leads to reattributions
	(iv) Fear of dental treatment
2. 'Sort it'	(i) Unusualness of symptoms drives help-seeking
	(ii) Orientation towards problem solving (If-THEN rules)
	(iii) Awareness of cancer
3. 'Don't want to think about it'	(i) Not consulting when suspecting symptoms are serious
	(ii) Supressing thoughts about cancer
	(iii) Misattribution linked to avoidance
	(iv) Fear linked to experiences of death and disfigurement

4.3.4.1 'It's only minor'

Nine patients reported that they did not initially think about cancer or other serious illness upon noticing the symptom. Although describing symptoms as '*irritable*', '*painful*' and '*unusual*', they attributed them to ulcers, friction with teeth, infections or dental conditions. Initial responses were to ignore the symptom or to use over the counter medications. When asked why they did not consider cancer, many patients cited a divergence between their symptoms and their ideas of how cancer would manifest; '*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). For some, symptoms seemed minor compared to other health problems that were

salient to them: '*No it was just like I say it was an incidental thing. It was only very minor compared to, like I say I had gall stones so I was having stomach ache and that was bothering me more than the ulcer, or what I thought was an ulcer*' (P21).

Generally, these patients sought help once persistence or worsening of symptoms made initial attributions seem untenable. For example, P36 became suspicious when an over-the-counter ulcer treatment failed; '*It wasn't Bonjela [analgesic paste] I used but it was something similar. (There was) No change whatsoever. Oh I had my own suspicions that it could be something a bit pernicious, which of course it proved to be*'. Delay related to misattribution was moderate. None of these patients experienced delays of greater than six weeks, with the median being about three weeks.

Two patients (P4 and P24) who misattributed symptoms to dental problems diverged from the above pattern. Although their symptoms had worsened considerably and interfered with eating and drinking, neither stated that they had considered the possibility of serious illness. When asked about their relationships with HCPs, both spoke of intense fear of dentists: '*I do not like the dentist one little bit from when I was a child. I avoid dentists like the plague. Since I was about eight or nine years old I had about nine to eleven fillings all done together, and all I was going in for was a routine check-up and from that day on I will not go near the dentist*' (P24). Neither, however, linked this fear to non-presentation. They presented after delays of 20 (P4) and 12 (P24) weeks, and then only when prompted to do so by relatives or partners; '*It was my girlfriend who 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 with me*' (P4).

4.3.4.2 'Sort it'

These patients were aware that symptoms could portend serious illness, and spoke of a desire to '*sort it*' by presenting to HCPs who could deal with this possibility. Although several mentioned being aware of cancer as a possible cause, and felt alarm about this possibility, they considered other causes also possible. The driver of presentation was symptom unusualness, and none tried to identify specific causes of symptoms; *'As soon as I realised that whatever it was shouldn't be there I acted on it y'know so it was like, it was more or less within the next day or so'* (P1). Some made immediate HCP appointments, others set specific timeframes of three or four days to see if their symptoms spontaneously remitted, then sought consultation if symptoms did not.

In SRM terms, these patients described as IF-THEN sequences (e.g., IF symptoms are unusual THEN seek help). The 'IF' component was generally derived from 'bottom up' thinking about symptoms.; *'I was alarmed but I wanted to get to the bottom of it to figure out exactly what it was so I could start dealing with it and that's what I did'* (P30). The THEN component was activated by patients' understandings of the options available to them. For example, Participant 9 remembered reading a magazine article, about cancer of the tongue before experiencing symptoms. She followed a rule proscribed in the article; *'if you have [an ulcer] more than ten days it's better to go and see a doctor.'*

Almost all 'sort it' patients described two beliefs as informing their response. First, they were aware of their elevated risk for diseases such as cancer that they attributed to smoking or age; *'I suppose when you get to a certain age and y'know you've smoked for a long time you think oh I've got cancer, so I was just seeking reassurance'* (P7). *'*Secondly, they were aware that early intervention could promote better outcomes '*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 found this lump' (P22). Put simply, P1 preferred to *'nip it* [illness] *in the bud'*.

4.3.4.3 'Don't want to think about it'

Eight patients also suspected cancer or other serious illness but did not seek immediate consultation. These patients reported some of the longest delays. Some were explicit that they thought their symptoms could be possible OSCC; *'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). The remaining four did not state that they suspected their symptoms to be cancer, describing their thoughts as either a *'sixth sense'* (P6) or a *'feeling'* (P5): *'Because I knew in my own mind it was more than that, it was more than an ulcer. What it was I didn't know but I knew. Something told me that's not right'* (P26).

Common across these patients' viewpoints was that they wanted to avoid thinking about the possibility of serious illness: *'I felt an ache but you get like a sixth sense that somethings wrong with you as well but I've always been like that like a sixth sense, y'know what I mean. Some people are and some people aren't, but I'm the type who's more anxious about going to the doctors.'* (P6). Unlike the 'sort it' response, where thoughts of serious illness promoted presentation, these patients tried to reduce emotional distress by suppressing thoughts about either symptoms or cancer: *'Well then 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 want to 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).

Four patients were explicit that they had strategically misattributed symptoms to minor conditions to avoid the inference that symptoms may be cancer. P36 (4-6 weeks until consultation) said *'I suppose if I'm truthful I didn't really want to accept it was anything worse than an ordinary ulcer because it wasn't troubling me too much at that stage'*. P38 (8-10 weeks until consultation) described how she continued to attribute symptoms to an ulcer to suppress thoughts of cancer; *'it's [cancer] 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 [cancer] surely. It might have been niggling in my mind but I had the hope that it wasn't anyway'*.

Patients who did not want to think about their symptoms also spoke of pre-symptom perceptions of vulnerability to disease. They expressed their vulnerability differently from 'sort it' patients, who spoke of an enhanced risk due to age or smoking. Patients who wanted to avoid thinking about serious illness spoke emotionally about fears of cancer based upon vividly recalled experiences of the deaths and disfigurements of friends and relatives who had cancer. P42 said he found information he heard about cancer *'frightening'*, because *'cancer seems to be the front runner of death'*. P5 reported '*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'*. Some patients linked their fears to vicarious experiences of cancer amongst family or friends that they found traumatic. P5 lost his Father to cancer which '*wasn't very nice to watch*'. He explicitly linking this experience to his suppression of thoughts about cancer; '*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 ma Dad went through'*.

4.4 Discussion

OSCC and other cancer delay literature emphasises the importance of symptom misattribution in presentation delay (Scott et al., 2007). In this current study, symptom misattributions represented by the phrase 'it's only minor' led to some delay, but patients generally presented after symptoms did not remit, and their delay was generally confined to three to four weeks. This study characterises two new ways of understanding why patients do or do not delay presentation. Some elected to 'sort it', which largely eliminated delay, whilst many of those who avoided thinking about potentially serious implications of symptoms, 'don't want to think about it' showed long delays.

4.4.1 Findings of the study in relation to current theory

'Sort it' and 'don't want to think about it' responses were associated with patients' pre-symptom understandings of serious illness. Patients showing the 'sort it' response perceived themselves vulnerable to diseases such as cancer, but believed that early intervention could mitigate disease impact. This awareness led them to make sense of their symptoms by approaching symptoms inductively or taking a 'bottom-up' approach. This means they responded to symptom characteristics that they found unusual without attempting to identify the causes of symptoms, i.e. they applied rules such as IF symptoms are unusual THEN seek help. This is consistent with other research on symptom presentation. OSCC Patients' beliefs that early presentation could ease symptoms and curtail worry were associated with less patient delay (Scott et al., 2009), whilst research on breast cancer has shown that people who both feel susceptible to illness and believe that illness is treatable are more likely to actively seek diagnoses (Dawson, Savitsky, & Dunning, 2006). 'It's only minor' responses were associated with long delays. Patients responding with avoidance suspected that symptoms

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may be cancer or other serious illness. However, recalling traumatic memories of cancer in friends or family, they avoided thinking about the implications of symptoms which led them to delay help-seeking. This finding is in line with previous research revealing that distress is associated with delay (Smith et al., 2005; Fish et al., 2015) Avoiding distress associated with thoughts of cancer can be interpreted this as a defensive response (Leventhal et al., 2001). This is consistent with research showing defensive coping styles to be associated with longer delays in OSCC (Tromp et al., 2004) and other cancers (Pederson, et al., 2013; Ruiter, et al., 2008).

The findings contribute to a greater understanding of why some patients in previous studies persisted with misattributions of symptoms to minor conditions for long periods of time. Four patients in the current study admitted that they made strategic misattributions of symptoms to minor conditions to avoid thinking about and responding to those symptoms. The researcher ascribes delay in these patients to avoidance of thinking about symptoms rather than misattributing those symptoms. Another two patients had long delays because they attributed symptoms to dental conditions, but feared dental treatment. Thus, for some patients, symptom misattributions are coincident with fears of illness or treatment. The real cause of long delays is likely to be fears of illness or treatment.

4.4.2 Limitations of the study

This study is not without its limitations. First, although the researcher used cognitive interviewing techniques to minimise the problem, patients' descriptions of their symptoms and their responses to them may be subject to errors or biases in retrospective recall. A second limitation is that it cannot be ruled out that it is possible that the differences in patients' presentation times are related to objective features of the symptoms. For example,

symptoms of immediate presenters may have been more unusual and severe than those of patients who made genuine misattributions. This interpretation is partly mitigated because the site and staging information in Table 3.2 shows approximately even distributions of OSCC site and stage across immediate presentation and short and long delay groups. A final limitation has implications for future research. This is a qualitative study with a small sample. Although a consecutive series of patients at a large clinic was used, the incidence of 'sort it' or 'don't want to think about it' responses or how large their relationships are to presentation delay cannot be estimated.

4.4.3 Reflections on potential researcher interpretive biases and the use of qualitative methods

The experience and prior assumptions a researcher has regarding the topic they are researching can inherently influence the data collected (Palaganas, Sanchez, Molintas, & Caricativo, 2017). Therefore, it is important to be transparent about these. The researcher is female and was in her mid-twenties when collecting and analysing the data. She is tertiary-educated, in contrast with most participants, a non-smoker and a light drinker. This means that the researcher would currently be at a low risk of developing OSCC. Further, the researcher had little experience with OSCC prior to engaging in this project. Thus, the researcher was demographically, and in terms of OSCC risk, dissimilar to the patients interviewed in the study. Dissimilarity can be viewed as an advantage in terms of objectivity and open mindedness (Song & Parker, 1995). However, dissimilarity between the researcher and the patients may have disadvantages in terms of her ability to draw information from patients and to interpret the information that was gained independently of assumptions.

This is not to say that the researcher adopted a dogmatic or inflexible view of the topic (Reeves, 1994). Whilst dogma might, and inevitably did, emerge, consciously and unconsciously, a key problem was simply that not fully understanding the accounts of participants led to lost opportunities. The researcher incrementally gained understandings of OSCC and the burden that it places on patients and carers, first through academic reading, then through her presence on the Head and Neck cancer ward and lastly through the interviews themselves. It is thus noticeable that some text in the initial interviews indicates occasional failure to follow-up on important material. The following from P3 provided an example;

'JB: And what were your initial thoughts when you noticed this pain when you were eating?

P3: Well That it wasn't normal. I just knew there was something wrong and I felt like that for quite a while.

JB: So are you saying then, at that stage you thought it was something….

P3: I thought it was something worse yes.

JB: Ok

P3: Back in February and when it got worse during the next few months.

JB: Ok

P3: When they told me the results at XXX I wasn't surprised

JB: Ok, so what did it look like this symptom when you noticed it?

P3: Like a little red blob on my tongue that was painful to touch, but the side of my tongue was painful as well as the top, so the whole area of my tongue was quite painful.'

The researcher in her first clarification wanted to uncover the patient's thoughts, but closed the discussion down and directed it toward the idea that the patient had noted something suspicious in the symptom, thus not allowing the patient to express herself in her own words. This was more than a technical interviewing problem, because it embodied the researcher's interest in the idea that the patient might suspect serious illness. After discussion with her

supervisor, the researcher improved her interviewing technique to allow patients more scope to express their own thoughts. Indeed, discussion with the supervisory team enabled the researcher to identify instances where she imposed her own meaning during interviews and data analysis, and to reduce this as much as possible (Hughes, 2012).

Nonetheless, this patient's and others' accounts showed the value of qualitative methods. First, the 'sort it' and 'don't want to think about it' have not previously been characterised in detail, and there was little theory that could have been applied in advance to predict these phenomena. Thus, qualitative methods allowed the researcher to induce why patients made the responses that they did and to introduce theory that could be tested. New topic areas were opened up that were not initially considered. This led the interview guide to evolve, for instance it was not expected that so many patients were sent away without being referred, so the interview guide extended to cover the delay process up until patients presented to a HCP who referred them to a specialist. Second, qualitative methods provide a description of thoughts and behaviours in depth and richness. Thus, by using qualitative methods the researcher was able to describe factors that cannot easily be quantified but are essential to the understanding of complex phenomena. Qualitative methods also allow for a flexible approach which meant that during interviews the researcher was able to tailor questions towards individuals' accounts. Aspects that were seen as relevant to each individual's help-seeking journey were questioned in more detail to gain a greater understanding of their experiences.

The main advantage of using framework analysis was that it was a systematic and thorough approach to managing large amounts of data. The researcher was able to maintain an transparent audit trail, enhancing the credibility of the findings. The researcher also used the framework to cross-tabulate data within and between cases. For example, the analysis could link the three main responses to symptoms with time taken to present those symptoms. Another advantage is that the analysis developed from descriptive accounts to explanatory

accounts with the aim of developing deeper interpretations of what patients said, For instance, some patients initially said that they delayed presenting their symptoms as they initially attributed them to minor conditions. However, they later said that they did not want to accept that their symptoms could portend serious illness. This inconsistency data led to the development of the sub-category 'Misattribution linked to avoidance', whereby it is thought that patients might use misattributions as a device to avoid thinking about symptoms.

4.4.4 Implications for future research and practice

The researcher suggests that future research uses quantitative methods in a much greater population of oral cancer patients to determine the incidence of 'sort it' and 'don't want to think about it' responses and how large their relationships are to patient presentation delay. This may provide support for the findings that peoples coping styles can affect the length of patient delay in oral cancer, as well as peoples' misattributions of symptoms. An idea for future research assessing reasons for patient presentation delay in oral cancer is to present hypothetical scenarios based on the symptoms of the patients in the current study to healthy, asymptomatic individuals. Then to ask those individuals to interpret the symptoms and indicate how they would respond. As this method would not examine pre-decisional processes that can be mis-recalled it could supplement the patients' responses and provide trust in the findings.

Health promotion strategies should place greater emphasis on aiming to improve presentation time in the 'don't want to think about it' group by addressing thoughts and feelings that underpin avoidance. One approach to identifying these thoughts and feelings is to compare precursors of 'don't want to think about it' responses to those of 'sort it' responses. Both responses were associated with pre-symptomatic perceptions of vulnerability, but these

perceptions were very different for each. Avoidance was associated with vivid and disturbing memories of cancer in family members or friends, rather than the relatively unemotional statements of risk expressed by 'sort it' patients. Further, avoidant patients did not express a similar optimism to 'sort it' patients that early intervention could mitigate serious illnesses such as cancer.

Although the delays caused by avoidance are the most concerning, genuine symptom misattribution can lead to moderate delays, with a median of 3-4 weeks that could be clinically significant (Hyde & Hopper, 1999). The 'it's only minor' group will need a different approach to the 'don't want to think about it' group in order to improve presentation times. An effective way could be to encourage 'it's only minor' people to become 'sort it' types by adopting the style of thinking that the 'sort it' patients in this study applied when noticing symptoms.

