

Patient and professional views and experience of oral precancer

Rachel Anne Green

Submitted for the degree of Doctor of Philosophy

School of Dental Sciences & Institute of Health and Society

March 2013

Abstract

Oral precancer (OPC) is a collective term for a number of disorders that may precede oral cancer. Treatment is aimed at preventing malignant transformation however, this is complicated by a lack of robust evidence concerning both treatment effectiveness and future cancer risk. Uncertainties surrounding prognosis and treatment options might be expected to impact on a patient's experience of their disease, as well as creating challenges for their management. The aim of this research was to explore the experience of OPC through the eyes of the patient and clinician to assess the impact of living with oral precancer and enable the identification of opportunities to improve outcomes.

The project comprised two qualitative studies, each employing semi-structured interviews. 28 patients with OPC, were recruited for study A, while 11 Oral and Maxillofacial Consultants were involved in study B. Data collection and analysis was iterative, following the principles of the 'constant comparative' method (Glaser 1965). Data collection stopped when data saturation was achieved. The data were analysed using thematic analysis.

The results indicated that during the diagnosis and management of OPC, clinicians were faced with challenges. These included: communicating a diagnosis, (particularly in terms of terminology), conveying risk meaningfully, meeting patients' additional information needs, encouraging behaviour change and making treatment decisions. The patient data indicated that for some, OPC represents a devastating diagnosis leading to feelings of fear and uncertainty impacting significantly on the individual's life. In addition, analysis also allowed a disease journey to be mapped and directly related to the findings from the clinician group thereby indicating opportunities where changes in practice may improve patient care. These points included: the diagnosis, where understanding terminology and comprehending risk were problematic, following a diagnosis, where meeting information needs was a challenge and during the management and review stages when treatment decisions were made and carried out.

Dedication

This thesis is dedicated to the memory of Nan Burnett.

Acknowledgements

Firstly, I wish to thank my supervisors for their time, expertise, enthusiasm, honesty and patience throughout this process: Dr Cath Exley, Professor Jimmy Steele and Professor Peter Thomson. I am aware of how lucky I have been to work under this supervisory team. The guidance and support I received extended way beyond my expectations.

I am grateful to those at Sunderland Royal Infirmary for their involvement in the project, identifying suitable participants and facilitating the recruitment process. I also wish to acknowledge the British Association of Oral and Maxillofacial Surgeons for awarding me a small research grant, which allowed professional transcription of each of the interviews undertaken.

I would like to thank my friends and family and in particular Kay, Peter, Ruth and Emily who have been a constant support, listening to my concerns when I have been in doubt and picking up the pieces when necessary.

I wish to acknowledge my colleagues and fellow PhD students both at Newcastle Dental Hospital and School and the Institute of Health and Society. Many of whom I would not have had the pleasure of meeting were it not for this experience and especially those who have provided kind words of encouragement when I have needed them most.

Last but not least I wish to thank each and every participant who gave their time to take part in each of the studies. Without them this thesis would not have been possible and for that I am grateful.

Table of Contents

Abstract	i
Dedication	ii
Acknowledgements	iii
List of Tables and Figures	viii
Chapter 1. Introduction and outline of thesis	1
Chapter 2. Literature review	3
2.1 Oral precancer – an overview	3
2.1.1 Classification of oral precancer	4
2.1.2 Potentially malignant disorders	5
2.1.3 Incidence and Prevalence	8
2.1.4 Transformation rates of oral precancer	8
2.1.5 Risk factors	9
2.1.6 Diagnosis	11
2.2 Management of oral precancer	15
2.2.1 Current management options	15
2.2.2 Elimination of risk factors	16
2.2.3 Surgical removal of the lesion	17
2.2.4 Medical management	19
2.2.5 Conservative management	20
2.2.5 Negotiating treatment decisions	21
2.3 An individual’s response to a diagnosis of oral precancer	22
2.3.1 Recognising symptoms and illness behaviour	23
2.3.2 Making sense of illness – lay theories	27
2.3.3 Response to illness - oral precancer as an acute illness	29
2.3.4 Response to illness - oral precancer as a chronic illness	31
2.4 Uncertainty in illness	34
2.4.1 Uncertainty surrounding the meaning of the diagnosis	35
2.4.2 Uncertainty surrounding treatment	37
2.4.3 Coping with and managing uncertainty	39
Chapter 3. Research Aims and Objectives	42
Chapter 4. Methodology and Method	43
4.1 Philosophical assumptions	43

4.2	Ontology.....	43
4.3	Epistemology	44
4.4	Methodology	44
4.5	Research approach	45
4.6	Qualitative interviewing.....	46
4.6.1	The interview style	48
4.6.2	Interview location.....	49
4.6.3	Interviewing sensitively	50
4.6.4	The influence of the interviewer	52
4.6.5	Interview dynamics.....	53
4.6.6	Interviewing colleagues.....	55
4.7	Sampling.....	56
4.8	Ethics.....	61
4.9	Analysis.....	63
Chapter 5. Patient Results and Discussion:.....		69
5.1	Introduction.....	69
5.2	Pre-diagnosis – An account of participants help seeking behaviour.....	71
5.2.1	Health seeking behaviour – the symptomatic patient.....	72
5.2.2	Barriers and triggers to seeking care in the symptomatic oral precancer patient.....	74
5.2.3	Health seeking behaviour – the asymptomatic patient.....	83
5.2.4	Transition from primary to secondary care – all patient groups	84
5.3	Initial consultation.....	85
5.3.1	Beginning of the doctor-patient relationship.....	85
5.3.2	Impact of the environment	88
5.3.3	Inference of the need for biopsy.....	89
5.4	Diagnosis.....	91
5.4.1	Understanding the diagnosis - the role of communication and patient response	92
5.4.2	Patient Information needs - seeking additional information.....	95
5.4.3	Influence of others at the time of diagnosis.....	99
5.5	Management.....	101
5.5.1	Risk factors associated with oral precancer.....	102
5.5.2	Experience of treatment – surgery.....	106
5.5.3	Experience of conservative management	108

5.6 Review/post treatment phase.....	109
5.6.1 Uncertainty	110
5.6.2 Fear	113
5.6.3 Reassurance	115
5.6.4 Influence of doctor-patient relationship at this stage	117
5.7 Ongoing effect of diagnosis/living with precancer	119
5.7.1 Attitude to disease	119
5.7.2 Withholding information/protecting family and friends	122
5.7.3 Practical impact of precancer on everyday life	123
Chapter 6. The Clinician study: Results and discussion	125
6.1 Communicating with patients (delivering a diagnosis).....	125
6.1.1 Significance of the terminology used	126
6.1.2 Desire to be positive	129
6.1.3 Risk communication.....	131
6.2 Addressing patients' information needs.....	132
6.2.1 Approaches and limitations of verbal communication.....	133
6.2.2 Other approaches to communicating additional information	135
6.3 Challenges associated with addressing risk factors	139
6.3.1 Smoking as a risk factor	139
6.3.2 Tackling the subject of risk factors with patients.....	140
6.4 Making treatment decisions	144
6.4.1 Options available	144
6.4.2 Factors influencing treatment decisions	145
6.4.3 Influence of the doctor-patient relationship at this stage.....	148
6.5 Difficulties encountered when managing patients with oral precancer	149
6.5.1 Management issues – How long to review and when to discharge.....	150
6.5.2 Communicating transformation risk post treatment	152
6.5.3 Importance of clinical environment on patient experience and outcome.....	153
6.5.4 Importance of the clinician on patient experience.....	154
Chapter 7. Conclusions from both studies with respect to the patient disease journey	157
7.1 Communicating a diagnosis	159
7.1.1 Choice of language	159
7.1.2 Communicating risk	161
7.2 Information needs and provision.....	163

7.2.1 Patient factors	164
7.2.2 Clinician factors	167
7.3 Behaviour change.....	168
7.3.1 Patients' experience of behaviour change	169
7.3.2 Approaches to behaviour change employed by clinicians	171
7.4 Management of oral precancer.....	172
7.4.1 Patient experience.....	173
7.4.2 Clinician experience	174
7.5 The influence of the clinician and the environment on patient experience.....	176
7.5.1 The clinician – the significance of the individual	176
7.5.2 The environment – the significance of the clinical set up.....	178
Chapter 8. Summary, recommendations for practice and further work.....	180
8.1 .Summary	180
8.2 Recommendations for practice.....	182
8.2.1 Communicating a diagnosis of oral precancer	182
8.2.2 Addressing patients information needs	182
8.2.3 Facilitating behaviour change.....	182
8.2.4 Making treatment decisions.....	182
8.2.5 The doctor-patient relationship.....	183
8.3 Further work.....	184
8.4 Final summary.....	185

List of Tables and Figures

Tables

Table 1. Precancerous lesions and conditions.....	4
Table 2. Oral precancerous disorders.....	5
Table 3. Criteria for diagnosing epithelial dysplasia	12
Table 4. Complications following laser surgery for oral precancer.....	19
Table 5. Medical options trialled in the treatment of oral precancer	20
Table 6. Mechanics Ten Variables.....	25
Table 7. Patients rights and obligations when assuming the sick role	30
Table 8. Doctors expectations and rights in the sick role	30
Table 9. Initial topics selected for inclusion in topic guides.....	47
Table 10. Patient study sample group variables.....	57
Table 11. Professional group sample criteria.....	59
Table 12. Phases of thematic analysis.....	64
Table 13. Triggers and barriers to care seeking in patients with potentially malignant oral symptoms	74
Table 14. Management options in oral precancer	145

Figures

Figure 1. Initial themes	67
Figure 2. Route to diagnosis – patient pathway	71
Figure 3. Oral precancer – the patient journey through care.....	158

Chapter 1. Introduction and outline of thesis

This thesis focuses oral precancer, both from the perspective of individuals who are diagnosed with it as well from the view-point of those who are involved in the management of patients with it. The term oral precancer is used to describe a group of disorders that may present in the oral cavity. The significance of these disorders is that they pose a higher risk of malignant transformation than healthy oral tissue. Because of this, treatments are aimed at preventing cancer development; however, a lack of robust evidence concerning both treatment effectiveness and future malignant change means that there are currently no clear guidelines for clinicians to follow. Accordingly, practice varies widely. In addition, because of a paucity of literature pertaining to patient experience of oral precancer it is not clear how this group of patients experience their disease and if the lack of clear clinical guidance has an impact on their disease journey.