4.4.5 Conclusion

In conclusion, this study characterises new responses to symptoms of OSCC, 'sort it' and 'don't want to think about it', as we as the beliefs and feelings that are associated with them. The researcher suggests that health promotion campaigns that aim to reduce patient presentation delay in OSCC should primarily focus on targeting individuals who are likely to supress thoughts about cancer.

Chapter 5: A qualitative analysis involving matched participants

5.1 Introduction

The study reported in the previous chapter, like others on presentation delay, relied on patients' self-report of the events that took place between detecting an initial oral symptom and being referred by a HCP to a specialist. This can lead to recall errors. There are various factors that lead to recall errors. One of these is interference, for instance the quantity of events that a person experiences is inversely related to the probability of them recalling a specific event (Biemer, Groves, Lyberg, Mathiowetz, & Sudman, 1991). Another factor is that emotional states, such as anxiety, can distort memory by increasing recall for anxiety congruent stimuli and decreasing recall for incongruent stimuli (Reidy & Richards, 1997). The interval between when the event takes place and when it is recalled is also important, with less recall being associated with longer interval (Zafar, Luby, & Mendoza, 2009). Other factors contributing to recall errors may include personal variables (age, gender, socio-economic status), interviewing technique, social desirability and motivation of the respondent (Coughlin, 1990).

Compared to contemporaneous accounts, retrospective accounts of the same incident show biased and reduced recall of intensity and frequency of symptoms. Van den Brink et al (2001) investigated whether children can recall prior headache complaints accurately by comparing data on a retrospective headache questionnaire and a four-week headache diary. Headache intensity and duration were over-estimated on the questionnaire compared to the diary. This implies that time altered qualitative and quantitative aspects of the way in which the children remembered their headaches. Headache severity and age appeared to affect the size of recall errors (Van den Brink et al., 2001).

Voldsgaard et al. (2006) assessed influenza symptoms during pregnancy by comparing women's accounts of influenza at the twenty-fifth week of pregnancy with their accounts one or two days after giving birth. It was revealed that after birth a significant number of women failed to state illnesses that they stated at a time in their pregnancy when they were more at risk from the illness. This may have been because the women were focused on other concerns after childbirth (Voldsgaard et al., 2006).

Anderson and Mikkelsen (2008) compared daily records of occupational injuries with retrospective questionnaire reports of injuries in the past month. It was found that self-reports of injuries were substantially under-reported even when the recall period was as short as one month. Anderson and Mikkelsen (2008) proposed that the loss of information in the study may be because the injuries seem to be minor and so they might not have been perceived as important to the individuals who endured them. Smith, Jobe and Mingay (1991) claimed that when an individual fails to judge an experience as being important sufficient retrieval cues may not be formed and this may affect recall accuracy. Ayhan and Isiksal (2004) compared responses to retrospective questions on health care visits with administrative records. Consistent with Anderson and Mikkelsen's research they found that memory errors are linked with the length of the time interval, as well as the importance of the event to the respondent. Therefore, it may be suggested that researchers emphasise the importance of recalling all experiences related to the research area (Anderson & Mikkelsen, 2008).

However, recall errors are not always distributed randomly, but are inadvertently biased by subsequent events (Van den Brink et al., 2001; Anderson & Mikkelson, 2006). Recall of decision making processes can be distorted by the hindsight bias, sometimes referred to as the 'knew it all along effect' (Hertwig, Gigerenzer, & Hoffrage, 1997). This describes the inclination after an event has taken place to view the event as having been predictable even though there was little or no objective bias for predicting it. Ash (2009) tested cognitive

reconstructive theories as explanations of the hindsight bias. Experiment one showed proof of hindsight bias after participants were exposed to ambivalent, incongruent outcomes but not after congruent ones. Experiment two replicated the hindsight bias results from the first study and discovered that the ratio of outcome consistent information the participants recalled was greater than predicted in the ambivalent and incongruent conditions but was the same as the ratio presented to participants in the congruent condition. The results endorse general predictions of sense-making models in explaining the hindsight bias. The sense-making account of cognitive processes depicts that individuals reinterpret their initial predictive judgements, so they believe that their predictions remain unchanged over time. Therefore, at the point of retrospection a larger amount of information consistent with the outcome of a situation would be available in memory, thus forming a reconstructed judgement that is more consistent with the given outcome (Ash, 2009).

Pieters, Baumgartner and Bagozzi (2006) showed that not only are remembered predictions more in line with experienced outcomes than genuine predictions, but remembered intentions are more in line with behaviour than actual intentions. Thus, an individual's behaviour knowledge becomes a retrieval cue when trying to recollect past intentions. Therefore, experienced outcomes and behaviour knowledge (people's knowledge about actual behaviour jointly impact on memory reconstruction (Pieters et al., 2006).

5.1.1 Current study

By necessity, studies into presentation delay are retrospective, in that cancers such as OSCC are unpredictable and prospective methodologies cannot be used. However, they are likely to be affected by memory bias, as patients frequently experience strong emotions at the time, and then experience cancer diagnoses which constitute major events in their lives. Efforts

were made in the previous chapter to reduce the issue of recall errors, such as interviewing the patients soon after diagnosis and applying cognitive interviewing techniques described in the previous chapter. However, it is unlikely that these techniques will fully eliminate errors.

An additional solution to the issue of recall errors is to recruit asymptomatic individuals with similar OSCC risk profiles to the patients, and match each to a patient of the same gender and similar age, smoking and alcohol use patterns. The asymptomatic individuals are asked to imagine those symptoms occurring to them and indicate how they would think, feel and respond to those symptoms. By matching patients and healthy volunteers with similar behavioural and demographic features, and presenting the volunteer with the symptoms reported by the matched patient, it is possible to directly compare the volunteer's hypothetical responses to those actually made by the patient.

Asking asymptomatic individuals to make hypothetical responses to symptom scenarios is commonly used to study presentation delay (e.g., Marcu, Lyratzopoulos, Black, Vedsted, & Whitaker, 2016). Non-patient scenarios provide 'real time' accounts of appraisal and decision-making, but it can be argued that hypothetical scenarios do not stimulate acute emotional responses in ways that real symptoms do. Nonetheless, scenario-based research findings show broadly similar patterns to retrospective studies (Brain et al., 2014). In one study, Lyubomirsky et al., (2006) employed both retrospective and scenario methods to find support for a prediction that emotion would inhibit symptom presentation. Their scenario elicited similar cognitive and emotional responses to patients' real symptoms.

The current study takes this approach further by formally matching patients and asymptomatic volunteers, in which volunteers with similar backgrounds and risk factors can respond to symptoms described by patients. Matched volunteer accounts can supplement patients' accounts of symptoms. This will enhance the trustworthiness of each method; where

commonalities exist between accounts this provides confidence in findings, where differences exist this allows the researcher to identify disparities and to direct questioning and analysis to resolve them. The aim of this study was to combine the retrospective method with the scenario based 'real time' method to create a more complete account of presentation delay based on an analysis of differences between patients who did and did not delay consultation.

5.2 Method

5.2.1 Participants

Participants were recruited through a busy medical practice in central Liverpool, the same city as the H&N Cancer Service. Both the H&N service and the practice draw patients from the entire city. The administration team at the medical practice searched through patient medical records to identify patients who matched the required characteristics of each patient in the previous study. Volunteers were eligible to take part if they could be matched to a specific patient in the previous study based upon five-year age categories (18-24, 25-29, 30-34, etc.), gender, smoking status (current smoker/ former smoker/ never smoked) and alcohol use (above or below the weekly NHS recommended consumption for their gender or under, 14 for women and 21 for men). After an initial mail out from the practice, two attempts were made to contact each patient if they did not respond to the mail out. If patients still did not respond they were replaced once in the sample and the process repeated. As it became difficult to match volunteers to patients of the exact criteria a few of the volunteers who were former smokers were matched to current smokers and vice versa.

Exclusion criteria were; (i) Individuals who have had a previous diagnosis of carcinoma of the head or neck, (ii) Individuals whose participation was considered to be unwise for

medical or psychological reasons by staff at the medical centre (iii) Dental staff and medical professionals who were likely to have high awareness of oral cancer

5.2.2 Interview schedule

Scenarios were developed describing matched patients' symptoms and patients' responses and attributions for symptoms, the progression of symptoms, and responses to those progressions. If patients made multiple consultations because the HCP misdiagnosed conditions or asked them to return if symptoms persisted, these were also described in the scenario. Patients' own phrasings were used where possible and timelines for events were provided.

Appropriate instructions and scenarios were developed. In particular, the researcher focused our attention on creating scenarios that were realistic and engaging. Prior to the research being carried out a sample of the scenarios and instructions were piloted with a small group of volunteers who were students at the University of Liverpool. A 'think aloud' methodology was trialled (Shadel, Niaura, & Abrams, 2004; Backlund, Skaner, Montgomery, Bring & Strender, 2003) to ensure that participants understood the task, that they were able to imagine the symptomology described and the scenarios felt realistic and that they do not guess the object of the research.

The scenarios were read to the volunteers by the researcher. After verbally describing initial symptoms, the researcher asked the volunteers to imagine that they experienced those symptoms. The researcher asked open questions about volunteers' thoughts and feelings about the scenario material and descriptions of how they would respond to these symptoms. Similar questions were asked of participants as in the first phase but worded in the present

tense; e.g. 'What do you understand about the symptom?', 'What do you think you think you might do?'. The matched patients' responses to symptoms were then described, and volunteers were asked to comment upon the patient's response. This process was repeated for subsequent scenario events such as symptom persistence and changes or when patients sought HPC advice. If the volunteer did not bring up oral cancer, that possibility was raised with him or her at the end of the scenario, and the volunteer was asked whether he or she had considered oral cancer. If the volunteer had considered oral cancer, he or she was asked for any thoughts or feelings about this, and, if he or she had not thought of cancer, why not. Where patients and volunteers' responses differed, volunteers were asked their opinions of why their views were different to the patient.

A think aloud methodology was used (Shadel et al., 2004; Backlund et al., 2003) and responses were recorded. Think aloud methods encourage participants to verbalise their thoughts while answering questions (Beatty & Willis, 2007). Verbalisation highlights the cognitive behaviour of an individual and uncovers information stored in the working memory at that present moment (Lundgren-Laine & Salantera, 2010). Consistent with think aloud methods participants were not required to expand on their responses straight away but were sometimes asked to do so at the end of the interview. Participants were prompted to make interpretations on the information presented to them, particularly the reasons for and against their symptom attributions and their decisions to seek help from a health care professional. Prompts were sequenced in order not to 'lead' participants. As with patient interviews, towards the end of the interview more focused questions were asked when participants felt they had fully answered questions in their own words.

To gain insight in to the participants' attitudes and beliefs towards seeing a HCP, volunteers were asked, 'How would you describe the relationship between you and your dentist/ GP?',

'How many times have you been to see a GP in the past year?', 'What kind of things make you see a GP?' and 'How do you think your GP would react if you presented with a symptom that turned out to be harmless?' Participants were also asked if they have routine check-ups with a dentist or GP. Participants were then asked questions to gain an insight in to their perceptions of oral cancer; 'What sorts of things had you heard about oral cancer?' 'What sorts of things had you heard about treatments of oral cancer?' These questions were not included if the participant covered responses to them earlier on in the interview. At all points participants were prompted to make interpretations on the information presented to them, particularly the reasons for and against their symptom attributions and their decisions to seek help from a health care professional. Prompts were sequenced in order not to 'lead' participants. Volunteer participants were thanked and provided with NHS leaflets that gave accurate information on incidence of OSCC, it's risk factors and how to identify initial symptoms. Participants were also advised to speak to GP if they have any concerns about OSCC.

5.2.3 Study Procedure

The administration team at the medical practice posted a letter along with an information pack inviting eligible patients to take part in the study. The information pack did not mention cancer, advising potential participants that the study was concerned with oral symptoms and the research was associated with a dental school. The interviews were mostly conducted face-to face in a private and secure area at the participant's home or the University of Liverpool. Interviews took place in a quiet room where participants were not likely to be disturbed. Two interviews were conducted over the phone when it was not convenient for the participants to meet with the researcher in person. The researcher followed a lone worker policy to ensure

that their safety was not put at risk. This involved reporting to a trusted person at The University of Liverpool when they arrived at the interview location and again when they had left the location.

The researcher introduced herself to the patient and reminded them of the purpose of the study. The researcher also informed the participant that a digital recording and written notes will be made during the interview. The participant was then asked if he or she had any questions regarding the study.

The participant was given a short questionnaire to fill in regarding demographic details and risk factors of oral cancer. The questionnaire asked them to specify their age, gender, ethnicity, postcode, marital status, highest level of education achieved, employment status, most recent occupation, smoking and drinking behaviour, and whether they are dependent on others for care, or whether others are dependent on them for care. This information was used to identify how closely each participant was matched to a patient, and to provide a context for the sample.

Once the interview had ended the researcher thanked the participant for their time and any questions or concerns the participant had were addressed. Finally, the researcher gave the participant a printed debrief sheet to read, which will explain the full purpose of the study.

The recordings of the interviews were transcribed verbatim and anonymised. All patients were given an ID number which was used on the transcripts and questionnaires in order for the investigatory team to identify the participants. Information such as gender, age group, smoking and alcohol use and some clinical information was attached to the transcripts.

5.2.4 Analysis

Analysis took place concurrently with data collection to inform the continued conceptual and procedural evolution of the interview guide. A comparative approach was adopted whereby matched patient and volunteer accounts were read together. Analytic categories were established based on the similarities and differences between accounts. Initially, categories were established empirically, based on the overt content of what was spoken. Categories were then established in a more theoretical sense by trying to determine the unspoken functions or meanings of speech locally and across the interview as a whole. For example, volunteers may try to provide socially acceptable responses, such as claiming to visit HCPs because they anticipate that this is a desired response. Therefore, interviews were not always viewed as providing direct access to participant's experiences, but rather they were interpreted in the context of the whole interview, field notes and consistency with the other party in the corresponding interview.

Each transcript was read by the researcher and supervisor. Consensus validity was verified by discussing the analysis within the team. Reflexive validity was revealed by assessing the extent to which conceptual categories developed and changed during the analysis. Validity of the final interpretations were assessed by referring to the literature to examine theoretical coherence with previous literature. The extent of this coherence and any inconsistencies will be reported. Catalytic validity also guided the analyses. This means that priority was given to aspects of the analysis that offered theoretical and practical progress (Baines, 2016).

Framework analysis was used, a highly systematic method of categorising and organising large qualitative data sets. It enables data to be compared with ease across participants as well as within individual participants (Gale et al., 2013). The researcher became familiar with the interview transcripts by re-reading them. The transcripts were also read at least once by

another member of the research team. Any analytical notes of thoughts and impressions were jotted down on the margin of the transcripts.

 After familiarisation the researcher applied codes to the interviews they had read in order to describe what they have interpreted in the interviews as important. An 'open-coding' approach took place; thus, anything relevant to how the participants responded to their symptoms from as many different perspectives as possible was coded. Codes referred to substantive things (e.g. as particular behaviours or incidents), the participants' beliefs emotions, as well as methodological/ impressionistic elements (e.g. how the participant was feeling during the interview). The aim of coding was to classify the data so that it could be compared systematically with other parts of the data set. Coding also alerted the researcher to consider aspects that may ordinarily be invisible because it does not 'fit' with the rest of the account. The researcher independently coded the first few transcripts. Regular meetings with the whole research team took place to discuss the codes so that alternative viewpoints could be offered ensuring that one particular perspective did not dominate. As the study was inductive, meaning we had no preconceptions of what we would find it was important to look out for the unexpected rather than just coding in a literal, descriptive way.

After the first few transcripts were coded the research team met to agree on a set of codes to apply to all the following transcripts. Codes were grouped in to categories to form a working analytical framework. Different versions of the analytical framework were formed before no additional codes emerged. The analytic framework could not be finalised until the last transcript was coded. The working analytical framework was applied by indexing following transcripts using the existing categories and codes. The codes were then abbreviated and written on to the transcripts.

A Microsoft Excel spreadsheet was used to create a matrix and the data was 'charted' into the matrix. Charting consisted of summarising the data by category from each transcript. The aim of charting was to reduce the data while preserving the original meaning and feel of the participant's words.

The data was then able to be interpreted. Characteristics of and differences between how the participants responded to symptoms were identified from the data to form theoretical concepts. The findings generated through this process went beyond description of particular cases to explanation of reasons for specific responses to symptoms.

5.3 Results

5.3.1 Participants

A total of 148 letters were sent to potential participants. Out of this number 27 people responded saying that they were willing to participate. Two of those people were unavailable to contact in order to arrange an interview, while one of those people did not match the inclusion criteria and were removed from the sample. Thus, number of participants included in the study was 24. Table 5.1 displays the length of time it took each patient to see a HCP after noticing symptoms compared to the length of time their matched participants said they would see a HCP after noticing symptoms.

Table 5.1: Length of patient delay and length of delay projected by the matched volunteers

Matched pair number	Length of Patient Delay	Length of delay projected by volunteers
1	1 day	1 week
5	17 weeks	4 weeks
6	16 weeks	2 days
9	2.5 weeks	<1 day
14	4 weeks	2 days
19	12 weeks	<1 day
21	4 weeks	2 weeks
22	2 days	1 day
23	6-8 weeks	<1 day
24	6-10 weeks	3 days
25	12 weeks	3 weeks
26	1 week	<1 day
27	1 week	2-3 days
28	1 day	1-2 weeks
29	4 weeks	1 week
30	1 week	<1 day
31	4 weeks	1 week
32	1 week	1 day
36	4-6 weeks	4 weeks
37	8 weeks	1 week
38	8-10 weeks	3 days
39	3 weeks	1 day
40	4 weeks	3-5 days
42	12 weeks	1 week

Table 5.2 Risk and demographic information of the volunteer sample

Participant match No	Age	Gender	Relationship Status	Highest Education Level	Most Recent Occupation	Employment Status	Dependency	Ethnicity	No of alcohol units per week	Smoking Status	No of cigarettes per day	No of years smoked for
1	49	Male	Single	GCSE's	Gardener	Unemployed	N/A	Caucasian	22+	Current Smoker	50	38
5	41	Male	Cohabiting	Undergrad Degree	Car Sales Manager	Employed	N/A	Caucasian	27	Current Smoker	20	21
6	41	Male	Cohabiting	GCSE's	Furniture Installer	Employed	Living with Dependent Children	Caucasian	12	Former Smoker	25	17
9	56	Female	Single	No Qualifications	Cleaner	Unemployed	Living with a Carer	Caucasian	0	Current Smoker	15	42
14	77	Male	Divorced/ Separated	A Levels	Unknown	Unemployed	N/A	Caucasian	20	Former Smoker	20	22
19	61	Male	Single	Postgrad Degree	Humanist Celebrant	Employed	N/A	Caucasian	23	Never Smoked	N/A	0
21	76	Female	Widowed	No Qualifications	Librarian	Unemployed	N/A	Caucasian	15	Current Smoker	8	60
22	56	Female	Married	GCSE's	Catering Assistant	Unemployed	N/A	Caucasian	0	Never Smoked	N/A	0
23	45	Female	Widowed	Diploma	Cleaner	Employed	Living with Dependent Children	Caucasian	15	Former Smoker	5	4
24	57	Male	Married	Postgrad Degree	Medical Researcher	Employed	N/A	Black	0	Never Smoked	15	15
25	70	Female	Widowed	GCSE's	Sales	Unemployed	N/A	Caucasian	2	Former Smoker	20	15
26	58	Female	Married	No Qualifications	Local government Officer	Employed	N/A	Caucasian	0	Current Smoker	15-20	44
27	61	Male	Married	A Levels	Electronics Engineer	Employed	Living with Dependent Adult	Caucasian	22	Former Smoker	40	15
28	70	Female	Married	Diploma	Child Protection Facilitator	Unemployed	N/A	Caucasian	27	Former Smoker	20	20
29	73	Female	Married	Diploma	Health Visitor	Unemployed	N/A	Caucasian	9	Current Smoker	10	50
30	45	Male	Married	Diploma	Graphics Designer	Employed	Living with Dependent Children	Caucasian	9	Former Smoker	10	11
31	66	Male	Married	GCSE's	Sales Director	Employed	N/A	Caucasian	27	Former Smoker	40	21
32	83	Female	Widowed	No Qualifications	Unknown	Unemployed	N/A	Caucasian	4	Never Smoked	N/A	0
36	72	Female	Widowed	No Qualifications	Catering Assistant	Unemployed	N/A	Caucasian	16	Current Smoker	10	42
37	60	Female	Widowed	GCSE's	Auxiliary	Unemployed	N/A	Caucasian	0	Never Smoked	N/A	0
38	41	Female	Single	Postgrad Degree	Performance Analyst	Employed	N/A	Caucasian	9	Former Smoker	5	5
39	76	Female	Widowed	Diploma	Writer	Employed	Living with Carer	Caucasian	0	Never Smoked	N/A	0
40	65	Male	Married	A Levels	Church Musician	Employed	N/A	Caucasian	2	Never Smoked	N/A	0
42	76	Male	Married	Diploma	Finance Director	Unemployed	N/A	Caucasian	28	Former Smoker	15	11

5.3.2 Overview

During the analysis, it became apparent that volunteers responded quite differently to the scenarios than the matched patients recalled doing. The heterogeneity of patient accounts where they could be grouped into 3 different responses (misattribution, 'sort it' and 'don't want to think about it') contrasts with the homogeneity of the volunteer accounts, who strongly and almost unanimously said that they would 'sort it'. Although volunteers considered minor conditions as explanations of symptoms, they sought out HCPs as a safety precaution in case they were wrong, or to stop the symptoms from becoming worse. Volunteers were often critical of patients for waiting as long as they did even when patients delayed for only short amounts of time. Most volunteers said they would see HCPs earlier than their matched patients did. Table 5.3 displays the response categories as well as the sub-categories within those categories.

Table 5.3: Volunteers responses arranged in to categories and sub categories

Categories	Sub-categories
1. 'Sort it'	(i) 'Time is of the essence'
	(ii) Perception of vulnerability to illness
	(iii) Persistent in challenging HCP's diagnosis
	(iv) Need to resolve uncertainty
2. Attribution of symptoms	(i) Volunteers concerned by misdiagnosis's
	(ii) Volunteers suspected cancer more often than patients
3. Volunteers critical of patients	(i) Volunteers critical of patients

5.3.2.1 'Sort it'

Unlike patients, many of whom reported misattribution or avoidance of thinking about symptoms, all volunteers except two indicated that they would see HCPs quickly. For them, the key driver of this was to reduce uncertainty about symptom origin. Generally, volunteers gave responses that were similar to 'sort it' patients of the previous chapter.

The volunteers often stated that they would impose a pre-defined waiting time, usually of a few days. If symptoms persisted would then seek consultation; *'Volunteer: I'd be off to see the medic. Interviewer: How long would you wait before seeing a medic? Volunteer: A couple of days. Interviewer: why do you think you'd see a medic? Patient: If I got something and I didn't know what it is I would'* (Volunteer 14)

Volunteers 22 and 23 highlighted the importance of seeing a HCP promptly. For example, volunteer 22 said, *'Well cause if it is cancer it's better to get help as soon as you can to stop it spreading, and why wait because the symptom might only get worse'* (Volunteer 22)

Additionally, Volunteer 23 said; ' *'it needs someone to look at it professionally cause you can't diagnose it, and the longer you leave it, time is of the essence with stuff like that'* (Volunteer 23).

In contrast patient 23 was reluctant to seek help; '*Probably a couple of weeks after, probably all in January. I probably let it roll on about three weeks before I went to the doctor… cause I had this problem already there's no way I would have gone to my doctors with a mouth ulcer, no way. No way I would have made the appointment cause I was actually not gonna even mention it to him cause I thought I don't wanna be bothering the doctor with a mouth ulcer, but I was sat in the surgery for another reason and that's the only reason I mentioned it to him. To this day I wouldn't have gone the doctors with a mouth ulcer*'

Similar to 'sort it' patients, volunteers showed an awareness that they could be vulnerable to illness and that early presentation may lead to illness mitigation. Volunteer 39 spoke about a friend of hers who died from oral cancer, and mentioned that other people would not have to go through the same experiences as her friend if they sought help and received treatment early; '*Well with my friend she lived nearly two years but it wasn't a very happy time, but it*

should be possible if you don't leave it until it's, I mean you can look up on the internet, you

see examples of people who have left it and it's all over their mouth, well y'know it's too late'

Further, most patients tended to accept the HCP's misdiagnoses, while the volunteers often said they would not accept the HCP's diagnosis. The volunteers also would be more persistent in challenging the diagnosis than the patients. Patient 29 believed her dentist when she was diagnosed with oral thrush *'I just thought maybe that's what it is oral thrush'* (Patient 29). However, her matched volunteer would ask for a second opinion; *'I'm thinking that's not a very wise thing to advise, um because thrush is obvious isn't it? Little white patches. No I wouldn't, I wouldn't have treatment for the thrush. I would go to my doctor'* (Volunteer 29)

Some patients indicated that they avoided thinking about symptoms. However, in all but one case their matched volunteers said they would seek HCP's opinions. Patient 38 spoke of her unwillingness to think about symptoms for fear that they may be cancer; *' 'it's [cancer] 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 [cancer] surely. It might have been niggling in my mind but I had the hope that it wasn't anyway''* (Participant 38). In contrast, faced with an account of those symptoms, Volunteer 38 spoke of her wishes to visit a HCP to resolve uncertainty about the symptom *'If it had been there for maybe three days I'd probably see someone about it. That's sort of based on having had mouth ulcers before and occasional mouth ulcers I'd think they'd go away after a day or two but any longer after that I'd probably be concerned'* (Volunteer 38)

As with the 'sort it' patients of the previous chapter, volunteers often said this was because they were more vulnerable to illness because of their age or their lifestyle factors such as smoking and drinking; *'I really would be worried and I'd try to see as many people as I could*

to discover what the issue was, especially with the history of smoking and having smoked before. You're probably more tuned in to the fact that things could go wrong like that' (Volunteer 6)

In contrast, patient 6 experienced greater fear, and felt constrained by fears that symptoms were indicative of serious illness *'you get an upset feeling in your stomach you know that something's not right but you're too scared to go anywhere about it'* (Patient 6)

5.3.2.2 Attribution of symptoms

Many patients misattributed symptoms to minor causes. In contrast, their matched volunteers considered the possibility that symptoms could be minor conditions, they believed that they would act to resolve uncertainties by seeking the help of HCPs. Although some patients misattributed their symptoms to other less minor conditions, as did their matched volunteers most of them said they would seek help sooner than the patients to resolve the problem and prevent the conditions from getting worse. Patient 24 stated; *'I started getting a bit of swelling on the left side of my face, And then typical fella, it's just a bit of tooth ache, an abscess. It will sort itself out'* (Patient 24). However, Volunteer 24 also considered a dental issue, but felt it wise to present to a HCP; *'Well generally I would refer that to probably my teeth, something happening going on and from experience I know that if you have tooth problem you'd rather just go and get it sorted because it wouldn't really just take care of itself'* (Volunteer 24)

Patient 42 was confident that symptoms were minor. *'You see going back a few years ago I had pre-cancer cells on my head and that was dealt with so I wasn't too bothered. I had an issue with a skin problem that was looked at all the time and that was found to be nothing So*

when this happened I didn't, I didn't think it was as serious as it turned out to be' (Patient 42). However, Volunteer 42 also interpreted the symptoms in line with previous experience but drew a different lesson - that it is important to seek help promptly, and that leaving symptoms can be harmful. *'Because I've had too many things going wrong with me to be perfectly honest, erm you know er I've had tests for bowel cancer. I've had the er skin problem and I've thought to get the problems resolved, find out the root cause and get them resolved, em and I think it is dangerous to leave things too long'* (Volunteer 42)

Several volunteers' accepted patients' interpretations of minor conditions, but they still felt that they would see a HCP because they would want help with managing that condition. Patient 40 attributed symptoms to an infection; *I had plenty of work on so I carried on as normal working and doing other things. We'd gone away down to my sons in the March, did some work for him, never really given it much thought, er of what was happening. It was probably just a throat infection, y'know or an ear infection* (Patient40). However, Volunteer 40 felt that an infection was sufficiently serious to consult a HCP. *'I'd be concerned about my hearing cause I'm a musician and of course I'd otherwise be concerned about the throat because I sing as well, but general health wise I'd be worried'* and '*I'd get myself to the hospital quick cause your ear affects your balance doesn't it?* (Volunteer40)

Additionally, other patients did not attribute their symptoms to cancer while their matched volunteers considered cancer as a possibility. Patient 19 and the matched volunteer had different views on the absence of pain from a symptom. Patient 19 thought that the absence of pain meant that the symptom was not harmful, *' 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'* (Patient 19)

Conversely volunteer 19 stated, *'Well it's not gonna be benign whatever it is. The issues could be anything from some sort of cyst up to er potential onset of mouth cancer, and the lack of pain doesn't really mean, doesn't give an indication of the fact that it's not potentially malignant or dangerous'* (Volunteer19)

Volunteer 19 was more concerned about the visual symptoms, *'the fact that it's flattened out doesn't mean it's getting better by any stretch of the imagination. In fact it's potentially more dangerous if it's changing shape'* (Volunteer 19)

Volunteer 25 explained that cancer is not always visibly obvious and can appear as a minor symptom. She said she would suspect cancer if a symptom persisted; *'Cancer itself tends to be a hidden thing. It hides behind a normal surface, presents itself as a simple sore but the cancer is way underneath that, erm it I think er that the time that it's taken to heal is not normal, even if she's been diabetic em some improvement would have been made however slight. I erm, I did think cancer at first because of that'* (Volunteer 25)

5.3.2.3 Critical of Patients

Although the volunteers were not told that the symptoms were cancer until the end of the interview, they expressed surprise and strongly criticised the patients for leaving their symptoms as long as they did. The following quotes emphasise that the ways in which the patients interpreted their symptoms and behaved did not seem logical to them, as well as show the volunteers passion for getting symptoms dealt with promptly, *'I think Mike's an idiot [laughs] I'm sorry but [laughs] four weeks? That's crazy* (Volunteer 31)

'Well I think she is very silly if she hasn't already gone, you know to have waited two to three days. She should go and see somebody who knows. It's all very well asking your friends but

unless they actually are doctors or dentists how do you know you're getting the right advice? And people so often say well don't fuss, don't worry, but she should '(Volunteer 39)

Volunteer 38 believed that her matched patient should have seen a HCP earlier as her symptoms were interfering with daily activities; '*I think Susan's a bit mad [laughs], em yea I think Susan should have gone and got it sorted out. I think that's concerning that she'd leave it for a month. If something's, if something's disrupting your day to day life to the extent that you can't talk properly and you can't eat, yea I'd be worried that Susan really needs to go and get that sorted out'* (Volunteer 38)

5.4 Discussion

The findings reveal that while there was variation in the patient's responses, 'sort it', misattribution and 'don't want to think about it' the majority of the volunteers showed 'sort it' responses. The 'sort it' volunteers applied inductive If THEN rules, similar to the 'sort it' patients, e.g. IF symptoms are unusual THEN seek consultation. Many of them developed clear time specific intentions to present, such allowing a short pre-defined time period to elapse before making a HCP appointment. Some volunteers would make appointments within twenty-four hours. The 'sort it' volunteers also expressed awareness that they are vulnerable to illnesses due to their age and lifestyle factors, and that prompt consultation is more likely to lead to illness migration. However, matched patients frequently did not connect those factors with their symptoms or state the importance of prompt consultation.