The work in this thesis has, therefore, been designed and conducted with a view to exploring patients' and professionals' views and experiences of oral precancer. Furthermore, the research presented seeks to map out and identify aspects of a patient's disease journey where implementing change may improve outcome.

Following this introduction, Chapter 2 reviews the current available literature and includes:

- An overview of oral precancer
- Management approaches in oral precancer
- An individual's response to illness
- Uncertainty in illness

Following the literature review the research aims and objectives are outlined, and chapters 3 and 4 describe the study's methodology and method.

Chapters 5 and 6 present the results and discussion from the patient study (study A) and the clinical professional study (study B). Chapter 5 discusses the varied and complex process of patients' experiences of disease from symptom appraisal through to treatment

and discharge from secondary care. This chapter highlights the individual nature of disease experience and in doing so presents a discussion of the factors that may influence this experience. In this way it is now possible to understand better the values and influences that may contribute to these patients' experiences. The results may also help clinicians to understand why some people react differently to others even where the process or treatment is apparently the same. Chapter 6 presents the results and discussion of the clinician-based study and specifically highlights several areas in which clinicians experience difficulty managing patients with oral precancer. In particular, this chapter explores approaches to communicating an oral precancer diagnosis and cancer risk, meeting patient information needs, discussing and encouraging patient behaviour change and making treatment decisions as well as unpicking the perceived relevance of the clinical set-up and doctor-patient relationship. In doing so, the clinician study results emphasize the differences in practice between clinicians as well as the factors which influence those practices.

Chapter 7 presents a summary of the results. This chapter examines the model of the patient journey through the health care system to focus on specific areas within this process where there is an opportunity to implement changes and hence potentially an opportunity to improve outcome.

Finally conclusions are outlined and recommendations from practice and future research are detailed in the remaining chapters.

Chapter 2. Literature review

Prior to conducting the research, which constitutes the main body of the work, a review of the literature was carried out during which the following areas were examined:

- An overview of oral precancer
- Approaches to managing oral precancer
- An individual's response to diagnosis
- Uncertainty in illness

The purpose of reviewing the literature with respect to oral precancer and its management is not only to allow a better understanding of this group of disorders but is also to consider why oral precancer is significant and how current evidence contributes to a clinician's approach to its management. In addition, by reviewing the literature relating to an individual's response to illness and the effect of living with uncertain illness it is possible to begin to explore the potential factors that may influence an individual's behaviour both prior to and following a diagnosis of oral precancer.

2.1 Oral precancer – an overview

Oral precancer, also referred to in the literature as premalignancy or potential malignancy, is a lesion or condition in the oral cavity which is more likely to undergo malignant change compared to healthy oral tissue. The significance of oral precancer is that it often precedes oral squamous cell carcinoma (OSCC), the most common type of oral cancer (Morse et al., 2007) and a disease associated significant mortality and morbidity (Warnakulasuriya 2009). The fact that OSCC is often preceded by oral precancer has led to the hypothesis that tumour genesis may be a two-step, or indeed multistep process, with the development of oral cancer being preceded by oral precancer. The concept of this two-step process of cancer development in the oral mucosa is well-established (Reibel 2003), although not universally accepted (Cowan et al., 2001). Histologically oral precancers are a lesions or conditions which are more likely to exhibit oral epithelial dysplasia or frank malignant change when compared to apparently normal tissue (Brennan, Migliorati and Lockhart 2007). The importance of oral epithelial dysplasia specifically is that its presence is considered to be the most

significant factor when predicting the likelihood of oral cancer development from premalignant disorders, with some suggesting that it heralds malignant change (Scully 1995).

2.1.1 Classification of oral precancer

Until recently oral precancers were classified as belonging to either one of two groups: precancerous lesions or precancerous conditions, with each category being associated with a future risk of oral cancer development.

Precancerous lesions	Precancerous conditions
Leukoplakia	Lichen planus
Erythroplakia	Submucous fibrosis
Palatal lesions in reverse smoker	Actinic keratosis
	Discoid lupus erythematosus

Table 1. Precancerous lesions and conditions
(adapted from (Kramer et al., 1978))

The definition of a precancerous lesion was put forward as ‘a morphologically altered tissue in which cancer is more likely to occur than in its apparently normal counterpart’, whereas a precancerous condition was described as ‘a generalized state associated with a significantly increased risk of cancer’ (WHO 1973).

In 2007, however, a report produced following a workshop coordinated by the World Health Organization (WHO) collaborating Centre for Oral Cancer and Precancer in the UK, subsequently recommended a change in classification of the above two groups, preferring the single category ‘potentially malignant disorders’ (Warnakulasuriya, Johnson and Van der Waal 2007). The change was put forward as it was felt that this single category more accurately reflected the fact that these conditions have the *potential* to develop into oral cancer rather than its development being a certainty. It was also felt that it was unlikely that all tissues would behave in the same way and where in some instances a two-step process from precancer to cancer may take place, in others a cancer may develop from a clinically normal tissue site. This concept is known as field cancerization. First described by Slaughter in 1953, and supported by others (van Oijen and Slootweg 2000) this theory proposes that tissue change may occur in any area of the aero digestive tract which has been ‘preconditioned’ by a carcinogen

(Slaughter, Southwick and Smejkal 1953). As such, if this concept is to be accepted, it can be appreciated that this process may complicate the management of oral precancer in that treatment aimed at targeting defined lesions may not eliminate risk of the future development of oral malignancy.

Finally, it should be noted that although many authors favour the term ‘potentially malignant’ over ‘precancerous’ or ‘pre-malignant’, ‘potentially malignant’ is not used universally throughout the literature and, therefore, all of the above 3 terms will be used interchangeably throughout this document to indicate an oral condition or lesion which carries an increased risk of cancer development.

2.1.2 Potentially malignant disorders

Leukoplakia and erythroplakia are the most common of the potentially malignant disorders and this is reflected in the oral precancer literature. However, there are a wide range of lesions and conditions which are considered to have malignant potential. These are detailed in table 2. It is worth noting that a number of other oral disorders are put forward in the literature as being potentially malignant in nature, however, for the purposes of this review only those detailed in table 2 will be discussed as these constitute the disorders recognised by the WHO Collaborating Centre for Oral Cancer and Precancer in the UK (Warnakulasuriya, Johnson and Van der Waal 2007). I will now go on to briefly discuss each in turn.

Oral precancerous disorders
Leukoplakia
Erythroplakia
Palatal lesions in reverse smoker
Oral submucous fibrosis
Actinic keratosis
Lichen planus
Discoid lupus erythematosus
Hereditary disorders with increased risk

Table 2. Oral precancerous disorders

Adapted from (Warnakulasuriya, Johnson and Van der Waal 2007)

Leukoplakia is the most common of the oral premalignant disorders (Poate and Warnakulasuriya 2006). Leukoplakia was until recently, defined as ‘white patches that carry an increased risk of malignant potential’ (Kramer et al., 1978), however, this definition was re-evaluated in 2007 and the following definition put forward ‘white plaques of questionable risk having excluded (other) known diseases or disorders that carry no increased risk for oral cancer’ (Warnakulasuriya, Johnson and Van der Waal 2007).

Clinically, leukoplakia presents in a variety of guises (Warnakulasuriya et al., 2010) but predominantly as a white patch and may be classified as either homogenous, typically uniformly flat and thin, or non-homogenous. Non-homogenous leukoplakias include both mixed red and white lesions (speckled or erythroleukoplakic lesions) nodular and verrucous leukoplakia. The nature of lesion appears to have significance in terms of the likelihood of malignant transformation, with non-homogenous lesions being considered a higher risk for malignant transformation than homogenous (Napier and Speight 2008). Within the umbrella term of leukoplakia, proliferative verrucous leukoplakia (PVL) is sometimes considered separately, although it is worth noting that the WHO workshop on potentially malignant oral mucosal lesions and conditions prefers to regard it as an extreme variant of leukoplakia. The reason it is sometimes differentiated from other lesions is because PVL lesions are much more likely to contain epithelial dysplasia than other leukoplakias and furthermore, are considered much more likely to progress to OSCC during the first decade following diagnosis (with one cohort study suggesting transformation in up to 70% of those affected) (Bouquot, Speight and Farthing 2006).

Moving on from discussing leukoplakia, erythroplakia is defined, as ‘a fiery red patch that cannot be defined clinically or pathologically as any other definable disease’ (Axell et al., 1984). Although not as common as leukoplakia, erythroplakia is more likely to display dysplastic or malignant changes (Mashberg and Samit 1989), in fact it is believed that over time the majority of erythroplakias will undergo malignant change (van der Waal 2010). As a result of this erythroplakia is considered a high risk lesion, although specific annual transformation rates are said to be difficult to calculate (van der Waal 2009).

Reverse smoking is not commonly practiced in the UK, and instead is primarily seen in female populations in east-central India (Mehta et al., 1969). This habit (smoking with the lit end of the cigarette inside the mouth) is associated with oral lesions found predominantly on the palate which have been shown to have the potential to exhibit both dysplastic and malignant change (Hebert et al., 2002).

Oral submucous fibrosis is a disorder in which fibrosis of the oral mucosa is seen to occur. It is observed primarily in south-east Asia where the principal risk factor of betel quid chewing is commonly practiced. Mucosal atrophy is a feature of the condition which is believed to increase the likelihood of malignant transformation when exposed to carcinogens. The malignant transformation rate is reported as being in the region of 0.5% (van der Waal 2009), however, figures such as these are based on the findings of follow up studies with a very small number of participants (Murthi et al., 1985).

Actinic keratosis is a potentially malignant disorder affecting the lower lip. It is thought to arise due to prolonged exposure to ultraviolet light. Figures suggest that transformation of actinic keratosis to squamous cell carcinoma may be something in the region of 12%-30% over 3 years for high risk patients (Zide 2008). However, exact rates of malignant transformation again are difficult to predict due to a paucity of studies (Thomson 2012).

Lichen planus is an autoimmune disorder of unknown aetiology in which T lymphocytes accumulate beneath the epithelium of the oral mucosa and increase the rate of differentiation of squamous epithelium. This results in hyperkeratosis and erythema sometimes with associated ulceration (Warnakulasuriya, Johnson and Van der Waal 2007). Although the subject of controversy within the literature with regard to whether lichen planus should be considered a potentially malignant disorder at all (van der Meij, Mast and van der Waal 2007), it is generally accepted that although there is evidence to support malignant potential in lichen planus, the risk of malignant transformation is difficult to ascertain due to the nature of the best available evidence (retrospective cohort studies and prospective incidence studies) (Lodi et al., 2005).