Some of the patients openly stated that they avoided thinking that their symptoms could be cancer as they found thoughts about cancer distressing, others spoke about intentionally misattributing symptoms to minor conditions to avoid the implication that symptoms could

be cancer. Although two volunteers did envisage that they might wish to deny or avoid the implication that symptoms may be cancer, the majority of volunteers who were matched to those patients did not envisage that they would suppress thoughts about cancer. Instead, they felt that they would see a HCP as soon as possible. This disconnect between what volunteers said that they would do and what matched patients actually did can be resolved if it is concluded that avoiding thinking about symptoms is an unplanned and non-volitional response. This is consistent with some literature that shows that avoidance of distressing stimuli is triggered unconsciously and is under limited volitional control (Arlow, 2000).

The volunteers were frequently uncertain about the origins of symptoms. However, unlike several matched patients who attributed symptoms to minor causes, they said they would consult a HCP to seek clarification of the causes of their symptoms. They were also frequently critical of patients for the misattributions that they made. Whilst, some volunteers misattributed the symptoms to less minor conditions such as infections, allergic reactions or dental issues, they still stated the importance of consulting HCPs to be sure that their attributions were correct.

5.4.1 An explanation of the findings

The homogeneity of the volunteers' responses was not what the researcher expected. This was because Lyubomersky et al's (2006) study involving both non-patient scenarios and retrospective methods showed broadly similar patterns between these methods. Moreover, the current study took the approach used by Lyubomersky et al. (2006) one step further by matching patients to non-patients based on risk factors of OSCC. Therefore, the researcher thought that the patients would respond similarly to their matched volunteers, meaning the

response categories 'sort it', misattribution and 'don't want to think about it' were expected to arise from the volunteers' data as well as the patients.

Through these differences, this study highlights the differences in how people respond when they are asked to imagine having symptoms as opposed to actually experiencing them. Although almost all the volunteers anticipated they would 'sort it' this response seems to be difficult to implement in reality when faced with real symptoms. Only half of the patients actually did 'sort it'. It could be that 'sort it' constitutes an ideal or socially desirable response to symptoms, one that people would like to employ in principle, but is either less desirable or more difficult when confronted by real symptoms. In reality people may experience either a high degree of distress which they try to manage by avoiding thinking about symptoms, or genuine uncertainty over whether their symptoms are worth disrupting their activities by consulting HCP's.

Many of the patients persisted with perceptions that their symptoms were harmless. However, it was not clear from the previous chapter why those patients put faith in their misattributions and did not seek consult as a safety option. The researcher suggests that misattribution of symptoms could be a cover for fear of cancer, and that fear leads to patient delay. This idea is supported by the responses from volunteers as the majority claimed they would consult HCP's promptly and 'sort it' whether or not they attributed the symptoms to cancer. As the volunteers did not have real symptoms they did not experience the same emotional responses towards them as the patients.

5.4.2 Limitations of the study

A limitation to the scenario approach is that volunteers responded to patients' descriptions of the symptoms, which may differ from the symptoms themselves due to biases of retrospective recall. Thus, patients' descriptions did not necessarily include the features of those symptoms that drove their responses. This could explain some divergences between the two samples. Another possible explanation of divergence is differential recruitment rates. Most patients agreed to participate, but higher non-participation rates were observed for the volunteer group. This may have led to greater representation amongst volunteers more interested in participating in research on health issues.

5.4.3 Conclusion

The findings reveal some of the limitations of employing hypothetical scenarios with healthy people. The scenario method overstated the likelihood of a 'sort it' response and understated avoidance and symptom misattributions. The inconsistencies between the retrospective and scenario data has led the researcher to believe that using a hypothetical scenario method is not a beneficial way of supplementing data from a retrospective method as it does not provide support for the reliability of each method. However, the volunteer sample was useful to this study, because it helped to identify how real symptoms, and the psychological states that they induce, change initial 'sort it' approaches to avoidance of symptoms and symptom misattribution in some patients.

Chapter 6: General Discussion & Conclusions

6.1 Thesis aims and focus

The aim of this thesis was to gain an understanding of the reasons for patient presentation delay in OSCC. Previous research into patient presentation delay in OSCC has proposed that patients fail to recognise that symptoms represent a potentially serious disease, often because alternative interpretations favouring minor conditions seem to be convincing (e.g. Scott Grunfeld, Main, & McGurk, 2006; Scott et al., 2007; Scott et al., 2008; Scott et al., 2009). However, it is unclear why those patients put faith in their misattributions and do not seek medical attention as a safe option. Research into patient delay in other areas of cancer has suggested that patient delay may have additional causes. These include, feelings of embarrassment and shame towards symptoms and specific fears of cancer, treatment, health professionals and examination (Smith, et al., 2005; Fish, et al., 2015).

6.2 Summary of the results

Chapter 3 presents one of the first detailed timelines of the events that took place between OSCC patients' first noticing symptoms and referral to a specialist. The analysis revealed that the median time of patient delay was 3-4 weeks. The patients often made multiple appraisals of symptoms before presentation. Those who sought help after a single appraisal showed the shortest delays while those who sought help after making two reappraisals showed the longest delays. Patients who consulted because they were forced to do so by other people revealed greater delay than patients who made a decision to seek help. A new finding was that 17 patients were not referred on their first visit to a HCP, and that some required multiple

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visits before referral to a consultant. In particular, patients took a considerable period of time to revisit a HCP between second and third visits.

For chapter 4 the same sample as the previous chapter was used to gain an understanding of appraisal and decision-making processes that lead to presentation delay of potential oral cancer symptoms. Three categories of response to oral symptoms were identified from chapter 4, 'It's only minor', 'get it sorted' and 'don't want to think about it'

'It's only minor' represented patients who reported that they didn't think their symptoms were serious upon noticing them, thus they didn't view it as necessary to seek help promptly from a HCP. It was the persistence or worsening of symptoms that drove patients in this category to seek help. 'Sort it' patients consulted HCP's promptly regarding their symptoms. Patients in this category were driven to seek help by the unusualness of symptoms. Although some considered cancer as a possible cause none attributed their symptoms to one specific cause. 'Don't want to think about it' represented patients who wanted to avoid thinking about the possibility of serious illness to reduce emotional distress. They reported some of the longest delays. Some patients in this category revealed that they misattributed symptoms to minor conditions to avoid the inference that symptoms may be cancer.

The existence of the 'don't want to think about it' response provided the first evidence that people cope in a defensive way to reduce distress associated with symptom detection. The 'get it sorted' response was unexpected, and shows that patients do not necessarily apply deductive approaches to symptom appearance, but they seek help simply because the symptom seems unusual.

Using a unique methodology, for chapter 5 the responses from the patient sample in chapter 4 were compared to a sample of healthy volunteers without OSCC who were matched to the patients based on specific characteristics. The volunteers were given a hypothetical scenario

based on their matched participant's symptoms and asked to indicate how they would respond.

The majority of the volunteers said they would consult quickly. Generally, volunteers gave responses that were similar to 'sort it' patients of the previous chapter. They showed awareness that they could be vulnerable to illness and that early presentation may lead to illness mitigation. While most of the patients as a whole accepted the HCP's misdiagnosis the volunteers often expressed that they would be more persistent in challenging the diagnosis than the patients. Another key finding was that some patients misattributed their symptoms to other less minor conditions, as did their matched volunteers. However, most of them said they would seek help sooner than the patients to resolve the problem and prevent the conditions from getting worse. Additionally, the volunteers strongly criticised the patients for leaving their symptoms as long as they did.

6.3 Explanation of differences between patients and healthy volunteers

As previous studies have shown broadly similar patterns in both retrospective and scenario methods (Brain et al., 2014; Lybubomersky et al., 2006) differences between the patients and the matched volunteers responses in chapter 5 was unexpected. Questions must be raised as to why the majority of the volunteers responded in similar ways to the 'sort it' patients, and did not indicate that they would be inclined to delay seeking help for symptoms due to avoiding thoughts about cancer or misattributing symptoms.

The researcher suggests that only by experiencing symptoms in reality negative emotions such as fear and anxiety are induced. It may be the emotion that drives avoidance and deliberate misattribution of symptoms. This would be consistent with coping theory.

Additionally, patients facing hypothetical symptoms did not need to think about the practical costs or barriers to presentation. Real symptoms are liable to have caused people to weigh up whether they think their symptoms are serious enough to disrupt their daily activities such as holidays, work or family commitments. Only one volunteer considered disruption of daily activities as a barrier to help-seeking. The researcher suggests that these two reasons help to explain why volunteers hypothetically behaved differently to patients. If confronted with real symptoms, it is speculated that the volunteers might have behaved in similar ways to the patients.

6.4 Limitations of the research

Both the retrospective method applied in chapters 3 and 4, and the scenario method in chapter 5 had limitations. The main limitation of using retrospective methods is that they are liable to recall errors. As explained, studies using this method in wider health research have shown to be flawed and weak in their recall of intensity and duration of symptoms (Van den Brink et al., 2001) as well as the frequency of symptoms (Anderson & Mikkelsen, 2008; Voldsgaard et al., 2006), and responses to symptoms (Anderson & Mikkelsen, 2008). In particular, recall of decision making processes can be distorted to subsequent events (Ash, 2009).

All studies that rely on retrospective methods are liable to recall errors. Attempts were made to reduce issues that can lead to recall errors. First of all, only newly diagnosed patients were interviewed before surgical treatment. This was to reduce the time between events taking place and events being recalled. Secondly, techniques derived from the Cognitive Interview Protocol were applied. Studies have shown that these techniques enhance the amount of information recalled whilst sustaining reliability (Paulo et al., 2013).

The main limitation of the scenario approach described in chapter 5 is that as this research demonstrated, responses to symptom scenarios can differ from *in vivo* responses. Although the patients were questioned thoroughly to gain clear descriptions of their symptoms, the volunteers may have struggled to imagine exactly what the symptoms would feel and look like, especially if they haven't experienced similar symptoms. Additionally, the patients' descriptions of the symptoms may have differed from the symptoms themselves due to biases of retrospective recall. This means the volunteers may not have been presented with the attributes of the symptoms that drove the patients' responses.

6.5 An examination of the results in relation to existing theory

The chapter 4 findings that the 'don't want to think about it' response leads to longer delays while 'sort it' leads to shorter delays relates to coping theory. Coping is concerned with efforts to manage adaptional demands and the emotions they generate (Lazarus, 2006). A longstanding distinction is made between problem-focussed coping, where the primary objective is to deal with the demand itself, and emotion-focussed coping, where the objective is to manage emotional states such as fear or despair. The coping methods used are determined by two appraisals; whether a demand endangers personal values or priorities, and, if so, an appraisal of how best to address the demand.

 'Don't want to think about it' patients were fearful of cancer. They engaged in emotion focused coping, whereby the primary goal was to reduce negative emotions such as anxiety or distress caused by thoughts that the symptom might be cancer or other severe illness. By avoiding thinking about the symptom or deliberately misattributing it to a minor cause they then delayed presentation. Research suggests people who engage in emotion-focused coping may not seek medical attention as this provides confirmation that the illness is real, leading to

an increase in distress (Stretch, 2002). Conversely, 'sort it' people took a problem-focused approach to their symptoms. They took constructive action to address the symptom, which meant they presented their symptoms to HCP's promptly. Research suggests that problem focused coping tends to prevail when people feel that something constructive can be done, while emotion focused coping tends to prevail when people feel that the stressor is something that will persist (Folkman & Lazarus, 1980). This is supported by the findings that 'sort it' people were aware that seeking help early would lead to their symptoms being treated more successfully. Previous studies provide support for a defensive coping view, revealing longer presentation delays in cancer patients with a disposition towards emotion focused coping styles (Pederson et al., 2013; Ruiter et al., 2008; Tromp et al., 2004).

Lazarus's (1999) transactional theory model is an appropriate model to understand findings because it focussed on interlinked concepts of appraisal, emotion and coping. When faced with a stressor such as a symptom a person appraises the situation. Appraisals are divided in to primary and secondary components. Primary appraisals involve making judgements about the significance of the stressor. Secondary appraisals concern the ability to cope with the situation and manage negative emotional reactions. How a person appraises the stressor determines the adoption of a stress related core theme. This refers to the meaning he or she applies to the situation at the time. The stress related core theme becomes paired with an emotional response which moderates the adoption of different coping strategies (Smith, Haynes, Lazarus & Pope 1993; Lazarus, 2006).

Lazarus' views of fear and challenge are important. Fear is associated with the core relational theme of threat derived from appraisals that one is unable to respond to emotionally important demands (Bennett & Lowe, 2008). In contrast, a sense of challenge is produced when people believe that they can respond to these demands (Lazarus, 1999; Hulbert-Williams et al., 2013). The researcher suggests that a 'sort it; approach comprising realistic

and strong beliefs that early medical intervention can improve cancer outcomes reduces both fear and emotion-focussed coping.

Both chapter 4 and 5 showed that patients and volunteers used IF-THEN rules upon detecting symptoms. The 'sort it' patients in chapter 4 applied 'bottom up' appraisals driven by the unusualness of symptoms when detecting symptoms, e.g. IF symptoms are unusual THEN consult. This form of appraisal led to prompt presentation of symptoms. The majority of the volunteers in chapter 5 also applied bottom-up appraisals when asked to imagine the symptoms, leading them to predict that they would present their symptoms quickly.

In contrast the 'it's only minor' patients in chapter 4 took 'top down' appraisals driven by existing understandings of illness. Those patients perceived their symptoms as not serious because the appearances of their symptoms seemed incompatible with their ideas of how serious illnesses such as cancer would manifest or because their symptoms seemed minor in the context of other medical problems. Appraising symptoms this way tended to lead those patients to delay reporting their symptoms for longer than the 'get it sorted patients. 'Don't want to think about it' patients did not appear to form any IF-THEN rules upon noticing symptoms which often led them to prolong their delay in presenting their symptoms to a HCP.

This distinction is potentially practically important. If 'top down' thinking is used, then patients may be more likely to make misattributions. Encouraging patients to use 'bottom up' thinking, whereby presentation becomes activated through symptom unusualness may reduce misattribution.

6.6 Recommendations for future research

This research presents novel and interesting findings regarding patient presentation delay in cancer. First, the 'don't want to think about it' response shows that fears about cancer contribute to delay in OSCC, which challenges previous research that suggests that patient delay in OSCC is caused because people fail to recognise that symptoms represent a potentially serious disease and not because people are fearful of symptoms. Second, this research shows that some people misattribute their symptoms to more minor conditions in order to avoid thinking that their symptoms are cancer, thus misattribution of symptoms can be linked to fear. As far as the researcher is aware this finding has not been found in patient delay research in OSCC as well as other areas of cancer.