Discoid lupus erythematosus is also an autoimmune condition of unknown aetiology. It is characterised by skin involvement but may also present intra-orally as well circumscribed white patches with elevated borders. They may also be surrounded by a

telangiectasia halo and have associated radiating white striae. They have known potential for malignant transformation (Pindborg et al., 1997), however, a lack of evidence makes quantifying the risk of malignant transformation difficult (Wei et al., 2011)

Finally, the hereditary disorders dyskeratosis congenita and epidermolysis bullosa may also have an increased risk of malignant change (Warnakulasuriya, Johnson and Van der Waal 2007), but are rare.

Although oral precancer may be considered as any of the above forms, as discussed, the majority of the literature focuses on the premalignant disorders leukoplakia and erythroplakia which represent the majority of oral precancers observed, the other disorders representing a much smaller proportion of precancers seen (Napier and Speight 2008).

2.1.3 Incidence and Prevalence

Obtaining meaningful information of the incidence and prevalence of oral precancer is difficult, with many studies focusing purely on leukoplakia. However, even then variances in the definition of leukoplakia make synthesising the data difficult (Napier and Speight 2008).

There are very few studies pertaining to the incidence, number of new cases per year, of oral precancers. However, those that are available predominantly relate to leukoplakia in Indian populations and have suggested a range of between 0.2/1000 to 30.2/1000 with the higher incidence rates being associated with high levels of tobacco use (Bhargava et al., 1975; Mehta et al., 1972).

In contrast to incidence more is known on the prevalence, the number of cases in a given population at any one time, with data being available worldwide. Survey based studies have reported variations in prevalence of oral precancer from between 24.8% (Axell 1987) to 0.2% (Mehta et al., 1969) although it is largely agreed that the realistic prevalence of oral premalignancy is between 1% and 5% (Napier and Speight 2008; van der Waal 2009). A difference in apparent prevalence is seen when figures from different geographical locations are examined.

2.1.4 Transformation rates of oral precancer

The transformation rate of oral precancer is defined as the frequency at which an oral precancer changes to become an oral cancer. The annual transformation rate of precancer is thought to be in the region of 1% (Johnson, Warnakulasuriya and Tavassoli 1996) however, some have suggested this is too high, and should more realistically be considered to be 0.5% (van der Waal 2009). Differences in reported transformation rates appear to be as a result of a lack of high quality evidence. In particular, differences in study design, follow-up duration and definition of oral precancer make interpreting this information challenging.

As by far the majority of premalignant disorders present as leukoplakias, there is a preponderance of literature available on the potential transformation rates of this disorder when compared to the other premalignant disorders (Lind 1987). Reports suggest that patients with leukoplakias have a 50 to 100 times greater chance of developing a OSCC compared to the general population (Cawson 1975). However, a wide variation in malignant transformation is documented with studies suggesting rates of between less than 1%– to 36% (Silverman, Gorsky and Lozada 1984). Given that the prevalence of oral leukoplakia in the general population is believed to be between 1%-5%, this is not an insignificant finding.

2.1.5 Risk factors

As with oral cancer, the literature suggests that the two main risk factors for the majority of the potentially malignant disorders are tobacco smoking and alcohol consumption (Jaber et al., 1999), furthermore, case controlled studies have demonstrated an association between these risk factors and oral epithelial dysplasia (Kulasegaram et al., 1995; Morse et al., 1996).

Focusing firstly on smoking as a risk factor for oral premalignancy, the literature suggests that smoking is a significant risk factor in the genesis of both oral precancer and oral cancer, particularly in European subjects (Jaber et al., 1999; Kulasegaram et al., 1995) with one survey based study finding that leukoplakia is 6 times more common amongst smokers than non-smokers (Baric et al., 1982). Where the majority of the literature focuses on cigarette smoking, it has also been put forward that cigar and pipe smoking significantly increase the risk of malignant change in the oral cavity (Winn 2001) and there is evidence that chewing tobacco products also puts an individual at an increased risk of developing oral malignancy. Of potential significance is that 2 cohort

studies have demonstrated that smoking cessation is associated with the potential for reversal of precancer (Ramseier et al., 2010), with some premalignant lesions being seen to regress and in some cases resolve completely following cessation of a smoking habit. The most frequently cited of these is a large Indian 10 year follow up study which demonstrated that following smoking cessation the incidence of oral leukoplakia substantially decreased (Gupta et al., 1995). In Europe a Swedish based study found that leukoplakias were reversible in patients who stopped or, indeed, reduced smoking (Roed-Petersen 1982). Clearly, this may have implications when it comes to managing patients with oral precancers. However, given the strength of the available evidence it is not possible to state conclusively that smoking cessation is fundamental to the elimination of oral precancer.

Although cohort studies suggest tobacco use appears to have a more significant association with epithelial dysplasia than alcohol consumption (Jaber et al., 1999), alcohol is still considered an independent risk factor (Maserejian et al., 2006) although it is thought that alcohol and tobacco smoking together may produce a synergistic effect, further increasing the risk of both oral cancer and precancer (Morse et al., 1996). It has also been postulated that the use of alcohol containing mouthwashes may be a risk factor for a small contingent of women who do not smoke or drink (Blot, Winn and Fraumeni 1983). However, this is considered controversial and has been disputed in more recent times (Gandini et al., 2012).

Morse et al., sought to discover if patterns of risk factor behaviours (smoking tobacco and drinking alcohol) differed for those individuals with oral cancer compared to those with oral epithelial dysplasia. They found evidence that where smoking is associated with oral dysplasia and oral cancer equally, alcohol is more strongly associated with oral cancer. Further they went on to suggest that a history of high alcohol intake in patients with oral epithelial dysplasia may predict cases of dysplasia at a higher risk of transformation (Morse et al., 2007) .

Other than tobacco use and alcohol consumption, poor diet has also been put forward as a risk factor for oral precancer development (Zain 2001). Although the impact of diet as a risk factor for oral precancer specifically is not fully understood it is believed that a diet rich in fruit and vegetables results in a reduced rate of oral cancer. This is supported by a meta-analysis by Pavia et al., (Pavia et al., 2006). The protective effects

of fruit and vegetables are attributed to their antioxidant activities. However, it is felt that the effects of diet are not as significant as those of tobacco and alcohol use (Marshall and Boyle 1996). Furthermore it is a difficult area to study as the risk factors do not always appear independently.

Human papilloma virus is put forward as another potential risk factor in oral precancer. Having been implicated as a risk factor in the wider literature (in cancer of the uterine cervix), a relatively recent systematic review pooling data from 39 studies concluded that a potentially important causal relationship exists between HPV, oral cancer and oral precancer (Syrjanen et al., 2011). However, the authors finish by stating that further work, in the form of prospective cohort studies, is required until HPV can ultimately be considered as a risk factor in oral precancer.

Other potential risk factors are seen in the literature including: immunosuppression and poor oral hygiene, oral health and genetic predisposition. However, despite evidence suggesting their involvement as risk factors, the level and mechanism of the involvement is not fully understood

2.1.6 Diagnosis

The diagnosis of oral precancer traditionally takes place following a visual inspection of the oral cavity which is subsequently followed up with a scalpel biopsy. The resultant sample is then examined histologically to determine a diagnosis and to assess for features of frank malignancy or features of dysplastic change.

Although a thorough intra-oral examination is a key constituent of assessing a patient for the presence of oral cancer or precancer, most authors agree the presence or absence of malignant change cannot be reliably determined by visual examination alone (Mirbod and Ahing 2000; Shugars and Patton 1997; Silverman 1988). Although some have suggested that there may be some features of the examination that may arouse suspicion. For example Bouquot and Whitaker have suggested that when it comes to clinical inspection of oral leukoplakia, an increase in thickness of the lesion correlates with a greater chance of finding dysplastic changes histologically (Bouquot and Whitaker 1994).

The current gold standard in the diagnosis of oral precancer is an incisional biopsy. This is reflected in the fact that the majority of oral and maxillofacial surgeons (OMFS) report taking a biopsy of lesions in patients with suspected premalignant disease (Kanas et al., 2011). The purpose of an incisional biopsy is to gain a tissue sample which can be subsequently analysed by a pathologist with a view to determining an accurate precancer diagnosis. Central to this process is the assessment of the sample for the presence of epithelial dysplasia which, as discussed, at the present time, is the best known predictor for malignant change within a lesion. Although an important factor in determining the risk of malignant change, oral epithelial dysplasia is not associated with any specific clinical appearance (Reibel 2003). Oral epithelial dysplasia is seen to occur where histological examination of the tissue reveals changes in cellular maturation and morphology. Criteria for diagnosing epithelial dysplasia are detailed in table 3.

Criteria for diagnosing epithelial dysplasia
Loss of polarity of basal cells
Presence of more than one layer of cells having a basaloid appearance
Increased nuclear-cytoplasmic ratio
Drop shaped rete ridges
Irregular epithelial stratification
Increased number of mitotic figures
Mitotic figures that are abnormal in form
The presence of mitotic figures in the superficial half of the epithelium
Cellular and nuclear pleomorphism
Nuclear hyperchromatism
Enlarged nuclei
Loss of intercellular adherence
Keratinisation of single cells or cell groups in the prickle cell layer

Table 3. Criteria for diagnosing epithelial dysplasia

Adapted from (Pindborg et al., 1997)

As dysplasia is a spectrum, typically these changes are assessed by a pathologist and graded as mild, moderate and severe. A diagnosis of carcinoma in situ is made where the dysplastic features involve all surface epithelia strata, which differs from OSCC in which there is evidence that the nests of epithelial cells have isolated the epithelial-

stromal interface and invaded the underlying lamina propria and deeper submucosa (Brennan, Migliorati and Lockhart 2007).

As previously outlined, the relevance of this histological assessment is that the presence of dysplasia within a lesion is thought to increase the risk of malignant change (Speight, Farthing and Bouquot 1996; van der Waal et al., 1997; Warnakulasuriya 2001) and in particular the latter grades are thought to be associated with a more substantial risk than the former grades (Rodrigues and Tuomainen 1998). When this is examined further it can be seen that studies have reported wide variations in transformation rates. For example 7% -50% in severe epithelial dysplasia (Bouquot, Speight and Farthing 2006), 3%-15% in moderate dysplasia and less than 5% in mild dysplasia (Speight 2007). However, it must be appreciated that where the categories mild, moderate and severe are routinely used, there are no truly reproducible criteria to define these categories (Barnes et al., 2005). Nevertheless, as a result of these assumptions the lesions displaying more severe grades of dysplasia are often treated in a more aggressive manner than the less severe grades.

Although a great deal of significance is subscribed to the results of the histological report, there exists potential for variability in that the assessment of the biopsied tissue is considered by some to be a somewhat subjective process. Indeed studies have shown a lack of standardisation in the diagnostic criteria (Pindborg, Reibel and Holmstrup 1985) as well as a lack of inter-observer agreement between pathologists with one study finding inter-observer agreement of only 54% between two experienced pathologists grading dysplastic lesions (Lumerman, Freedman and Kerpel 1995). However, others have suggested no significant inconsistencies in inter-examiner reliability between pathologists assessing the same tissue samples, reporting agreement when grading of 92% (Lippman et al., 1993). As a means of reducing this potential disparity, it has recently been recommended that the grading of dysplasia be altered from 3 to 2 grades reclassifying the mild risk the category low grade and combining moderate and severe dysplasia into the single category high grade dysplasia (Warnakulasuriya et al., 2008), however, it is not yet known if this produces more consistent reports as the allocation into either one of these groups is still a subjective process. Given the significance ascribed to the histological assessment, variability at this stage may mean the difference between regular review and surgical intervention in terms of patient treatment options.

Another aspect affecting the reliability of a biopsy and subsequent histopathological assessment is whether the sample can be considered truly representative of the entire lesion from which it is taken. This was explored in a study by Holmstrup et al., in which 101 surgically removed premalignant lesions were examined histologically and the results compared to the histology from a preoperative biopsy (Holmstrup et al., 2007). Their findings indicated that an under diagnosis was made in 35% of the lesions examined. In other words the secondary analysis indicated a more severe diagnosis than the initial biopsy indicated. Indeed in 3% of cases where the biopsies had shown no, slight or moderate dysplasia, carcinomas were observed in the excised tissue sections.

In an effort to gain a better understanding of oral precancer at a cellular level and ultimately to enable us to identify the lesions which are at greater risk of malignant transformation, there is a growing body of research which seeks to understand molecular alterations in normal cellular turnover, and in particular biomarkers which may allow identification of abnormal processes. This is because carcinogenesis is a process by which dysregulation of cell proliferation, differentiation and death (apoptosis) is seen to occur. When such dysregulation occurs, the result of this uncoordinated process gives rise to the changes amounting to dysplasia as described above and potentially invasive neoplasia. This dysregulation is thought to occur as a result of genetic mutations, sometimes secondary to exposure to a particular carcinogen. The resultant mutations can result in abnormalities in processes such as cell growth and survival. However, although work is continuing in this area, at present there are no biomarkers which can be used in the diagnosis of oral precancer (Pitiyage et al., 2009).

In summary, this section has presented an overview of oral precancer, beginning with classification of precancers and noting the relatively recent change in classification from the two groups precancerous lesions and conditions to the single group potentially malignant disorders. Each disorder has been briefly described, with a recognition that information pertaining to oral leukoplakia accounts for the vast majority of the available literature. The prevalence and incidence of the potentially malignant disorders have been presented along with what is known regarding their risk of malignant change. Finally oral dysplasia has been put forward as the current best available predictor for malignant change and the possible drawbacks of using dysplasia for this purpose have been outlined. The following section will now go onto discuss how oral precancer is currently managed.

2.2 Management of oral precancer

Since the majority of oral precancers are asymptomatic, the primary objective of their management is to prevent malignant transformation (Lodi et al., 2008).

One of the key challenges of oral precancer management is predicting which lesions will go on to progress to oral squamous cell carcinoma. Unfortunately, at the present time, there is no means of accurately predicting exactly which lesions are more likely to transform compared to others. Currently, the degree of dysplasia present within a precancer is seen as the most reliable marker for malignant transformation. Although discussions in the previous section have outlined the limitations of using dysplasia for this purpose, it is generally agreed that lesions exhibiting severe dysplasia pose more of a risk of malignant transformation than those with mild or moderate dysplasia (Bouquot, Speight and Farthing 2006). However, some longitudinal studies have indicated that even mildly dysplastic or benign mucosal lesions have been shown to present a risk of progression (Zhang et al., 2005). Clearly this may pose a problem when it comes to managing oral precancer.

2.2.1 Current management options

At the present time there are no evidence-based guidelines available on the management of oral precancer. This is because the evidence pertaining to treatment effectiveness in oral precancer is weak, primarily based on cohort studies. This further complicates the treatment planning process, with clinicians having to rely on the current best available evidence alongside personal experience. Such a situation is likely to lead to variations in practice and this is reflected in the literature (Epstein et al., 2007; Marley et al., 1996; Marley et al., 1998).

Currently, the literature details the following possible options in the management of oral precancer:

- Elimination of risk factors

- Surgical removal of the lesion
- Medical management
- Conservative management

2.2.2 Elimination of risk factors

It was discussed in the previous section of this chapter that tobacco use and alcohol consumption, and to a lesser extent diet and viral infection, are considered risk factors for the majority of oral precancers. It has also been discussed that there is limited evidence to suggest that if these risk factors are eliminated, improvement or resolution of a precancer potentially may occur (Gupta et al., 1995). As a consequence, efforts aimed at eliminating such risk factors often form an integral part of the management plan of an individual with oral precancer.

If we first consider tobacco use in the UK, because of the wider impact of tobacco use on an individual's health, clear guidelines exist regarding the delivery of smoking cessation advice and providing access to specialist services. In the case of hospital practitioners, every patient contact should be utilised to promote a healthy lifestyle (DoH 2012a). Specifically, in the case of patients who smoke, this should involve referring each patient on to a specialist smoking cessation service (NICE 2008). Evidence available prior to the introduction of these guidelines suggested that the smoking status of an oral precancer patient was not always determined during a consultation (Marley et al., 1998). It would not be unreasonable to assume from this that smoking cessation was, therefore, not always engaged in. It will be interesting to see the impact of such guidelines in future studies of smoking cessation in oral precancer management.

Even where professionals are promoting smoking cessation, there is evidence that, in the long term, a high percentage of patients with oral precancer continue to smoke. For example, a study by Poate and Warnakulasuriya sought to evaluate the success of interventions to eliminate tobacco use in a population of patients with oral precancer attending a UK based oral dysplasia clinic. Their study looked at 180 patients, 83% of which were current users of tobacco products. Using a combination of brief intervention advice, medication and referral to a specialist smoking cessation clinic,

their cessation success rate was only 20% (Poate and Warnakulasuriya 2006). Similar results have been shown in other studies (Hamadah, Hepburn and Thomson 2007).

There is much less in the literature with regard to the management of the other risk factors implicated in oral precancer development and progression, other than the general message that education regarding their relevance and interventions to promote healthier lifestyles should be encouraged (Reichart 2001).

2.2.3 Surgical removal of the lesion

Currently surgical management of precancer remains the preferred treatment of choice for most professionals (Marley et al., 1998; Nankivell and Mehanna 2011; van der Waal 2009). Surgical treatment may involve scalpel excision, laser excision or laser ablation. (Historically cryotherapy has also been used as a surgical option but will not be discussed in depth here because it is not currently recommended as a valid treatment for this purpose (Lodi and Porter 2008)). Generally it is felt that scalpel or laser excision is preferable to laser ablation because the latter method makes it impossible to analyse the lesion histologically following surgery to assess for the presence of a primary neoplasm in an area of dysplastic epithelium (Thomson and Wylie 2002).

Unfortunately, at the present time, there are no randomised control trials assessing the effectiveness of the surgical management of oral precancer. This leads to doubts regarding its value as an effective treatment (Lodi and Porter 2008). Indeed, a Cochrane review assessing interventions in oral leukoplakia, the most common of the potentially malignant disorders, concluded that there was insufficient evidence to assess the effectiveness of surgical interventions preventing the future development of OSSC (Lodi et al., 2008). As a result, evidence must be sought from observational studies. As an example, in their retrospective study, Lummerman et al., demonstrated a 15.4% risk of malignant transformation for untreated dysplastic lesions compared to 6.2% in cases where the dysplastic lesions were excised (Lumerman, Freedman and Kerpel 1995). However, unfortunately, although results such as these suggest that a reduction in transformation rates may be possible, it remains the case that surgical intervention will not eliminate the potential for malignant transformation in all cases (Holmstrup et al., 2006).

As the aim of surgical treatment is removal of the precancerous lesion and its associated risk of malignant transformation, it is interesting that the topic of width of the margin removed alongside the lesion has never been discussed in detail (van der Waal 2009), in the same way that its importance has been noted in the oral cancer literature (Nason et al., 2009). This may be significant when it is considered that pathological changes in the epithelium may be present beyond the clinically visible oral precancerous lesion (van der Waal 2009). Indeed, if we look to the work of Hamadah et al., their study involving 78 patients undergoing laser excision, found that of the lesions excised as part of the study, 45% of the excision margins showed some degree of dysplasia (Hamadah and Thomson 2009). Indicating that further work in this area may be of value as an aid to surgical planning.

An additional aspect of surgery which should be considered as part of the treatment planning process is that of the possible postoperative surgical complications. An awareness of the potential complications will assist in the decision making process, particularly in an area where so much uncertainty regarding treatment effectiveness remains. There is, unfortunately, very little in the literature regarding complications following surgical treatment of oral precancer. Goodson et al., however, recently published a retrospective study involving 82 patients having previously undergone laser excision of a precancerous lesion (Goodson et al., 2012). The range of complications reported by their group are summarised in table 4. Interestingly they reported that all patients complained of at least one postoperative complication. Further studies documenting potential complications may, therefore, be of benefit in planning treatment in that patients will be better informed when determining if the benefits of surgical treatment outweigh the risks.

Complications after laser surgery for oral precancer
Pain
Bleeding
Paraesthesia of the lingual nerve
Swallowing difficulties
Obstructive swelling of the submandibular gland
Tethering of the tongue
Difficulties with speech

Table 4. Complications following laser surgery for oral precancer
(Adapted from Goodson et al., 2012)

2.2.4 Medical management

Moving on from surgical management, medical treatment is a lesser employed approach to oral precancer management than surgery (Marley et al., 1998). However, the potential benefits of medical management are clear: firstly the opportunity to treat the whole of the oral cavity, rather than a specified lesion, this is of particular interest given the concept of field cancerization, and secondly, the less invasive nature of the treatment, removing the potential for the undesirable postoperative complications that may be seen with surgery.