Third, the 'sort it' response comprises the thought processes that lead some people to present their symptoms early. Much of the research on patient presentation delay in OSCC has focused on why people show long delays in reporting symptoms but does not compare those responses to the reasons why others reported their symptoms early. Scott et al. (2009), for example found that some patients reported symptoms early to resolve uncertainty. However, Scott et al. (2009) did not examine the underlying beliefs for this, whereas this study found that these patients expected that early intervention might mitigate illness.

Finally, the research shows how people respond when they consult a HCP who does not refer them to a specialist for their symptoms. The researcher suggests people with a 'sort it' approach are more persistent in challenging the HCPs decision not to refer them. Previous research indicates that the patient delay process ends when patients consult a HCP. However, the current research shows that for many people this is not the case.

As this research is primarily qualitative, the sample sizes are small and therefore the findings discussed are not representative of the wider population. This piece of research should be

regarded as one that develops hypothesis regarding patient delay in OSCC. Further research that uses quantitative design should be used to find support for these findings.

The transactional model could be applied to test the relationship whether emotional focused coping driven by negative thoughts about cancer is associated with longer patient delays in OSCC, and whether problem focused coping driven by positive thoughts about overcoming cancer is associated with shorter patient delays in OSCC. This will also enable the proportion of 'sort it' and 'don't want to think about it' to be identified. Lazarus' distinction between threat and challenge becomes important here. This view would predict that people whose core relational theme is threat would be more likely to delay consultation. This theme, in turn, is more likely to be pertinent amongst people who do not feel that they can reduce the threat (e.g., by consulting a HCP) and those who experience high levels of pre-symptomatic fear. Conversely, people whose core relational theme is challenge are less likely to delay. They would be characterised by beliefs that consultation is likely to reduce the impact of illness and lower pre-symptomatic fear of cancer.

6.7 Recommendations for future practice

Earlier in the thesis (Chapter 1 section 3), it was argued that mass-reach interventions are needed to reduce presentation delay in cancer. Mass reach campaigns require simple and short, but powerful, messages. This research has provided some indications of the form of these messages.

It follows that health promotion messages should provoke minimal distress, and offer patients realistic hope that OSCC is treatable. A large body of health promotion research shows that messages presented in distressing ways can induce defensive coping (Van 't Riet & Ruiter,

2013). Thus, reducing presentation delay should involve messages that promote awareness of vulnerability, but do not do so in ways that are distressing. This will require sensitivity from campaign developers, because it can be difficult to predict how campaign messages will affect specific audiences. The health promotion literature also shows that recommending explicit, effective and easily-implemented actions to mitigate the threat of illness reduces defensive coping (Peters, Ruiter, & Kok, 2013). Thus, messages should inform audiences that prompt presentation increases the likelihood that medical intervention will be both successful and less invasive. A third potential solution arises from our finding that the families and friends of patients placed pressure on fearful patients to consult HCPs. Messages can be targeted, not only toward the individuals with symptoms, but toward families and friends to encourage people they know with oral symptoms to seek consultation.

Other patients appeared to genuinely misattribute symptoms to minor causes. With the exception of two patients who had long delays because they attributed symptoms to dental conditions and feared dental treatment, symptom misattribution only led to moderate delays of 3-4 weeks. However, rapid growth of some OSCCs means that even these delays could be clinically significant (Hyde & Hopper, 1999). Comparison with 'sort it' responses provides insights into how symptom misattribution can be reduced. 'Sort it' patients' decisions to present to HCPs were driven by the unusualness of symptoms. In SRM terms, these patients pursued clear inductive IF-THEN rules; IF symptoms are unusual THEN seek HCP consultation. This 'bottom-up' approach contrasts with the 'top-down' approaches underpinning misattribution - these patients perceived their symptoms as not serious because the appearances of symptoms seemed incompatible their ideas of how serious illnesses such as cancer would manifest or because their symptoms seemed minor in the context of other medical problems.

The idea that interventions should teach people to recognize OSCC symptoms (Scott et al., 2007) may be misguided. A focus on symptom recognition may unwittingly stimulate further 'top-down' processing and, thus, induce the misattributions that that symptom recognition approaches seek to avoid. Instead, media messages could aim to facilitate inductive symptom appraisal processes of 'sort it' patients, by promoting IF-THEN rules that are activated by symptoms that are unusual and persist for more than several days. People could then be encouraged to make time-specific intentions to seek consultation. 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.

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Appendix A

Patient Study Information Sheet

Sponsored by The Aintree Head and Neck Patient Research Forum

Participant Information Sheet (Patient)

AWARE - Understanding Patient Presentation in Oral Cancer

You are being invited to take part in a research study. Before you decide to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
This research is about why some people delay reporting possible oral cancer symptoms. We wish to develop ways of encouraging people with symptoms to report them to a doctor or a dentist as soon as possible. Understanding how you reacted to your symptoms can help us to do this.

Who is doing the study and who has approved it?

The study is being carried out by Juliet Bell, a student who is studying for her doctorate at Liverpool University. She works The University of Liverpool, Institute of Psychology Health and Society, and is supervised by Mr Richard Shaw and Mr. Simon Rogers (Consultant Maxillofacial Surgeons), Dr Stephen Brown (Health Psychologist) and Professor Peter Salmon (Clinical Psychologist). It has been approved by the Local Ethics Committee.

Why have I been chosen?

You have been chosen as you have been referred to the service with suspected oral cancer.

Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you choose to take part you will be given this Patient Information Sheet and a signed Consent Form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the care you receive.

What will taking part involve?

If you agree to take part, the researcher, Juliet will interview you once. She will talk with you for up to around 45 minutes. The exact length of time will depend on how much you wish to say. She would talk with you at Aintree hospital but could meet you in your home if you prefer. It is also possible to conduct the interview on the telephone if this is more convenient.

The interview will be electronically audio-recorded. Juliet will ask for your permission to keep the recording of the interview and to use it in the research. The audio-recording will be typed up by Juliet. All information which identifies you or anyone else will be removed. No personal information (such as names, addresses, doctors' names etc) will be included in the research. Once the interview has been typed up, the audio-recording will be destroyed.

What are the possible disadvantages of taking part?

The interviews will take time but you do not have to spend longer talking to the researcher than you want to. Interviews might involve talking about things that are upsetting to you. However, you do not have to talk about anything you do not want to. If you or the researcher thinks that you need support with any of the problems that you talk about, the researcher would help you access the care that you need.

Will there be benefits of taking part?

There are no specific benefits from taking part. However, many patients value the opportunity to talk about their experiences with someone who is not involved in caring for them. By taking part in the research you will help us to further improve care and support for patients in future.

Why do you want to know my age, gender and diagnostic information when I don't want to participate?

One of the problems with research is that we know nothing about people who so not want to participate, and we are worried that they may be dissimilar to people who do participate. If we know some basic information about you, we can deal better with this problem. You do not have to provide this information if you do not wish to.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been treated during this study, you can approach the Chief Investigator (Dr Stephen Brown) who is listed below, any member of the treatment team, or contact the customer relations team at the Aintree Hospital

Will my taking part in this study be kept confidential?

We are interested in how a healthy person would interpret your symptoms. Thus, we would like to present a verbal description of your symptoms, as you have described them, to another participant who is selected because they are a similar age, gender and use alcohol and tobacco in a similar way to you. We will not reveal any identifying or personal information or describe any aspect of your diagnosis or treatment.

We will not tell anyone else what you have said and we will not tell you anything that anyone else in the study has told us – including your relative or friend. All information collected for this study will be kept safely and securely on password-protected computer files and on locked-up paper records. Dr Brown, the Chief Investigator, will be the custodian of all study data. All information about you will be kept secure and confidential. Direct quotes from your interview may be used in study reports but any information which identifies you (for example, your name and occupation, names of family, friends, doctors or hospitals, addresses and dates) will be removed from the typed transcripts of the interview. Your name will not appear with any of the information you give us – you will be identified by a code number.

Of course, if you told us something that made us worry that you are at risk of harming yourself or someone else, we would have to tell someone, such as your consultant or GP.

What will happen when the study ends?

With your permission, transcripts of audio recordings of interviews will be electronically stored on a University of Liverpool password-protected computer for 15

years in a central file store. Access to these transcripts by researchers not involved in the current study will be subject to further ethical review.

After all identifying details have been removed from the transcribed records of interviews these will be analysed by the researcher and her supervisors. The results will be written up by Juliet and submitted to the University of Liverpool as part of her Doctoral qualification. They will also be published in reports and scientific journals, without giving your name or disclosing your identity. If you wish, we will be happy to send you a summary of what we have found at the end of the study.

How can I find out about the study results?

The Liverpool Head and Neck Cancer Service or the Chief Investigator will be able to provide you with written information about study outcomes. We will also put outcome information on the website of the Liverpool Psychology in Cancer Care Research Group (http://www.liv.ac.uk/clinpsy/psychology-in-cancer-care/index.htm).

What do I need to do next?

If you are happy to take part, or are interested in hearing more about the study please sign the enclosed reply slip and return it in the envelope provided and Juliet will telephone you

Who can I contact for further information?

Juliet Bell (PhD student) juliet.bell@liverpool.ac.uk
Dr. Stephen Brown (Chief investigator) 0151 794 5526 or slbrown@liverpool.ac.uk

Thank you for taking the time to read this.
You should keep this information sheet for future reference

Appendix B

Consent Form (Patient Consent to be Approached)

UNIVERSITY OF LIVERPOOL

Aintree University Hospitals **NHS**
NHS Foundation Trust

Where quality matters

Participant Consent to be approached by the research team (Patient)

AWARE - Understanding Patient Presentation in Oral Cancer

Name of Staff Member: _____

Please initial here

1. I understand the explanation that the Clinical Trials Nurse has given regarding my possible participation in the study.	
2. I agree to the treatment team providing my name and telephone number to the research team so that they may contact me by telephone with regard to my possible participation in the study.	
3. I do not wish to participate in the study, but am happy that relevant sections of any of my medical notes may be looked at by responsible individuals from the University or Liverpool. I give permission for these individuals to have access to my records.	

Name of participant	Date	Signature
Name of nurse	Date	Signature

Sponsored by The Aintree Head and Neck Patient Research Forum

Appendix C

Consent Form (Patient Consent to Participate)

Participant Consent Form (Patient)

AWARE - Understanding Patient Presentation in Oral Cancer

Name of researcher: Juliet Bell

Please initial here

4. I confirm that I have read and understand the information sheet dated 27/2/13 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
5. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
6. I understand that audio recordings will be made as part of this study, and that brief quotations from some interviews may be included in study reports without giving my name or disclosing my identity.	
7. I understand that relevant sections of any of my medical notes may be looked at by responsible individuals from the University or Liverpool and any authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
8. I understand that you wish to present my description of symptoms (but not diagnosis or other clinical information) to another person to see how he or she responds to them.	
9. I agree to electronic versions of transcriptions (a written record) of my interviews, with all names removed, being stored at the University of Liverpool 15 years after the end of this study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature

Sponsored by The Aintree Head and Neck Patient Research Forum

Appendix D

Patient and Volunteer Study Questionnaire

Participant Number:

AWARE Study Questionnaire

Please fill in the blank or circle the appropriate option for each of the following questions.

- **What is your age?** _____

- **What is your gender?**   Male   Female

- **How would you classify yourself?**

  Caucasian/ White   Black

  Hispanic   Arab

  Asian   Multiracial

  Other *(Please specify)*   _____

- **What is your postcode?**   _____

- **What is your current marital status?**

  Married   Widowed

  Divorced/ Separated   Cohabiting

  Single   In a relationship but not living together

- **Which of the following describes you?**

  Living with a Dependent Adult   Living with a Carer

  Living with Dependent Children   None of the Above

- **What is your highest level of education?**

  Left school before completing GCSE's   Diploma

  GCSE's   Undergraduate Degree

  A level   Post Graduate Degree

- **Are you currently employed?**   YES/ NO   (Please Circle)

- **What is your current or most recent occupation?**   _____

- **How much alcohol do you drink in a typical week?**
  _____

- **How would you classify yourself?**

  Current Smoker

  Former Smoker

  Never Smoked

- **How many cigarettes do you smoke a day? (If you are a former smoker how many cigarettes did you used to smoke?)** _____

- **What age did you start smoking? (if applicable)** _____

- **What age did you stop smoking? (if applicable)** _____

Appendix E

Patient Study Interview Guide

Interview Guide (patients)
AWARE - Understanding Patient Presentation in Oral Cancer

Interviews will be at a time convenient for the patient. The interview will be conducted at the hospital, at the participant's home or by telephone as the participant prefers. For consistency, and to ensure that the research questions are addressed, a semi-structured approach will be used with participants prompted to address specific topics in each interview.

Closed questions will be avoided as much as possible as these constrain the information gained from the participants. For this reason also, interruptions from the interviewer will be kept to a minimum with interviewer dialogue limited to reflecting, prompting and summarising, with open or closed questions and probing where necessary. To avoid generalised responses, participants will be encouraged to speak about their specific experiences as much as possible.

However, open-ended questions do not always generate full access to memory. Cognitive interviewing techniques will be used when participants report imprecise memory. These involve cueing of memory through immersion of participants in the time and context in which the events occurred. This is done by the use of probe questions such as 'What were you doing when you first noticed the symptom?', 'At what point did you consider that the symptom may be cancer?' or 'When did you first feel afraid?'. Other, more focussed, questions will be used to clarify or test the meaning of what is said (e.g., 'when you said___, did you mean ___?').

The style will be conversational and, except for opening and closing exchanges the sequencing of topics will depend on the participant. Questions and prompts below are resources on which the interviewer will draw and should not be imposed to disrupt conversational style.

1. Introduction

2. Reassurance of confidentiality (including reassurance that their doctors and nurses and other clinicians will not be told what the participant has said and that their treatment will not be affected by what they say, unless they say something that indicates risk)

3. Clarification of research aims

4. Elicit and answer questions about the interview process and the Patient Information Sheet

5.0 The interview questions will be guided by the structure below:

    5.1 The initial nature of symptoms; physical description of the symptom when first noticed (appearance, texture, size, etc.), sensations induced by the symptom (pain, numbness etc.), their thoughts and feelings about the symptom, interpretations of symptom meaning, courses of action considered (seek help, discuss with friends/family, wait and see, ignore etc.).

5.2 The persistence or progression of symptoms and participant responses to them. Participants will also describe the points at which their interpretations of symptoms changed and why, and will describe the points at which they considered presenting and the reasons that they did or did not do so.

5.3 If patients had considered cancer as a possible cause, they will be asked about why they made that interpretation, their confidence in it, and the role that it played in decisions to present or not.

5.4 Additional Questions:
Do you have routine dental check-ups?
How would you describe the relationship between you and your dentist?
Do you have regular check-ups with a GP?
How would you describe the relationship between you and your GP?
What kinds of things would make you see a GP?
How many times have you been to see a GP over the past year?
How do you think your GP would react if you presented with a symptom that turned out to be harmless?
Up until you had the symptom, what had you heard about oral cancer?
Up until you had the symptom, what had you heard about treatments for oral cancer?

6. Does the participant have any questions or any concerns about anything that has been talked about?

7. Thank participant for taking part.

Appendix F

Liverpool Interview Protocol

(Health-Oral LIP Adaption: Wheatcroft & Wagstaff, 2014)

THE LIVERPOOL INTERVIEW PROTOCOL (Health-Oral LIP Adaptation: Wheatcroft & Wagstaff, 2014*)

INTRODUCTION

Thank you for agreeing to meet with me. The aim of today will be for you to tell me as much as you can remember about your oral symptom, starting from when you first noticed the symptom up until when you went to a medical professional to seek help. I also want to reassure you that your information is confidential and that your doctors and nurses and other clinicians will not be told what you tell me and that your treatment will not be affected by what you say unless you tell me something that may indicate some kind of risk.

Before asking you any questions I will go through a couple of ways to help you relax and remember things that you have thought about and seen. The first is a very brief breathing exercise, with or without your eyes closed. The second is a short set of instructions to help you think generally about what happened. Do you have any questions?

EYES* (Optional)
Many people find this works best if they close their eyes whilst thinking about things that have happened. How do you feel about closing your eyes during these methods and when answering questions?

After you have received these procedures I will ask you some questions about the events in question; but please do not start to speak about these events until after I have described each procedure. I will tell you when I want you to answer some questions. Ok, let's start with some relaxation.

BREATHING*
(Please close your eyes.)
This is a very simple focused breathing exercise designed to help you relax and concentrate. So sit comfortably; keep your spine straight; keep your back straight and focus your attention now on your breathing. As you breathe in and out in a natural manner, focus on your breathing; breathing in and out in a natural manner. Take a few deep conscious breaths but don't strain. Just focus on your breathing, breathing in and out in a natural manner. Let the flow of your breath settle into its own natural rhythm; keep focused and aware during the whole process but concentrate on your breathing, breathing in and out in a natural manner. Allow your attention to focus on the changing rhythms of your breathing; and if your attention begins to wander, gently but firmly bring it back to your breathing. Now keep focusing on your breathing as you listen to the following instructions. Throughout the following instructions continue focusing on your breathing, breathing in and out in a natural rhythm.

Good, I'm now going to give you a very simple procedure, designed to help you remember your thoughts and what happened.

CONTEXT* (amended)
I would like you to try and picture when you first noticed symptoms as if it were happening right now. Run through your thoughts; try to replay what you were thinking in your head, as if it were replaying before you, and you are thinking about it right now. Imagine you are there; try to mentally note again everything you thought and did at the time. Think about what is happening. Think about what you were doing at the time. Notice whether you thought about any appearances, size, texture and sensation of physical changes associated with the event. Try to picture yourself as if you were still there and thinking about everything for the first time. Think about everything, noting every single detail, no matter how small, irrelevant or trivial it may seem. Notice any feelings you have. Notice your reactions and thoughts. I'd like you to keep picturing and remembering, remembering what happened as you answer the following questions. Think back and play the thoughts and events back in your head at any point when you need help remembering.

REPORT ALL* (amended)
I'm now going to ask you to describe as many details as you can remember about your thoughts and what happened. So now, talking slowly and keeping relaxed, please tell me everything you can remember about what happened; tell me now about everything that you can remember, noting every detail, no matter how small or unimportant it may seem. So, when you are ready, please begin talking ………

DO NOT INTERRUPT DURING THIS PHASE

Identify topics and enter into questioning procedure via generation of prompts/probing techniques.

Appendix G

Patient & Volunteer Debrief Sheet

Debriefing Sheet (Patient and Volunteer)

Aware - Understanding Patient Presentation in Oral Cancer

What was the purpose of the study?

We are interested in finding ways to encourage people with symptoms that might be oral cancer to see their doctor or dentist as soon as possible. Previous studies have tried to study this by asking patients to remember how they reacted to symptoms. We feel that this is a flawed way of doing this because people tend to forget what really happened or to them.

Our approach is to ask patients how they reacted to their symptoms, and to present these same symptoms to a healthy person to ask them how they would react. Thus, we can compare 'real time' reactions with the reactions that patients remember.

What happens now?

The interviews will be analysed by Juliet Bell with help from her supervisors. They will be written up for publication in scientific journals and for Juliet's doctoral thesis at the University of Liverpool. You can obtain a summary of the findings from The Liverpool Head and Neck Cancer Service or the Chief Investigator. We will also put outcome information on the website of the Liverpool Psychology in Cancer Care Research Group (http://www.liv.ac.uk/clinpsy/psychology-in-cancer-care/index.htm).

(Healthy Volunteers) Am I at increased risk of cancer?

Oral cancer is not common, but people who drink alcohol and smoke are at increased risk. We have included a pamphlet describing oral cancer for your information. This does not mean that we believe you are at increased risk. If you are concerned that you may be at risk, we suggest that you speak to your GP.

Sponsored by The Aintree Head and Neck Patient Research Forum

Can I withdraw from the study?

Yes. You can withdraw at anytime up to the publication of results by informing Juliet or Dr. Brown. We will then destroy all records pertaining to you.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been treated during this study, you can approach the Chief Investigator (Dr Stephen Brown) who is listed below.

Who can I contact for further information?

Juliet Bell (PhD student) 0151 794 4348 juliet.bell@liverpool.ac.uk
Dr. Stephen Brown (Chief investigator) 0151 794 5526 or slbrown@liverpool.ac.uk

Thank you for taking the time to read this.
You should keep this information sheet for future reference

Appendix H

Volunteer Study Recruitment Letter

[Date]

Dear [patients name]

I am writing to you to ask if you would consider taking part in a research study that I am carrying out. My name is Juliet Bell and I am a student, currently studying for my doctorate at Liverpool University. The research is about how people deal with mouth disease symptoms. I am interested in the choices that people make when they detect specific symptoms.

I work at The University of Liverpool, Institute of Psychology, Health and Society. I am supervised by Dr Brown (Health Psychologist), Professor Salmon (Clinical Psychologist) and Professor Shaw (Head and Neck Surgeon). The study has been approved by the Local Ethics Committee.

The Brownlow General Practice has agreed for suitable candidates who are registered to the practice to be invited to take part in the study. If you agree to participate you will be given a description of the symptoms reported by another person. We wish to compare your response to that person so that we can understand how that person may have interpreted those symptoms at the time that they occurred. We have asked them about their interpretation, but these symptoms occurred some time ago and we are concerned that their memory may be unreliable. You have been selected as you are similar in age, gender and alcohol and tobacco use to that person.

Your participation would involve an interview with me. I will talk to you for up to 45 minutes. However the exact length will depend on how much you wish to say. I could meet you in your home if you prefer or conduct the interview on the telephone if this is more convenient. The interview will be electronically audio-recorded and I will type up the audio-recording. All personal information, including names and addresses etc will be removed from the research.

There are no specific benefits in taking part. However by taking part in the research you will help us to understand how people respond to oral symptoms.

If you are willing to take part in the research study or have any further questions about the study please respond to this letter by [3 weeks in which the letter was sent]

 You can contact me by e-mail: juliet.bell@liverpool.ac.uk

Alternatively you can write to: **Juliet Bell, G04 Whelan Building, The University of Liverpool, Brownlow Street, Liverpool, L69 3GB**

Thank-you very much for reading this letter

Yours sincerely,

Juliet Bell

Appendix I

Volunteer Study Information Sheet

Volunteer Information Sheet

AWARE - Understanding Responses to Oral Symptoms

(A version of this will be communicated to potential participants over the telephone. This document will be given to them immediately before the interview.)

You are being invited to take part in a research study. Before you decide to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
This research is about how people deal with mouth disease symptoms. We are interested in the choices that people make when they detect specific symptoms.

Who is doing the study and who has approved it?

The study is being carried out by Juliet Bell, a student who is studying for her doctorate at Liverpool University. She works at The University of Liverpool, Institute of Psychology Health and Society, and is supervised by Professor Richard Shaw (Head & Neck Surgeon), Dr Stephen Brown (Health Psychologist) and Professor Peter Salmon (Clinical Psychologist). It has been approved by the Local Ethics Committee (reference: 13/NW/0056)

Why have I been chosen?

We want to compare a similar age person with no mouth problems (you) to patients that do suffer from mouth problems in the way that they describe the symptom.

Do I have to take part in the study?

No. It is up to you to decide whether or not to take part. If you choose to take part you will be given this Information Sheet and a signed Consent Form to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will taking part involve?

If you agree to take part, the researcher, Juliet Bell will interview you once. She will talk with you for up to around 30 minutes. The exact length of time will depend on how much you wish to say. She could meet you in your home if you prefer, or conduct the interview on the telephone if this is more convenient.

The interview will be electronically audio-recorded. Juliet will ask for your permission to keep the recording of the interview and to use it in the research. The audio-recording will be typed up by Juliet. All information which identifies you or anyone else will be removed. No personal information (such as names, addresses, etc) will be included in the research. Once the interview has been typed up, the audio-recording will be destroyed.

What are the possible disadvantages of taking part?

The interviews will take time but you do not have to spend longer talking to the researcher than you want to. You do not have to talk about anything you do not want to.

Will there be benefits of taking part?

There are no specific benefits from taking part. By taking part in the research you will help us to understand how people respond to oral symptoms.

What if there is a problem?

If you wish to complain, or have any concerns about any aspect of the way you have been treated during this study, you can approach the Chief Investigator (Dr Stephen Brown) who is listed below.

Will my taking part in this study be kept confidential?

We will not tell anyone else what you have said and we will not tell you anything that anyone else in the study has told us. All information collected for this study will be kept safely and securely on password-protected computer files and on locked-up paper records. Dr Brown, the Chief Investigator, will be the custodian of all study data. All information about you will be kept secure and confidential. Direct quotes from your interview may be used in study reports but any information which identifies you (for example, your name and occupation, names of family, friends, doctors or

hospitals, addresses and dates) will be removed from the typed transcripts of the interview. Your name will not appear with any of the information you give us – you will be identified by a code number.

What will happen when the study ends?

With your permission, transcripts of audio recordings of interviews will be electronically stored on a University of Liverpool password-protected computer for 15 years in a central file store. Access to these transcripts by researchers not involved in the current study will be subject to further ethical review.

After all identifying details have been removed from the transcribed records of interviews these will be analysed by the researcher and her supervisors. The results will be written up by Juliet and submitted to the University of Liverpool as part of her Doctoral qualification. They will also be published in reports and scientific journals, without giving your name or disclosing your identity.

How can I find out about the study results?

The Liverpool Head and Neck Cancer Service or the Chief Investigator will be able to provide you with written information about study outcomes.

Who can I contact for further information?

Juliet Bell (PhD student) juliet.bell@liverpool.ac.uk
Dr. Stephen Brown (Chief investigator) 0151 794 5526 or slbrown@liverpool.ac.uk

Thank you for taking the time to read this.
You should keep this information sheet for future reference

Appendix J

Volunteer Consent Form

Participant Consent Form (Healthy Volunteer)

AWARE - Understanding Responses to Oral Symptoms

Name of researcher: Juliet Bell

Please initial here

10. I confirm that I have read and understand the information sheet dated 30/07/15 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have these answered satisfactorily.	
11. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason affected.	
12. I understand that audio recordings will be made as part of this study, and that brief quotations from some interviews may be included in study reports without giving my name or disclosing my identity.	
13. I agree to electronic versions of transcriptions (a written record) of my interviews, with all names removed, being stored at the University of Liverpool 15 years after the end of this study.	

Name of participant	Date	Signature
Name of researcher	Date	Signature

Appendix K

Volunteer Interview Guide

**AWARE - Understanding Patient Presentation in Oral Cancer
Volunteer interview Protocol**

Interviews will be at a time convenient for the participant. The interview will be at the participant's home or conducted by telephone as the participant prefers.

The interviews will be structured by the presentation of information regarding the matched case (pilot interviews will be used to 'fine tune' how this information is presented). At all points, participants are to be encouraged to make interpretations based on the information provided to them. Consistent with 'think aloud' methods (26), it is important to allow participants to speak uninterrupted. Prompts should not 'lead' participants and should only be used when the participant has completed his/her speech.

A think aloud methodology will be used and the responses will be audio-recorded. Participants will not be immediately asked to expand on their responses because this may disrupt the flow of their responses, but may be asked to do so at the end of the interview. Participants will be asked to make a decision as to whether they would seek help or not and to convey reasons for that decision.

1. Introduction and explanation of the task. This will include the rationale that we are concerned about how people interpret oral symptoms, the nature of the scenario task and the nature of the 'think aloud methodology'.

2. Reassurance of confidentiality

3. Elicitation and answering of questions about the interview process and the Volunteer Information Sheet

4.0 The interview questions will be guided by the structure below:

4.1 The matched Phase 1 participants' initial descriptions of symptoms will be presented and the Phase 2 participants will be asked how they would respond emotionally and cognitively to these. They will be asked to say what they think the symptoms might mean, and what they would do next.

4.2 The persistence or changes in symptoms described by the matched Phase 1 patients will then be presented. Phase 2 participants will be asked to respond, as described above.

4.3 If a participant has considered cancer as a possible cause, s/he will be asked why s/he made that interpretation, the confidence in it, and the role that it played in any mention of a decision to seek medical help or not. If the patient has not considered the possibility of oral cancer, it will be raised and the patient asked to consider this.

4.4 If the participant hasn't spontaneously mentioned whether s/he would seek medical help or not, the participant will be asked at this stage and to give reasons for his or her response.

4.5 More specific questions will be asked about key areas if the participant hasn't spoken about them:

Do you have routine dental check-ups?

How would you describe the relationship between you and your dentist?

Do you have regular check-ups with a GP?

How would you describe the relationship between you and your GP?

What kinds of things would make you see a GP?

How many times have you been to see a GP over the past year?

How do you think your GP would react if you presented with a symptom that turned out to be harmless?

Up until you had the symptom, what had you heard about oral cancer?

Up until you had the symptom, what had you heard about treatments for oral cancer?

5. Provide a verbal debrief, explaining that the symptoms are those of somebody who has been referred to an oral cancer service. Explain that the symptoms are not necessarily cancer and that, if they are, the patient is receiving appropriate care. The debrief sheet contains a description of oral cancer risk and symptoms, and you should guide the participant to these and answer any questions that the participant may have.

6. Does the participant have any questions or any concerns about anything that has been talked about?

7. Thank participant for taking part.

Appendix L

Tables Illustrating the Process of Framework Analysis

Table 1: A coding matrix used to identify codes and categories from transcripts using P1 as an example.

Patient 1: Quotes from transcript	Description (Codes)	Preliminary thoughts (What is this about?)	Initial Sub-categories
'What was going through my mind was actually get that biopsy done, find out what's going on and get it sorted. That's it'	'Get it sorted'	Dealing with symptoms promptly	Sort it
'The dentist said it could be one or two things but it's not the horrible word. It's, it's just your gland so I went back the next day and said that's a load of bullshit'	'Went back' to seek help for symptoms/ Dentist's opinion is 'bullshit'	Challenging HCP's diagnosis	Taking constructive action to deal with symptoms
'As soon as I realised that whatever it was shouldn't be there I acted on it y'know so it was like-- it was more or less within the next day or so y'know. I didn't sit in a cupboard and hide'	Acted upon' concerns straight away/ 'Didn't sit in a cupboard and hide'	Facing up to issues and not avoiding them	
'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'	'Something not quite right' about symptom	Symptom not right/ Can't identify exact cause of symptom	Symptoms are abnormal

N.B. The initial sub-category 'Sort it' became a main category

Table 2: A coding matrix used to identify codes and categories from transcripts using P5 as an example.