In order to select an adequate medical treatment, a compound must be found that is safe, long lasting and effective (Scully 1995). To this end, research has demonstrated a number of possible treatments, both topical and systemic which have shown promise in the field of oral precancer, but as yet a single agent has yet to be identified which can satisfy all of the above criteria. Table 5. lists medical treatments which have been trialled in the treatment of oral precancer.

Medical options trialled in the treatment of oral precancer
Carotenoids and retinoids
Vitamin C
Vitamin E
Topical Chemotherapy
Polyamine inhibitors
Glutathione S-transferase stimulators
Immunotherapy
Gene therapy
Photodynamic therapy

Table 5. Medical options trialled in the treatment of oral precancer
(Adapted from Scully, C. 1995)

The previously discussed Cochrane review on the management of oral leukoplakia, (Lodi et al., 2008), also reviewed the evidence for the role of medical management in patients with oral leukoplakia. They noted that there were only a few randomised control trials of relevance and that upon examination of the evidence, concluded that, there was no robust evidence to suggest that any of the medical options investigated were effective in preventing relapse or malignant transformation. This perhaps explains the apparently low proportion of UK OMFS consultants currently advocating medical management in the oral precancer patient (Kanas et al., 2011).

2.2.5 Conservative management

An alternative to surgical or medical treatment in oral precancer is conservative management. Also referred to as active surveillance, review or watchful waiting, conservative management is usually instituted following a diagnostic incisional biopsy and involves patient monitoring, typically by means of intra oral visual inspection. Photography may also be used as an adjunct to this process as well as repeat incisional biopsies to assess for pathological tissue changes.

In a recent survey of UK based OMFS consultants, Kanas et al., explored, amongst other things, the use of photography and follow-up in the management of oral potential malignancy. In terms of the use of photography as part of the surveillance process, they noted that 72% of consultants photographed the lesion ‘always’ or ‘most of the time’

(Kanas et al., 2011). This appears to represent a change in practice when the work of Marley et al., is considered. In their survey, conducted 13 years earlier just 13% of the UK based OMFS consultants they surveyed routinely photographed potentially malignant lesions. This finding perhaps indicates the value clinicians place on the clinical appearance of an intraoral lesion.

Kanas et al.'s survey also examined review of precancer patients. They determined that 96% of the OMFS consultants surveyed would follow up patients whose diagnostic biopsy had contained severe dysplasia, whilst 70% would review those with moderate dysplasia. Where these figures would appear to follow recommendations in the literature indicating a continued need for surveillance following an oral precancer diagnosis (Mehanna et al., 2009), they do not indicate the frequency, nor the duration of such reviews. This is important if it is considered that in oral leukoplakia, for example, observational studies report that only 33%-42% (Lind 1987; Silverman, Gorsky and Lozada 1984) of those lesions which undergo malignant change, are thought to do so in the first 2 years following diagnosis. This suggests that long follow up periods may be advisable for these patients.

By exploring the possible management options in oral precancer, it can be seen that a lack of robust evidence may create difficulty for the professional when attempting to plan treatment for an oral precancer patient. This could potentially explain the disparity in treatment practices (Marley et al., 1998), and although calls have been made for the formulation of national guidelines (Kanas et al., 2011), little progress has been made due to a persistent lack of high quality evidence. It can be appreciated therefore that uncertainties associated with the effectiveness of the current available management options may impact on decisions made in clinical practice.

2.2.5 Negotiating treatment decisions

Given that the evidence base for the management of oral precancer is inconclusive, it can be appreciated that decisions surrounding treatment options in oral precancer may be challenging. Evidence previously discussed has demonstrated that management practices vary between units, however, at this point it is also worth considering how such treatment decisions are made given the difficult circumstances.

Making treatment decisions in a health care setting should ideally involve, as a minimum, a health care professional and the patient. In the UK and indeed in many other countries worldwide (Legare et al., 2008) the concept of shared decision making (SDM) is currently felt to be the preferred model for decision making in medicine. (This process is commonly described as: involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment and reaching an agreement about which treatment to implement (Charles, Gafni and Whelan 1997). Indeed the government document 'Equity and excellence: liberating the NHS' states that SDM within the UK's National Health Service should 'become the norm' (Pg. 3) (DoH 2010). It is suggested that for SDM to take place, clinicians will need to spend time developing the necessary skills, which should be underpinned by good basic communication skills (Elwyn et al., 2012) and although some clinicians have expressed doubt over the effectiveness of the SDM process, several randomised control trials support its use (Stacey et al., 2011). Furthermore these studies have demonstrated the advantages of SDM, which include an increase in patient knowledge, an increased confidence in the decisions made (including an increased understanding based on accurate expectations of both positive and negative consequences of treatment) and more active involvement in care.

In practical terms SDM seeks to enable a patient to make their own treatment decisions, while the clinician facilitates this process by 1) providing information and 2) supporting patients while they weigh up their options. A process which sometimes involves the use of specially designed tools. At present there is no available information in the literature relating to the process of decision making in oral precancer management, an area which will be explored further with the study groups.

2.3 An individual's response to a diagnosis of oral precancer

So far the literature reviewed has focused on the group of disorders that may be considered under the umbrella term oral precancer and the possible ways they may be managed with the last section touching upon shared decision making during the treatment planning process. The remainder of the literature review will move on to focus on oral precancer from the patient perspective, examining what it can mean, for an

individual, to experience disease. Specifically there will be a focus on response to illness and factors which may affect this response.

When discussing an individual's response to oral precancer, it is important initially to consider the following points. Firstly, the presentation of oral precancer in the oral cavity is somewhat variable, where for some people oral precancer may be accompanied by mild symptoms, for others it is completely asymptomatic. Signs such as an unusually coloured patch in the mouth may also go unnoticed, often being discovered only during a routine dental intra-oral examination. It is likely, therefore, that a lack of salient signs and symptoms will influence an individual's medical help-seeking behaviour. Secondly, the disease trajectory of oral precancer is somewhat uncertain and is accompanied by an underlying threat of disease progression into oral cancer. For some patients, sometimes following an intervention, complete regression of the disease occurs, rendering the person disease free. However, for the remaining individuals whose disease neither transforms nor regresses, it assumes a chronic course. From this it can be seen that it is unlikely all people diagnosed with oral precancer will respond in the same way. For some oral precancer will be an acute condition of temporary significance, constituting a transitory and limited disruption in their lives. Whereas for others, oral precancer may be thought of as a chronic illness, insofar as its disease course is persistent and long lasting. The following section will explore response to illness taking into account the complex and unclear pathway of oral precancer, a topic on which there is very little to be found in the literature.

2.3.1 Recognising symptoms and illness behaviour

The decision to seek treatment for an illness usually starts with the experience of symptoms. This does not mean that every individual experiencing a symptom will seek medical help, nor will they necessarily consider themselves to be ill. The way in which an individual interprets and acts upon a symptom is called 'illness behaviour' (Mechanic 1962) and it is this behaviour which determines whether a decision to attend a doctor is made.

It has long been recognised that much ill health does not reach medical attention. This is known as the 'clinical iceberg' (Last 1963) (Hannay 1980) in which illnesses presented to medical professionals constitute only the tip of the iceberg. An example of

this is demonstrated by the work of Scambler et al., in which a group of women were asked to keep a diary for six weeks, documenting any symptom experienced (Scambler, Scambler and Craig 1981). Their findings indicated that although symptoms were a frequent occurrence, medical attention was not sought in each case. In fact it was reported that on average a medical consultation was conducted for every 18 symptoms recorded. Waiting until multiple symptoms have been experienced can lead to delay in seeking treatment which can impact on disease outcome.

Although no work exists in the literature relating to oral precancer and illness behaviour specifically, studies looking at patients with signs or symptoms of oral cancer have shown that these patients often delay seeking medical attention, with some studies reporting delay in up to 54% of cases (Scott et al., 2006; Scott, Grunfeld and McGurk 2006; Scott, McGurk and Grunfeld 2008). This is significant as detecting head and neck cancers at an early stage is believed to be the most effective means of reducing death and disfigurement from this disease. (Dolan, Vaughan and Fuleihan 1998) These studies were selected for review because some of the signs and symptoms of oral precancer are common to oral cancer, for example the presence of an intra-oral red or white lesion. It is likely that if patients with symptoms of oral cancer delay seeking medical attention, patients with oral precancer too may delay seeking medical help.

Although these and other studies have shown that people do not always seek medical attention for a symptom, they do not always indicate the possible reasons for this behaviour. In a bid to explore what prompts an individual to seek treatment generally, Mechanic and Volkart conducted a study investigating the circumstances under which symptomatic individuals are prompted to seek medical care (Mechanic and Volkart 1960). Following on from this earlier work Mechanic later went on to define ten variables thought to affect a person's decision to attend for a medical consultation. (Mechanic 1978a) (Table 6.)

1.	Visibility, recognisability, or perceptual salience of signs and symptoms
2.	The extent to which the symptoms are perceived as serious
3.	The extent to which symptoms disrupt family, work and other social activities
4.	The frequency of the appearance of signs or symptoms, their persistence or their frequency of recurrence
5.	The tolerance threshold of those who are exposed to and evaluate the signs or symptoms
6.	Available information, knowledge and cultural assumptions and understanding of the evaluator
7.	Basic needs that lead to denial
8.	Needs competing with illness responses
9.	Competing possible interpretations that can be assigned to the symptoms once they are recognised
10.	Availability of treatment resources, physical proximity, and psychological and monetary costs of taking action

Table 6. Mechanics Ten Variables

(adapted from (Mechanic 1978a))

Observing the limitations of these variables, Mechanic noted that the relationship between symptom experience and help seeking behaviour is complex and that the ten variables identified are often seen to interact with one another. When investigating a person's response to the detection of precancerous signs or symptoms, the first of Mechanic's variables: visibility, recognisability, or perceptual salience of signs and symptoms is of particular relevance. As discussed, one significant feature of oral precancer is that, for many, it is an asymptomatic disease. This can also be true of oral cancer in the early stages. Indeed, it has been shown that even when oral signs or symptoms are present they are often misinterpreted both by the patient and the professional. This is demonstrated by the work of Guggenheimer et al., who, when investigating factors associated with delay in oral cancer, found that patients were unable to distinguish between ominous and innocuous manifestations of their disease (Guggenheimer et al., 1989). They went on to suggest that patients had a tendency to attribute oral signs or symptoms to previously experienced common oral or dental conditions. Furthermore, Guggenheimer et al., also reported that in addition to patient delay, professional delay occurred in around a third of cases. In other words, as a

separate incidental finding, once individuals presented themselves to primary care professionals with signs or symptoms of oral cancer, delay was noted when referring these patients on to secondary care. While no additional information was sought the authors put forward incomprehensive examination, misleading signs and symptoms, low index of suspicion and lack of experience as potential explanations for this.