Patient 5: Quotes from transcript	Description (Codes)	Preliminary thoughts (What is this about?)	Initial Sub-categories
'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'	Starting to 'panic' about symptom 'Don't want to know' if symptom is serious	Feeling anxious about what symptoms could be Not wanting to face up to issues	Tendency to avoid fears of serious illness
'ma 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 abit'*	Sister is concerned 'Scared of surgery'	Sister expresses concern over her brother's symptoms but leaves him feeling scared of the consequences of help-seeking	Significant others stress seriousness of symptoms
			Fears of consequences of help-seeking

Table 3: Development of initial concepts and sub-categories for the four initial categories of response – Progression from the four themes of the initial analysis to the three themes of the final analysis.

Initial Category	Initial Concepts	Refined Sub Categories	Final Sub Categories
Sort it	Uncertain about exact cause of symptoms	Symptoms are abnormal	Unusualness of symptoms drives help-seeking
	Taking constructive action to deal with symptoms	Taking constructive action to deal with symptoms	Orientation towards problem solving
	Persistent in challenging HCP's diagnosis		
	Symptoms could indicate serious illness	Awareness of cancer	Awareness of cancer
	Early treatment could lead to better outcomes		
	Influence of health promotion messages		
It's only minor	Symptoms attributed to previously experienced conditions	Mismatch between symptoms and perceptions of cancer	Mismatch between symptoms and perceptions of cancer
	Mismatch between nature of symptoms and expectations of cancer		
	Other health conditions more concerning	Other conditions more salient	Other conditions more salient
	Failure of self-medication led to uncertainty	Persistence/ worsening of symptoms led to uncertainty	Persistence/ worsening of symptoms led to uncertainty
	Dental phobia	Fear of dental treatment	Fear of dental treatment

Put it Off	Presenting symptoms when it best suits HCP's	Prioritising symptoms	Other conditions more salient
	Not letting symptoms interfere with work commitments/ leisure activities	Barriers to help-seeking	Not seeking help when suspecting symptoms are serious
	Trying to convince self that symptoms are harmless	Not wanting to accept symptoms could be serious	Misattribution linked to avoidance
Avoidance	Concerns that symptoms could be threatening	Not consulting when suspecting symptoms are serious	Not consulting when suspecting symptoms are serious
	Significant others prompt consultation	Significant others stress seriousness of symptoms	
	Not researching causes symptoms	Tendency to avoid fears of serious illness	Suppressing thoughts about cancer
	Avoiding paying attention to symptoms		
	Fear linked to the media	Fears of consequences of help-seeking	Fear linked to death/ disfigurement
	Fear linked to experiences of friends/ family		

N.B. After refining the sub-categories it appeared that the concepts in the 'Put it off' category overlapped with the concepts in the Avoidance and 'It's only minor' categories. The 'put it

off' category was therefore removed from the analysis. The avoidance category was then renamed 'don't want to think about it'.

Table 4: Patients responses arranged into final categories and sub-categories

Categories	Sub-categories
1. 'It's only minor'	(i) Mismatch between symptoms and perceptions of cancer
	(ii) Other health conditions more salient
	(iii) Persistence or worsening of symptoms leads to reattributions
	(iv) Fear of dental treatment
2. 'Sort it'	(i) Unusualness of symptoms drives help-seeking
	(ii) Orientation towards problem solving (If-THEN rules)
	(iii) Awareness of cancer
3. 'Don't want to think about it'	(i) Not consulting when suspecting symptoms are serious
	(ii) Supressing thoughts about cancer
	(iii) Misattribution linked to avoidance
	(iv) Fear linked to experiences of death and disfigurement

Appendix M

Framework Analysis Matrix for Patient Study

ID No	MBSAPOC	OHCMS	POWOSLTR	FODT	UOSDHS	OTPS	AOC	NCWSSAS	STAC	MLTA	FLTEODAD
1					—	—					
2					—						
3									—		
4				—							—
5								—	—		—
6		—						—	—	—	—
7					—	—	—				
8								—	—		
9					—	—	—				
11		—									
13	—		—								
14	—		—								
15					—	—					
18					—						
19	—	—	—								
20					—						
21	—	—									
22					—	—	—				
23		—						—			
24				—						—	
25								—			
26					—						
27					—						
28					—	—	—				
29	—										
30					—	—	—				
31								—			—
32	—		—								
33					—	—					
34					—		—				
36								—		—	
37								—			
38									—	—	—
39	—		—								
40	—		—								
41	—		—								
42									—		—
43					—						

N.B. Dashes are used to mark the subcategories that apply to each of the 38 patients in the qualitative analysis

Codes for Sub-Categories

MBSAPOC= Mismatch between symptoms and perceptions of cancer

OHCMS= Other health conditions more salient

POWOSLTR= Persistence or worsening of symptoms leads to reattributions

FODT= Fear of dental treatment

UOSDHS= Unusualness of symptoms drives help-seeking

OTPS= Orientation towards problem solving (If-THEN rules)

AOC= Awareness of cancer

NCWSSAS= Not consulting when suspecting symptoms are serious

STAC= Supressing thoughts about cancer

MLTA= Misattribution linked to avoidance

FLTEODAD= Fear linked to experiences of death and disfigurement

Appendix N

Framework Analysis Matrix for Volunteer Study

ID no	TIOTE	POVTI	PICHCPD	NTRU	VCMB	VSCMOTP	VCOP
1		—		—			
5							
6	—	—		—			—
9	—			—	—		
14				—			
19	—	—		—		—	—
21		—	—	—		—	
22	—			—		—	
23	—	—		—		—	—
24	—			—	—		
25			—	—		—	—
26		—		—		—	
27				—		—	
28		—		—		—	
29	—	—	—	—		—	
30		—	—	—		—	
31				—		—	—
32	—	—		—	—		—
36							
37			—	—		—	
38			—	—		—	—
39	—	—	—	—		—	—
40			—	—	—		
42	—	—		—	—		

N.B. Dashes are used to mark the subcategories that apply to each of the volunteers in the qualitative analysis. Volunteers 5 and 37 do not fit the analysis so are not included in the matrix.

Codes for Sub-Categories

TIOTE= Time is of the essence

POVTI= Perception of vulnerability to illness

PICHCPD= Persistent in challenging HCP's diagnosis

NTRU= Need to resolve uncertainty

VCBM= Volunteers concerned by misdiagnosis's

VSCMOTP= Volunteers suspected cancer more often than patients

VCOP= Volunteers critical of patients

Appendix O

Paper in Preparation (I Want to 'Sort it' or 'I Don't Want to Know': Patients' Responses to

Oral Cancer Symptoms and Time Taken to Consult Health Care Professionals)

I Want to 'Sort it' or 'I Don't Want to Know': Patients' Responses to Oral Cancer Symptoms and Time Taken to Consult Health Care Professionals.

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ABSTRACT

Delay in presenting symptoms to health care providers (HCPs) increases oral squamous cell cancer (OSCC) mortality and morbidity. Our aim was to identify why patients do or do not delay presentation. This qualitative study used semi-structured interviews with a consecutive sample of 38 recently diagnosed patients, who described events from noticing symptoms to presentation. Cognitive interviewing was used to minimize recall error. Patients reported median delay of 3-4 weeks. Three responses were evident. Several attributed symptoms to minor conditions, but presented when symptoms did not remit. Patients suspecting serious illness made either '*sort it*' or '*don't wanna know'* responses. '*Sort it'* patients felt at risk of illness, but saw benefits to early treatment. They presented immediately. '*Don't wanna know' patients* reported intense pre-symptomatic fears of cancer, and avoided thoughts about symptoms. They showed the longest delays. We describe how to augment 'sort it' and reduce avoidance responses to cancer symptoms.

Oral squamous cell carcinoma (OSCC) is the fastest growing cancer in the UK and has doubled in incidence between 2002 and 2011 (Schache, Powell, Cuschieri, et al., 2016). The 2012 age standardized rate was 5.8/100,000 for males and 1.7/100,000 for females, with five-year mortality of 48% in that year (CRUK, 2013). Delay between symptom onset and treatment leads to more advanced disease at presentation and consequent higher mortality and morbidity (Neal, et al., 2015). Delays of three months increase the probability that the symptom will progress to later stage cancer by 4.5 times (Brouha, Tromp, Hordijk et al, 2005). The largest contributor to this delay is time elapsed between patients detecting symptoms and presenting them to a health care professional (HCP) (Rogers, Brown, Woolgar et al, 2009). 20-30% of patients with oral cancer symptoms delay presentation for more than three months after noticing symptoms (Amir, Kwan & Landes et al, 1999; Rogers, et al, 2009).

Most OSCC cases occur outside monitored populations, such as patients with oral dysplasia or other precancerous conditions (Petersen, 2009). Thus, interventions to facilitate prompt presentation cannot be targeted toward specific 'at risk' individuals, and should focus on the general population (Petti, 2009). Mass-reach communications have potential to facilitate earlier cancer symptom presentation, and are likely to be maximally effective when message development is grounded in theory (Austoker, et al., 2009). This research seeks to understand why patients delay presentation.

Background

OSCC presentation delay research employs a number of theoretical perspectives that describe processes of symptom detection, appraisal and decision-making (Whitaker, Scott & Wardle, 2015). Probably, the most influential is the self-regulation model (Leventhal, Leventhal & Contrada, 1998). The SRM views presentation as a coping response to a sense of threat

generated by patients' subjective interpretations of their symptoms. When patients detect symptoms, their appraisals of the meanings of those symptoms determine their perceptions of threat. Appraisals may be inductive or deductive. Inductive appraisals are 'bottom up', driven by perceptions of symptom characteristics (e.g., a symptom is serious because it is painful or unusual). Deductive appraisals are 'top down', driven by existing understandings of illness (e.g., the symptom is consistent with cancer). The SRM posits that coping decisions logically follow IF-THEN rules, e.g., 'IF symptoms are unusual or consistent with cancer THEN consult a HCP'.

Theoretically-guided studies on presentation delay in OSCC suggests that delay occurs because top-down appraisal processes fail (Brouha, 2006; Scott, McGurk & Grunfeld, 2007; Scott, Grunfeld, Main & McGurk, 2006). Patients do not link OSCC symptoms to cancer or other serious illnesses. Instead they attribute symptoms to minor conditions, such as ulcers or dental problems, because symptoms are either similar to those associated with these conditions (Scott, McGurk & Grunfeld, 2007) or inconsistent with patients' expectations of how cancer will manifest (Andersen, et al., 2010; Scott, Grunfeld, Main & McGurk, 2006). Presentation becomes triggered only as symptoms persist or deteriorate to the point that initial attributions become untenable. The policy implication of this research is that media campaigns should teach people to better recognise and understand symptoms of OSCC (Scott, Khawaja, Low et al, 2012).

However, the above studies also suggest that patients who attribute OSCC symptoms to minor symptoms frequently experience uncertainty about doing so and consider cancer or other serious conditions (Scott, Grunfeld, Main & McGurk, 2006). Thus, it is important to understand why patients choose to attribute uncertain symptoms to benign rather than serious conditions, and why they do not simply consult a HCP as a 'safe option'. Further, symptom misattributions usually favor transient conditions, and should become less convincing as

symptoms persist or deteriorate. Yet, patients frequently maintain misattributions over six to twelve months (Scott, Grunfeld, Auyeung & McGurk, 2009; Scott, Grunfeld, Main & McGurk, 2006), and the reasons that they hold on to long-term misattributions are yet to be described.

SRM theory proposes an alternative reason for delay that has, to date, received little attention from OSCC researchers; that patients delay presentation because they use a defensive coping response to attenuate negative emotions associated with symptoms (Leventhal, Leventhal & Cameron, 2001). Thus, patients may avoid or deny symptoms and their implications. Although there is yet little evidence to support this, it is feasible that patients might prefer to attribute symptoms to minor causes because this reduces distress. Some evidence suggests that defensiveness might occur in practice. Many patients delay presentation, not because they perceive symptoms to be trivial, but because they fear that symptoms may be cancer or other serious illness (Smith, et al., 2005; Balasooriya-Smeekins, et al., 2015). A more specific line of support comes from studies showing that presentation delay is associated with habitual tendencies toward a defensive coping style in OSCC (Tromp, Brouha, Hordijk, et al., 2005) and other cancers (Pederson, et al., 2013; Ruiter, et al., 2008). However, we are aware of no research that explicitly shows the specific ways in which people respond defensively to symptoms or how this influences presentation delay.

Current Study

The aim of this study was to resolve ambiguities associated with current explanations of presentation delay in OSCC; specifically to understand why some patients attribute symptoms to minor conditions, even when they are uncertain about the causes of those symptoms, and why they do not consult HCPs as a 'safe' option. Further, we wanted to explore whether, how and why patients might engage in defensive coping. To achieve this,

we interviewed a consecutive sample of OSCC patients to identify the reasons for their decisions to present or not present. SRM ideas concerning symptom appraisal and defensive coping formed a general framework to guide the investigation, but we also wanted to be open to patients' own ways of responding to symptoms that are not necessarily consistent with our theoretical ideas. Thus, our research questions are inductive and we took a qualitative approach.

METHOD

Patient Sample: Ethical approval was obtained from the UK National Research Ethics Service (North West) reference:13/NW/0056. From July 2014 to September 2015, we recruited a consecutive sample of patients with recently diagnosed OSCC in a large regional Head and Neck Cancer service. The key criterion for inclusion was that patients had noticed symptoms before consulting HCPs. Patients were introduced to the study by members of the clinical team who introduced the study and referred interested patients to a female researcher (JB) present at the clinic. The researcher explained the study, provided a written explanation of study aims and methods and patient's rights, and obtained consent to approach patients by telephone to request and interview and, if agreed, arrange a time and date for the interview.

Procedure

Patients were interviewed by JB in their homes or at the clinic, after diagnosis but before surgical treatment. Patients were asked to recall how their symptoms progressed, how they responded to those symptoms and how they made decisions to present or not. Retrospective accounts are frequently have significant omissions or are inaccurate (Anderson & Mikkelsen, 2008; Van den Brink, Bandell-Hoekstra & Abu-Saad, 2001, Voldsgaard, Schiffman, Mendick et al, 2006). Patients may simply forget, or they may inadvertently construct interpretations in

the light of, or to explain, subsequent events (Gilbaut, et al., 2004). The potential for recall error and omission is greater for subtle and complex appraisals (Gershon & Ephrat, 2003).

We used cognitive interviewing to improve accuracy and comprehensiveness. Cognitive interviewing facilitates memory retrieval of complex and emotionally distressing events (Paulo, Albuquerque & Bull, 2013) using three techniques; focussed meditation, context reinstatement and instructions to 'report everything'. Focused meditation combines relaxation techniques with an induced attentional focus on current experience to improve memory for details (Wagstaff, Cole, Wheatcroft et al, 2007). Context reinstatement creates contextual overlap between encoding and retrieval environments by asking interviewees to reconstruct emotional, physical, and cognitive states present at recalled events (Holliday, Humphries, Brainerd & Reyna, 2011). Instructions to 'report everything' require participants to report all thoughts and feelings that they can remember. Here, the intention is to eliminate self-editing of thoughts (Paulo, Albuquerque & Bull, 2013). A focussed meditation exercise was performed near the beginning of the interview. Context reinstatement and 'report everything' techniques were used throughout. To ensure that the interviewer correctly implemented cognitive interviewing techniques, audio-recordings of sessions were reviewed by a practitioner in cognitive interviewing (JW).

Interview content

Interviews were conducted with the aid of an interview guide. The first objective of the interviews was to develop a timeline of key events; including first noticing symptoms, noticing changes or persistence of the symptoms, reappraisals of symptoms, when patients decided to present symptoms to HCPs, and when they did so. We asked participants to remember details such as day of the week, what else they were doing on that day and

temporal proximity to public holidays, birthdays and other events in their lives that they could accurately date.