Another of Mechanic variables may be identified when looking again at the work of Scott et al., In this study the patients saw persistence of symptoms (variable 4) as a significant factor which prompted the person to seek medical advice (Scott et al., 2009). However, attending as a result of persistent symptoms clearly relies on the person being able to identify the presence of a sign or symptom in the first instance which may not always be the case for the oral precancer group.

Looking further at factors affecting medical consultation, Zola conducted a study investigating the importance of timing on decisions to seek medical care (Zola 1973). Through this work he highlighted the significance of the context in which an individual conducts an assessment of their symptoms. Specifically, he identified five 'triggers' thought to precipitate a consultation:

1. The occurrence of an interpersonal crisis
2. The perceived interference with social or personal relations
3. 'Sanctioning' (pressures from others to seek consultation)
4. The perceived interference with vocational or physical activity
5. A kind of 'temporalizing of symptomatology' (the setting of a deadline, e.g. if it has not resolved by next week I'll make an appointment at the GP)

The importance of sanctioning (trigger number 3) is seen in another of the Scott et al., 's studies investigating patient delay for potentially malignant oral symptoms (Scott et al., 2006). This qualitative study reported that people who discussed their experience of symptoms with others tended to seek help soon after they developed their oral symptoms as a result of what was described as 'encouragement to seek help'.

Another consideration is that of gender specific illness behaviour, and the evidence that women consult doctors more frequently than men. There is a longstanding view that women report many more of their symptoms than men (Mechanic 1978b). This is of

significance in oral precancer as, despite rising levels of disease in women, males continue to be predominantly affected. As an example, Napier and Speight report that over two thirds of those diagnosed with oral precancer are male (Napier and Speight 2008).

The works described in this section highlight that the experience of a symptom alone is often not enough to bring about a medical consultation, but additional processes may need to occur before health seeking behaviour occurs. The following section will go on to explore the cognitive explanations patients may use to make sense of their illness following symptom recognition.

2.3.2 Making sense of illness – lay theories

Once an individual has identified signs or symptoms as an indicator of illness, many use complex explanatory models in order to make sense of their illness. These models are also known as lay theories. Armstrong suggests that lay theories probably stem from three origins:

1. Idiosyncratic – based on the patient's own observations and experiences
2. Popular – knowledge derived from friends and relatives
3. Expert models of illness – information from biomedicine (Armstrong 1994)

Lay theories are of relevance to the individual not just at the outset of illness but throughout the course of their disease. These explanatory models may influence many factors including; recognition of a symptom, the decision to seek medical attention, the relationship with the medical professional, acceptance of diagnosis, satisfaction with care, acceptance of treatment, and avoidance of perceived risk factors. It is vital, therefore, for the medical professional to take into account that the patient attends for consultation not only with signs or symptoms of disease but also with a complex belief system which may or may not agree with their own. For example, in a paper examining lay beliefs about familial risk in common chronic diseases, Walker et al., found that people at risk of developing such diseases included fatalism in the mental models they developed to cope with and control the risk of disease development (Walker et al., 2004). Such a belief can have significant implications on the success of potential

management strategies, such as reduction of risk factors. For oral precancer this would be of importance as risk factor modification is often a part of the management strategy.

Work by Williams proposed that a person's belief about their illness, specifically thoughts regarding its cause, play an integral part in locating their disease in the context of their lives, through a process he called 'narrative reconstruction' (Williams 1984). Through his work, he described three individual's accounts of their illness (arthritis) and noted each person's viewpoint when recounting their explanations surrounding disease development. Each interviewee attributed the genesis of their illness to a very different cause – working conditions, gender specific factors and God's will. Although the three individuals were experiencing the same disease process it was noted that all three used their opinion of disease origin to alter the social narrative accompanying their lives and in so doing, made sense of their present lives by giving meaning to the disruption caused by illness. In Williams' study none of the explanations provided by the patients accounting for disease development was seen to correlate to a biomedical explanation for their disease. Williams suggests that medical professionals should consider differing beliefs about causes of illness as a possible explanation for the resistance of some patients to medical accounts for their disease.

Lay theories may be used not only to help explain how individuals attribute cause to their particular illness, but they may also influence which individual's present for advice, help and information when faced with illness (Furnham 1994). If information gained from friends and family leads to a consultation with a medical professional this is known as the 'lay referral system' (Freidson 1970). The lay referral system has parallels to the medical referral system in that advice is sought from more knowledgeable individuals, and action taken based on this advice.

As well as providing disease explanation and affecting help-seeking behaviour, lay knowledge can be used to enhance professional understanding of the relationship between social circumstance and individual behaviour (Popay and Williams 1996). For example, in work carried out with low-income female smokers, smoking appeared to provide a way of coping whilst dealing with full time care of young children and poverty (Graham 1987). As a risk factor in a number of diseases including oral precancer, smoking cessation is often advised, however, factors such as personal

circumstance, as outlined above, must be considered when attempting to effect behaviour change.

This section has explored how individuals make sense of illness, specifically looking at the influence of lay theories. Following on from this response to illness will now be examined.

2.3.3 Response to illness - oral precancer as an acute illness

Once an individual has made the decision to seek treatment and a diagnosis is made, they must then try to cope with that illness. In the case of an acute illness, this may be straightforward as it is not expected to last, however, in the case of a chronic illness; the readjustment needed may be more complex.

If we consider oral precancer as an acute illness then we assume that having the disease is a temporary state from which the patient either recovers or their disease transforms into oral cancer. In acute disease, it has been suggested that a person's ability to perform their normal social role is impaired, returning only when the transition is made from ill back to healthy. In other words, acute illness affects not only the individual but also societal order. This is seen as undesirable, as Parsons states:

it is clear that there is a functional interest of society...in the minimization of illness (p.430) (Parsons 1951)

The concept of the sick role was introduced to describe the relationship between the doctor and the acutely sick person who is no longer able to perform normal social roles (Parsons 1951). From the patient perspective there are four main aspects of the sick role, two rights and two obligations (Table 7.) and from the doctor's perspective, four expectations and three rights (Table 8.).

Rights	Obligations
1. The sick person is exempt from their normal social roles	1. The sick person is obliged to see being sick as undesirable and want to get well as soon as possible
2. The sick person is not held responsible for his or her state	2. The sick person is obliged to seek qualified help

Table 7. Patients rights and obligations when assuming the sick role
(Adapted from (Parsons 1951))

The Parsonian sick role is best illustrated with the example of a temporary acute physical illness. With a physically limiting illness it is possible to see how someone may move away from their normal social role and put themselves in the hands of a medical professional, temporarily relinquishing their independence. If the illness is not physically limiting however, as is often the case in oral precancer, an individual may be capable of carrying out normal social tasks e.g. employment, parental tasks, whilst still seeking professional help.

Expectations	Rights
1. Apply a high degree of skill and knowledge	1. Granted right to examine patients physically
2. Act for the welfare of the patient and community	2. Autonomy in professional practice
3. Be objective and emotionally detached	3. Occupy position of authority in relation to the patient
4. Be guided by the rules of professional practice	

Table 8. Doctors expectations and rights in the sick role
(Adapted from (Parsons 1951))

Further difficulties with the sick role in relation to oral precancer appear when considering risk factors for oral precancer. Examples are seen in the literature where a person may be held responsible or blamed for their illness particularly in relation to alcohol consumption (Chalfant and Kurtz 1971) and smoking related disease (Chapple,

Ziebland and McPherson 2004), the two main risk factors in oral precancer. In this way one of the 'rights' of the sick person are revoked (one of Parsons rights being the sick person should not be held responsible for their disease). It would seem, therefore, that the sick role is a conceptual model that does not apply equally to all people who experience illness. Having highlighted difficulties in attributing response to oral precancer as an acute disease, response to oral precancer as a chronic illness will now be discussed.

2.3.4 Response to illness - oral precancer as a chronic illness

When considering the impact of chronic disease on an individual, the concepts of self and identity are especially important. Self may be considered a coming together of multiple elements to constitute the individuality of a person. Self is a cognitive construct that is constantly being reconstructed (Kelly and Field 1996), and can therefore be altered by life events including illness. Identity, on the other hand, is public and is a view held by others based on shared behavioural or personal aspects of the individual. The two are closely related and so the umbrella term self-identity is often seen in the literature.

Gerhart puts forward two view-points as possible explanations of the relationship between illness, self and identity. She calls these the crisis model and the negotiation model (Gerhardt 1989). In the crisis model, becoming ill is about identity change. Symptoms of body alterations lead to societal reactions which in turn lead to internalisation and alterations in the self. Early oral cancer and precancerous lesions are often subtle and asymptomatic (Neville and Day 2002). As a result changes in the body are often not visible and the person may, therefore, choose to try and pass themselves off as normal in order to avoid these societal reactions (Goffman 1963). In contrast, the negotiation model characterises chronic illness as a process of loss of self. In this model, an illness, like oral precancer, does not necessarily affect a person's outward appearance but affects how people perceive themselves.

Outward evidence of illness can be important as it has been shown that the presence of a visible physical abnormality may evoke a negative reaction (Goffman 1963). Such a negative response is known as stigma, which was defined by Goffman as an 'attribute that is significantly discrediting' (Pg. 3) leading to a 'spoiled identity' for the individual

concerned. People who have an illness that is not visible may still be stigmatised if their condition becomes apparent or the person chooses to reveal it, for example in HIV and AIDS where stigma is a significant problem often resulting in the discrimination of this group (Parker and Aggleton 2003). Where the experience of cancer as an illness is associated with stigma, (Muzzin et al., 1994) it is not known if those with precancer experience similar social responses. A paper by Chapple et al., however, highlighted the relationship between smoking, lung cancer and stigma, which was felt by the participants to be particularly difficult due to the perceived self-inflicted nature of the disease (Chapple, Ziebland and McPherson 2004). This association between stigma and smoking related illness may be of significance to the oral precancer study group as the disease is strongly associated with smoking.

Another well-established concept associated with chronic illness is that of biographical disruption. If we consider Gerhardt's views on chronic illness, this concept would fall into the explanations put forward by the negotiation model. Bury (1982) describes chronic illness as a disruptive event which results in a change in the individual's inner biography. He suggests that chronic illness is an experience where the structure and form of a person's everyday life and the knowledge supporting this form is altered. A new biography must therefore be established incorporating the effects of the illness.