The second objective was to understand patients' appraisal and decision-making processes. After the timeline was established a focussed meditation exercise was conducted (Fisher & Geiselman, 1992). Patients were asked to mentally recreate and describe their experiences from when they first noticed their symptom up until they were referred to a specialist with suspected OSCC. Open-ended questions were generally used. The interviewer reflected, prompted, summarized, and probed where necessary. Participants were encouraged to speak about key events taken from the timeline. Questions explored the nature of patients' symptoms, perceptions and interpretations of symptoms, courses of action that considered, how they chose the course that they did, and why they did or did not follow it. Where patients had not considered cancer as a possible cause of symptoms, they were asked why not. At the end of the interview, patients were asked whether they had past or current oral conditions, such as ulcers or infections that we thought might influence their perceptions and interpretations of OSCC symptoms. Final questions asked how patients felt about their GP and dentist, and how they felt these HCPs would respond if they reported symptoms that proved to be trivial. Interviews lasted a median time of about 40 minutes.

Data Analysis

Data analysis was inductive, using framework analysis with open coding (Gale, 2013). We were particularly alert to elements of the text pertaining to SRM concepts, including patients' appraisals of their symptoms and how these related to decisions to present or not, how and why they may have responded defensively to symptoms, and noted when the above concepts were absent from patients' accounts. An overall analytic framework was established and refined using a constant comparative approach of testing themes in the light of the data and searching for both confirming and disconfirming evidence in the transcripts.

JB led the analysis by creating initial codes and framework. At first, analyses were largely descriptive. Subsequent iterations of the analysis built a more inductive picture, recognizing that patients' accounts might contain justifications and rationalisations for any delay. In this process, we were guided by inconsistencies or contradictions within and between patients' transcripts (although we did not lose sight of the possibility that accounts may also contain unmotivated inaccuracies). We also considered the possibility that patients engaged in commonly-used discourse to explain their thoughts and actions (e.g., 'I must have been in denial') rather than describing underlying reasons. Each transcript was read by at least two investigators and analysis was finalized when theoretical saturation was reached. Standards by which the analysis was assessed included theoretical and catalytic validity (Stiles, 1999), by which we mean that findings should have the potential to add to existing theory and inform media campaigns. 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 the data collection period were approached. 19 refused and four could not participate for medical or psychological reasons. 43 consented, but five were eliminated because their interviews revealed that cancer detection was incidental, usually through routine dental examination, and that they had not noticed symptoms. This left a sample of 38. The mean age of the patients was 60.00 (SD=11.5), 17 were female. The cancer stage, cancer site, age and gender for each patient are displayed in table 1.

Overview

Table 1 also shows patients' estimates of time from symptom appearance to first presentation to a HCP. Longest time was 20 weeks, the shortest 1 day and the median 3-4 weeks. The

median is similar to that of 39 days reported by Scott, Grunfeld, Auyeung and McGurk (2009). We describe three distinct responses to symptoms: symptom misattribution, '*sort it*' and '*don't wanna think about it*'. Those who misattributed symptoms did not consider the possibility of serious illness. Most of presented 3-4 weeks after their symptoms did not remit. Patients who suspected serious illness exercised one of two responses. Some elected to '*sort it*' and pursued appointments with HCPs almost immediately. These patients spoke of being aware of increased risks of serious illness attributable to age or smoking, but believed that early medical intervention could mitigate disease progression. Other patients suspected cancer, but expressed reluctance to think about it – '*Don't wanna know*'. Several of these patients recalled previous traumatic experiences of cancer in family and friends and feared cancer, and did not report that early intervention could help them. These patients reported some of the longest delays.

Symptom Misattribution

These patients reported that they did not initially think about cancer or other serious illness upon noticing the symptom. Although describing symptoms as '*irritable*', '*painful*' and '*unusual*', they attributed them to ulcers, friction with teeth, infections or dental conditions. Initial responses were to ignore the symptom or to use over the counter medications. When asked why they did not consider cancer, many patients cited incompatibility between their symptoms and their ideas of how cancer would manifest; '*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). For some, symptoms seemed minor compared to other health problems that were salient to them: '*No it was just 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, or what I thought was an ulcer' (P21).

We probed the hypothesis that attributions to minor conditions might be defensive at the end of their interviews. Patients did not say so, and we did not find evidence for this in their accounts. Further, these patients sought help when symptom persistence or deterioration made initial attributions seem untenable. P36 became suspicious when an over-the-counter ulcer treatment failed; *'It wasn't Bonjela [analgesic paste] I used but it was something similar. (There was) No change whatsoever. Oh I had my own suspicions that it could be something a bit pernicious, which of course it proved to be'.* Delay related to misattribution was moderate. Few experienced delays of greater than six weeks, with the median being about three weeks.

Two patients (P4 and P24) who misattributed symptoms to dental problems diverged from the above pattern. Although their symptoms had worsened considerably and interfered with eating and drinking, neither stated that they had considered the possibility of serious illness. When asked about their relationships with HCPs, both spoke of intense fear of dentists: *'I do not like the dentist one little bit from when I was a child. I avoid dentists like the plague. Since I was about eight or nine years old I had about nine to eleven fillings all done together, and all I was going in for was a routine check-up and from that day on I will not go near the dentist'* (P24). They presented after delays of 20 (P4) and 12 (P24) weeks, and then only when prompted to do so by relatives or partners; *'It was my girlfriend who 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 with me'* (P4). .

'Sort it'

These patients felt that symptoms could portend serious illness, and spoke of a desire to '*sort it*' by presenting to HCPs who could deal with this possibility. Although several mentioned being aware of cancer as a possible cause, and felt alarm about this possibility, they considered other causes also possible. The driver of the 'sort it' response was symptom unusualness, not specific beliefs about cancer. Indeed, none tried to identify causes of symptoms; *'As soon as I realized that whatever it was shouldn't be there I acted on it y'know so it was like, it was more or less within the next day or so'* (P1). Some immediately made HCP appointments, others set specific timeframes of three or four days to see if their symptoms spontaneously remitted, then sought consultation if symptoms did not. Almost all presented within a week.

In SRM terms, these patients described IF-THEN sequences (e.g., IF symptoms are unusual THEN seek help). The 'IF' component was generally derived from 'bottom up' thinking about symptoms; *'I was alarmed but I wanted to get to the bottom of it to figure out exactly what it was so I could start dealing with it and that's what I did'* (P30). The THEN component was activated by patients' understandings of the options available to them. For example, Participant 9 remembered reading a magazine article, about cancer of the tongue before experiencing symptoms. She followed a rule proscribed in the article; *'if you have it* [an ulcer] *more than ten days it's better to go and see a doctor.'*

Almost all 'sort it' patients described two beliefs that informed their responses. First, they were aware of their elevated risk for age or smoking-related disease; *'I'd try to see as many people as I could to discover what the issue was, especially with the history of smoking and having smoked before. You're probably more tuned in to the fact that things could go wrong' (*P6). Secondly, they were aware that early intervention could promote better outcomes '*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). Put simply, P1 preferred to *'nip it* [illness] *in the bud'.*

'Don't wanna know

Other patients also suspected cancer or other serious illness, but did not seek immediate
consultation. These patients reported some of the longest delays. All considered the
possibility of serious disease. Some were explicit about this: *'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). Others were less able to define their suspicions, describing their perceptions as
either a '*sixth sense*' (P6) or a '*feeling*' (P5): '*Because I knew in my own mind it was more
than that, it was more than an ulcer. What it was I didn't know but I knew. Something told me
that's not right'* (P26). These patients reported some of the longest delays of 6-20 weeks.

Common across these patients' viewpoints was that they did not want to consider the
possibility of serious illness: ''*I felt an ache but you get like a sixth sense that something's
wrong with you as well but I've always been like that like a sixth sense, y'know what I mean.
Some people are and some people aren't, but I'm the type who's more anxious about going to
the doctors.*' (P6). Unlike the 'sort it' response, where thoughts of serious illness promoted
presentation, these patients tried to reduce emotional distress by suppressing thoughts about
either symptoms or cancer: '*Well then 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).

Four patients said that they had strategically misattributed symptoms to minor conditions to avoid the inference that symptoms may be cancer. P36 said *'I suppose if I'm truthful I didn't really want to accept it was anything worse than an ordinary ulcer because it wasn't troubling me too much at that stage'*. P38 (8-10 weeks until consultation) described how she continued to attribute symptoms to an ulcer to suppress thoughts of cancer; *'it's [cancer] 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 [cancer] surely. It might have been niggling in my mind but I had the hope that it wasn't anyway'*.

These patients also spoke of pre-symptom perceptions of vulnerability to disease. They expressed their vulnerability differently from 'sort it' patients, who spoke of an enhanced risk due to age or smoking. Patients who wanted to avoid thinking about serious illness spoke emotionally about fears of cancer based upon vividly recalled experiences of the deaths and disfigurements of friends and relatives who had cancer. P42 said he found information he heard about cancer *'frightening'*, because *'cancer seems to be the front runner of death'*. P5 reported '*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'*. Other patients also linked their fears to vicarious experiences of cancer amongst family or friends that they found traumatic. P5 lost his Father to cancer, which '*wasn't very nice to watch*'. He explicitly linking this experience to his suppression of thoughts about cancer; '*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 ma Dad went through'*.

DISCUSSION

OSCC and other cancer delay literature emphasizes the importance of symptom misattribution in presentation delay (Scott, et al., 2007). In this study, symptom

misattributions caused delay, but patients generally presented after symptoms did not remit, and their delay was generally confined to three to four weeks. This study describes two other reasons that patients do or do not delay presentation. Some elected to 'sort it', which largely eliminated delay, whilst many of those who avoided thinking about potentially serious implications of symptoms showed long delays.

'Sort it' and 'don't wanna know' responses were linked to patients' pre-symptom understandings of serious illness. Patients showing the 'sort it' response perceived themselves vulnerable to diseases such as cancer, but believed that early intervention could mitigate disease impact. This awareness led them to take a 'bottom-up' approach. They inductively responded to symptom characteristics that they found unusual. They did not attempt 'top down' reasoning by attempting to identify the causes of symptoms from what they knew about oral diseases. This is consistent with other research on OSCC symptom presentation. Scott et al. (2009) showed that some OSCC patients presented early because they believed that early presentation could mitigate illness or curtail worry about illness (Scott et al, 2009). Research on breast cancer has shown that people who feel both susceptible to illness and believe that illness is treatable are more likely to seek diagnoses (Dawson, et al., 2006).

Recalling traumatic memories of cancer in friends or family, 'don't wanna know' patients also suspected that symptoms may be cancer or other serious illness. This caused themconsiderable distress (Smith, Pope & Botha, 2005; Balasooriya-Smeekins, et al., 2015; Whitaker, Cromme, Winstanley, Renzi & Wardle, 2015). The contribution of this study is to show that their attempts to regulate distress contributed to delay. Patients tried to alleviate distress by not thinking about the implications of symptoms (Leventhal, Leventhal & Cameron, 2001). This finding is consistent with a large body of health psychology research showing that people commonly avoid thinking about health issues that may cause them distress (van 't Riet & Ruiter, 2013), and more specifically with research linking defensive

coping styles with longer delays in OSCC (Tromp, et al., 2005) and other cancers (Pederson, et al., 2013; Ruiter, et al., 2008).

The 'Don't wanna know' response was associated with some of the longer delays we observed. Mass-reach communications aimed at improving presentation times will need to mitigate this response. One approach to doing this is to compare precursors of avoidance responses to those of 'sort it' responses. Both responses were associated with pre-symptomatic perceptions of vulnerability, but perceptions of vulnerability were very different for each response. 'Don't wanna know' was associated with severe distress induced by vivid and disturbing memories of cancer in family members or friends. 'Sort it' patients saw risk in a less distressing way, as an objective fact of life for older people and smokers. Further, avoidant patients did not express a similar optimism to 'sort it' patients that early intervention could mitigate serious illnesses such as cancer.

It follows that health promotion messages should provoke minimal distress, and offer patients realistic hope that OSCC is treatable. A large body of health promotion research shows that messages presented in distressing ways can induce defensive coping (van 't Riet & Ruiter, 2013). Thus, reducing presentation delay should involve messages that promote awareness of vulnerability, but not do not do so in ways that are distressing. This will require sensitivity from campaign developers, because it is difficult to predict how campaign messages will affect specific audiences. The health promotion literature also shows that recommending explicit, effective and easily-implemented actions to mitigate the threat of illness reduces defensive coping (Peters, Ruiter & Kok, 2013). Thus, messages should inform audiences that prompt presentation increases the likelihood that medical intervention will be both successful and less invasive. A third potential solution arises from our finding that the families and friends of patients placed pressure on fearful patients to consult HCPs. Messages

can be targeted, not only toward the individuals with symptoms, but toward families and friends to encourage people they know with oral symptoms to seek consultation.

Other patients appeared to genuinely misattribute symptoms to minor causes. With the exception of two patients who showed long delays because they attributed symptoms to dental conditions and feared dental treatment, symptom misattribution only led to moderate delays of 3-4 weeks. However, rapid growth of some OSCCs means that even these delays could be clinically significant (Hyde & Hopper, 1999). Comparison with 'sort it' responses provides insights into how symptom misattribution can be reduced. 'Sort it' patients' decisions to present to HCPs were driven by the unusualness of symptoms. In SRM terms, these patients pursued clear inductive IF-THEN rules; IF symptoms are unusual THEN seek HCP consultation. This 'bottom-up' approach contrasts with the 'top-down' approaches underpinning misattribution - these patients perceived their symptoms as not serious because the appearances of symptoms seemed incompatible their ideas of how serious illnesses such as cancer would manifest or because their symptoms seemed minor in the context of other medical problems.

Focus on teaching people to recognise OSCC symptoms (Scott, et al., 2007) may be misguided. A focus on symptom recognition may unwittingly stimulate further 'top-down' processing and, thus, induce the misattributions that that symptom recognition approaches seek to avoid. Instead, media messages could aim to facilitate inductive symptom appraisal processes of 'sort it' patients, by promoting IF-THEN rules that are activated by symptoms that are unusual and persist for more than several days. People could then be encouraged to make time-specific intentions to seek consultation. 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.

This study has several limitations. First, although we have used cognitive interviewing techniques to minimize the problem of errors or biases in retrospective recall, it would be unwise to assume that we have eliminated them. A second 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. For example, symptoms of immediate presenters may have been more unusual and severe than those of patients who made genuine misattributions. This interpretation is partly mitigated because the site and staging information in Table 1 shows approximately even distributions of OSCC site and stage across immediate presentation and short and long delay groups. A final limitation is that this is a qualitative study. Although we used a consecutive series of patients at a large clinic, we cannot estimate the incidence of 'sort it' or 'don't wanna know' responses or how large their relationships are to presentation delay. Quantitative research is needed to do this.

In conclusion, understanding 'sort it' and 'don't wanna know' responses allows a better understanding of patient delay and development of new recommendations for mass-reach messages. The first aim of messages is to reduce avoidance of thinking about symptoms by promoting the positive message that treatments are likely to be less invasive and more effective the earlier they are implemented. The second is to encourage patients to take inductive 'sort it' responses; to seek HPC consultation for oral conditions that seem unusual or persist for more than a defined time period.

Compliance with Ethical Standards

Ethical approval: This article does not contain any studies with animals performed by any of the authors. All procedures involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent: Informed consent was obtained from all individual participants included in the study.

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