Biographical disruption has been explored and applied to a number of chronic diseases, including, rheumatoid arthritis (Bury 1982) and chronic pain (Richardson, Ong and Sim 2006). Where these chronic diseases have a propensity to peak and trough in terms of their symptoms, this is not always the case in oral precancer. As yet there has been no attempt in the literature to explore the process of biographical disruption with oral precancer or indeed oral cancer patients. Attempts have been made, with some success, to apply the concept to a group of patients with prostate cancer (Navon and Morag 2004) and a group of women with cervical precancer (Rajaram et al., 1997). In the first of these two papers men's difficulties classifying themselves into culturally available categories following hormonal treatment for prostate cancer is explored. The authors indicate that the men were unable to consider themselves wholly male, in a cultural sense, post treatment. As a result their pre-treatment relationships are affected. This paper demonstrates that in spite of clinically successful treatment, significant disruptions to an individual's life (in terms of their sense of self) may continue. Looking specifically at precancer, the second of the two studies involved women who

had received a diagnosis of cervical precancer. The authors put forward the case that these women, whilst they did undergo biographical disruption, found that there were specific difficulties associated with this process. It was felt that these difficulties primarily stemmed from uncertainty, especially the perceived uncertainty of the diagnosis. The group had particular difficulty distinguishing between cancer and precancer. As a result the meaning of their illness was often put into context by drawing on past personal experiences of cancer rather than precancer (i.e. cancer affecting a friend or relative). It was found that a significant proportion sought additional medical information which in turn brought clarity to their diagnosis and brought about the 'mending (of) the personal identity' (p.529) (Rajaram et al., 1997).

The concept of biographical disruption was later re-evaluated by Williams in 2000. In his paper, Williams reflects on the strengths and weakness of the concept of biographical disruption (Williams 2000). In particular Williams highlights the importance of timing, context and circumstance on biographical disruption. Biographical disruption requires that disruptive event occurs resulting in a re-working of an individual's inner biography and a subsequent change in the individual's self-concept. Focusing on the timing of the disruptive event, Williams states that what may be considered a disruptive event for some, may for others be accepted as part of normal everyday life. One example used was that of disease considered to be age related and therefore seen as 'normal' or 'expected'. In these circumstances he suggests that disease is biographically anticipated rather than biographically disruptive.

As we have explored by looking at the work of Bury, illness, particularly chronic illness, results in a change in the way a person perceives themselves. The perception of self is closely associated with self-images which are developed and maintained throughout life through social relations (Charmaz 1983). Positive self-images are required for a positive sense of self, however, it is proposed chronic illness can lead to the 'crumbling away' of former self-images. Experiences then altered by illness may result in positive images diminishing, being replaced by new ones framed by an 'ill' point of reference. These new images may not be as positive and worthwhile as previous images. The resultant struggle to maintain a sense of self-worth leads to a 'loss of self' which can have a marked effect on an individual. Charmaz states that this 'loss of self' is exacerbated by four social psychological conditions:

1. living a restricted life
2. existing in social isolation
3. experiencing discrediting definitions of self
4. becoming a burden

Again, no work in the literature could be found pertaining to oral precancer. However, a study Røing and colleagues examined patient experience of oral cancer and treatment, (Røing, Hirsch and Holmstrom 2007) through this work they demonstrated that oral cancer patients undergoing treatment for their disease experience all four of these psychological conditions. As an example, in terms of social isolation, one study participant comments that following treatment for oral cancer he no longer received invitations to friends for dinner. It can, therefore, be seen that in oral cancer the effects of the disease and its treatment could conceivably result in a loss of self through the means suggested by Charmaz.

This section of the literature review has focused on an individual's illness behaviour, specifically examining how people respond to the discovery of signs and symptoms and the processes which may take place prior to that individual seeking medical attention. This was then followed by an exploration of how lay theories may impact on how individuals make sense of their disease and finished by exploring oral precancer as either an acute or chronic illness. The next and final section of the literature review will go on to consider the impact of uncertainty in illness. As previous sections have pointed out, a number of uncertainties exist for clinicians managing patients with oral precancer. I felt, therefore, that it may be possible that individuals with oral precancer may also experience uncertainty.

2.4 Uncertainty in illness

This section will focus on uncertainty in illness. As little exists in the literature on the topic of uncertainty in oral precancer, this discussion will draw upon work primarily from the cervical precancer literature. Although it is recognised that there are several important differences between cervical and oral precancer groups, there are also a number of common features which make reviewing this small body of literature worthwhile. Specifically: both diseases are associated with the threat of developing an

invasive cancer (Kalliala et al., 2010; Napier and Speight 2008) both may present without signs or symptoms (Khan, Appleton and Turner 2008; Neville and Day 2002), both have the potential to regress over time (Moscicki et al., 2010; Ramseier et al., 2010) and both currently have unclear treatment pathways (Kumar et al., 2013; Melnikow et al., 2002).

Initial review of the cervical precancer literature, and in particular studies which address the patient experience of cervical precancer, highlight one finding of particular note; that of the uncertainty commonly associated with a cervical precancer diagnosis (Juraskova et al., 2007). Further reading suggests that, for patients', uncertainty is predominantly associated with ascribing meaning to their diagnosis and making treatment decisions (Kavanagh and Broom 1997). This is perhaps not surprising in an area where, like oral precancer, robust evidence regarding treatment effectiveness is lacking (Melnikow et al., 2002). Importantly, it would seem that uncertainty for many individuals with cervical precancer group is a negative attribute, which studies suggest may contribute to the confusion and increased anxiety often seen in this patient cohort (Gray et al., 2006; Shinn et al., 2004).

This section will, therefore, go on to explore uncertainty associated with a diagnosis, uncertainty associated with treatment decisions and will finish by considering how individuals cope with and manage uncertainty. As discussed, evidence from the cervical precancer literature will be sought, however, the wider literature will be considered to further illustrate a number of the points made.

2.4.1 Uncertainty surrounding the meaning of the diagnosis

For patients with cervical precancer, the point of diagnosis is often a challenging one. In particular, studies indicate that patients may have difficulty comprehending their diagnosis, which can result in confusion and, in some cases, results in patients coming to the conclusion that their condition has no diagnostic label (Karasz, McKee and Roybal 2003). Furthermore, the impact of an uncertain diagnosis can be significant and may lead, for example, to difficulty seeking further information about their disease as well as negative thoughts surrounding the diagnosis (Fylan 1998).

In relation to comprehending the diagnosis, it appears that the terminology used to describe it is relevant (Juraskova et al., 2007). Confusion associated with a cervical precancer diagnosis may be exacerbated by the terminology used, which patients often find inaccessible and difficult to understand. Precancer in particular, when used as a diagnostic term, may be unfamiliar and misunderstood as cancer as patients draw upon their wider understanding of cancer to make sense of their diagnosis (Kavanagh and Broom 1998). This can lead some to conclude that a precancer diagnosis will unavoidably result in an eventual cancer diagnosis (Juraskova et al., 2007). The effect of making this link is highlighted in a study exploring women's understanding of cervical precancer, in which Kavanagh and Broom report that some women, after linking precancer with cancer, began to have thoughts about death and dying (Kavanagh and Broom 1997). In another study involving patients with cervical precancer, the diagnosis was seen to preoccupy daily life and was experienced negatively as a threatening condition (Posner and Vessey 1988). Other works support this finding and further suggest that individual's may experience anxiety following a precancer diagnosis regardless of the level of severity of the precancer (Wardle, Pernet and Stephens 1995).

As well as patients reporting feelings of uncertainty in association with specific diagnostic terms (like precancer), where the diagnosis is viewed as ambiguous feelings of uncertainty may be perpetuated further. Indeed, studies indicate that were patients with cervical precancer interpret their diagnosis as vague, they sometimes conclude that there is no discernible label for their condition (Karasz, McKee and Roybal 2003). Difficulty with a lack of label can be seen in its most extreme form using the example of those with medically unexplained symptoms. For these patients there is no diagnostic label. In a study by Nettleton et al, interviews were undertaken with patients attending UK neurology departments (Nettleton et al., 2005). Each participant was symptomatic, but despite medical investigation, did not have a current clinical diagnosis. One feature common to the participants' narratives was that of chaos, characterised by confusion and uncertainty. The authors describe participants as having particular difficulty with no clear beginning or end to their illness, with patients having 'no route maps for a metaphorical journey'(Pg.206). For these patients it is not possible to say whether they will improve, deteriorate or indeed to give any indication of what their outcome would be. Although a diagnostic label is present in oral precancer, it is conceivable that uncertainty and confusion may exist where patients are in doubt over their diagnosis. It

is possible that these patients may then subsequently experience difficulties comprehending disease trajectory.

A further factor seen in the cervical precancer group which appears to be of significance in relation to uncertainty at the diagnosis stage is the notion that the person often feels well. This may make it difficult for individuals to take on board an unexpected diagnosis because there is a difficulty accepting that they might be 'ill'. Indeed Hounsgaard et al., have demonstrated that when feeling well, individuals with cervical precancer are unprepared to do anything other than confirm they are well (Hounsgaard, Petersen and Pedersen 2007). This can lead to frustration at feeling apparently healthy when also potentially ill. This may be of significance when considering the individual with oral precancer, for whom there are often no detectable symptoms.

Within the context of receiving a diagnosis despite a lack of salient signs or symptoms, another interesting concept present in the cervical precancer literature is the concept of mistrust in one's body (Juraskova et al., 2007). For example, some of the women in Juraskova et al's study describe a sense of betrayal by their body as a result of its inability to warn them of the disease present. This concept was particularly felt by those who took care of themselves or considered themselves to be healthy (Juraskova et al., 2007). Again, it may be possible that people with oral precancer feel similarly due to the often asymptomatic nature of the disease.

2.4.2 Uncertainty surrounding treatment

As well as uncertainty presenting at the point of diagnosis there is also potential for patients to experience uncertainty during the management phase of their disease. This may be especially so for oral precancer patients in that, as discussed, given the often asymptomatic nature of their condition, it may be difficult for individuals to accept that they are ill. It would not seem unreasonable to suggest, therefore, that this may potentially impact on an individual's ability to make or engage with treatment decisions. However, even where individuals acknowledge that they are ill, a lack of clear evidence pertaining to treatment effectiveness may lead again to uncertainty; this time associated with the aim or perceived success of the treatment.

If we begin by considering treatment of the asymptomatic patient, looking to the wider literature, it is possible to draw parallels between oral precancer and hypertension. In common with oral precancer, hypertension may be a largely asymptomatic disease however, it is associated with the threat of progression to something more sinister (although rather than malignancy the risk instead includes: stroke, myocardial infarction, heart failure, chronic kidney disease, cognitive decline and premature death (NICE, 2011)). When considering the treatment of hypertension, the aim, much like that in oral precancer, is to prevent the patient from developing a more serious condition. However, in hypertension, unlike precancer, treatment often takes the form of medical management. In relation to this, the literature suggests that many patients with hypertension experience difficulty complying with a medical regimen (Crowley et al., 2013). It appears that failure to adhere to medical treatment, for some, is directly related to individuals questioning the need for treatment at all, given their apparent good health (Chrostowska and Narkiewicz 2010).

Although the literature on hypertension may allow us to appreciate areas of potential significance when managing asymptomatic disease with drug therapy, this currently represents the least common approach to oral precancer management with conservative management or surgery instead being more usual options (Marley et al., 1996). The role of uncertainty in each of these management options will now be discussed.

When focusing on conservative management, the wider literature suggests that uncertainty regarding the aim of conservative management may result in concern and distress. For example, if we look at prostate cancer (in which, similar to oral precancer, there is no specialty agreement regarding optimal treatment), one management option often employed for early-stage prostate cancer is that of ‘watchful waiting’ (Donovan et al., 2002). Watchful waiting, also known as conservative management, surveillance, expectant management, deferred therapy or active evaluating, provides an option by which the disease is monitored and if progression is seen surgical treatment may be considered. This approach avoids the undesirable side effects of more aggressive (surgical) interventions. However, watchful waiting may be associated with its own undesirable effects, primarily associated with uncertainty regarding the aim of this management approach. In particular studies have noted a number of negative responses to watchful waiting including: ‘living under a dark shadow’ (Hedestig, Sandman and Widmark 2003) ‘analogous with doing nothing’ (Bailey and Wallace 2007) or the

perception that watchful waiting is the equivalent of ‘watch(ing) while I die’ (Donovan et al., 2002). Significantly though, Bailey et al., demonstrated that this type of uncertainty may be managed. They demonstrated the effectiveness of a watchful waiting intervention in helping men cope with the uncertainty associated with watchful waiting in prostate cancer (Bailey et al., 2004). Moving away from the prostate cancer literature and looking once again at the cervical precancer literature, studies also indicate that for people with cervical precancer ‘observation may also cause anxiety’ (Melnikow et al., 2002), which, furthermore, may be heightened with each review appointment (Hounsgaard, Petersen and Pedersen 2007).

Much like oral precancer, as well as conservative management, patients with cervical precancer may alternatively undergo surgical treatment for their disease. Although there is much less in the literature on the topic of uncertainty in precancer surgery, a study by Meana et al., indicates that highly anxious women with cervical precancer often opt for surgical over conservative management (Meana et al., 1999). Although the study design does not allow the reasons for this finding to be explored it is possible that these patients are choosing surgery in order to remove their disease and relieve themselves from the uncertainty associated with monitoring it instead. A desire to obtain relief from uncertainty is seen elsewhere in the literature (Williams et al., 1999).

2.4.3 Coping with and managing uncertainty

It can be seen from the previous section that uncertainty plays a significant role in a number of illnesses including that of cervical precancer. With this in mind it is important to consider how this uncertainty is addressed by clinician’s particularly in instances where uncertainty results in a negative outcome for the patient.

Before considering how to manage uncertainty, Brashers states that first we should consider how uncertainty is viewed by patients (Brashers 2001). He states that uncertainty is not interpreted uniformly, for example in the cervical precancer literature outlined previously uncertainty is viewed predominantly as a negative attribute and is linked to negative emotional responses. However, uncertainty is not always viewed negatively and for some can be seen as important for maintaining hope (for example where long term prognosis is uncertain). To this end, the way uncertainly is experienced by an individual will influence how a clinician seeks to facilitate its

management. Where historically the literature has focused on uncertainty reduction, where uncertainty is seen as positive this may not be the most appropriate strategy. It has been proposed, therefore, that rather than aiming to eliminate uncertainty, for some diseases *managing* uncertainty is more appropriate.

However, uncertainty is appraised by an individual, the most important aspect of uncertainty management is communication (Brashers 2001). Taking cervical precancer once again as an example it has been suggested that not only is good communication between the doctor and patient of importance in coping with uncertainty, but that poor communication itself may in fact generate uncertainty (Karasz, McKee and Roybal 2003). Associated with the genesis of uncertainty in cervical precancer are problems with lack of reassurance, lack of adequate consultation time or a feeling of being rushed and, linked with the latter, lack of opportunity to ask questions. Particularly of note in Karvanagh and Broom's study was the observation that being told 'not to worry' did not satisfy most women. Poor communication and a failure to address important concerns led to dissatisfaction with care and further led some women to conclude that their physicians were incompetent (Kavanagh and Broom 1997). Conversely, the same group indicated that they appreciated doctors who expressed uncertainty about their own knowledge, suggesting that doctors should not be apprehensive about communicating their own uncertainty.

Looking to the wider literature, in patients with pulmonary artery hypertension, Flattery identified several ways in which a group of these individuals coped with uncertainty. In common with the observations of others (Brashers 2001) information seeking was strategy used by some of this group (Flattery et al., 2005), with the internet being cited as a particularly common source of additional information. However, Flattery suggests that as this source of information is not always reliable health care providers should assess available sites and refer their patients to the most appropriate and accurate resources.

For patients with cervical precancer, studies suggest that not only do these women take part in information seeking behaviour, but that their information needs are not always met. This may lead to women seeking advice from sources other than their treating clinician including the internet, leaflets, media and other clinical staff. Clinicians should be aware of patients information seeking behaviour, particularly as studies have

shown that while many internet sources are often not dependable, patients believe them to be useful and accurate (Metz et al., 2003).

This section has briefly discussed the role of uncertainty in illness, beginning with the mechanisms by which uncertainty may occur at the diagnosis stage. It went on to consider uncertainty associated with management of a disease and concluded by considering the significance of communication and information seeking when managing uncertainty. This section completes the literature review. The following chapter will go onto describe the aims and objectives of the studies undertaken as part of this work.

Chapter 3. Research Aims and Objectives

Aim

To investigate both patients and professionals experiences of oral precancer with a view to identifying opportunities to improve patient care.

This will be achieved through two separate but related studies.

Study A objectives

This study will critically examine patients' experiences and understanding of oral precancer through a series of qualitative semi-structured interviews. The study's objectives are:

1. To gain an insight into the understanding patients have of their disease
2. To explore what patients recall of the information they receive in relation to their disease
3. To explore their views of the medium through which information was given
4. To explore the impact of the diagnosis on the individual's life and health related behaviours
5. To explore their views of their ongoing clinical management

Study B objectives

Study B will look at oral precancer from the clinician perspective using qualitative semi-structured interviews. The study's objectives are:

1. To determine how the diagnosis of oral precancer is explained to a patient and to ascertain how concerns are addressed.
2. To determine if behaviour change, specifically modification of risk factors, is considered an important factor in the management of oral precancer and if so what action is taken to assist patients with this
3. To determine the how decisions are made relating to management options for patients with oral precancer.

Chapter 4. Methodology and Method

The aim of this chapter is to explain the decisions made regarding the approach taken with respect to the conduct of the project. In doing so, this chapter aims not only to describe the specifics of the research method (the details of the process itself) but also the underlying methodology underpinning the research alongside the theoretical perspective to which the methodology relates.

4.1 Philosophical assumptions

Each methodological approach is informed by a set of assumptions about the researcher's ontological (beliefs about the nature of reality) and epistemological (beliefs ways of knowing and learning about the social world) beliefs. Which in turn inform the research approach taken and ultimately the study design.

4.2 Ontology

If we begin by examining ontological perspectives, the stance taken here essentially describes the researchers view on the nature of reality (Nicholls 2009), which in the context of the social sciences refers to social reality. The most prominent ontological viewpoints are realism and idealism, with realism and idealism being at either end of a spectrum. In realism, it is put forward that social reality is external and exists independent of our human beliefs or understanding. Idealism, on the other hand, purports that social reality is only knowable through the human mind. It can be seen therefore, that in idealism multiple realities may exist as individual human interpretations are subjective and therefore unlikely to be uniform. To consider these two stances alone is to oversimplify things somewhat. In between these viewpoints there exist a number of variants. Subtle realism is one such variant of realism which, in common with realism states that an external reality exists independent of our understanding, however, it states that reality is only knowable through the human mind and socially constructed meanings (Mays and Pope 2000). This viewpoint, therefore, acknowledges that the researcher is likely to have an impact on the research in that their subjective perceptions and understandings will be involved in the interpretation of the

research. It is this view (subtle realism) that I have chosen to subscribe to and will inform the interpretation of the research findings.

4.3 Epistemology

Epistemology is concerned with the way we seek to know about the world (Green and Thorogood 2011). There are, in essence, two main epistemological stances that exist in the social sciences:

- Positivism
- Interpretivism

These stances are essentially polar opposites in that positivists rely on the belief that there is one objective reality, that this reality can be measured and understood and that it remains unaffected by the researcher. A positivist standpoint is typically associated with quantitative research in which a deductive approach is taken to empirically test a hypothesis. Interpretivism on the other hand, takes the viewpoint that there are multiple ways of knowing the world because people are different and are likely to experience the world in different ways (Nicholls 2009). They acknowledge that the researcher potentially affects the research being carried out. Interpretivism is primarily associated with qualitative research and is the stance that is applied to this research.

4.4 Methodology

Once the philosophical framework of the researcher is established, there is a vast array of methodological approaches which may be applied to each framework. The approach taken throughout this study was a generic qualitative approach (Caelli, Ray and Mill 2003). This is an approach increasingly practised within the health sciences which utilises the core characteristics of qualitative research (the characteristics used in this study will be highlighted in the forthcoming paragraphs) and is an approach which is deemed appropriate where the study in question seeks to “understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (p.3) (Caelli, Ray and Mill 2003) .

4.5 Research approach

As the label given to the chosen methodology might suggest (generic qualitative research), the approach taken throughout this study was qualitative. In terms of potential approaches to the study design there are two main research paradigms: qualitative and quantitative. When designing a study, the approach adopted will be informed not only by the researcher's theoretical perspective, but also by the nature of the research question.

Qualitative research seeks to understand human behaviour; it seeks to investigate the meanings people attach to their experiences of the social world. The goal of qualitative research is to develop concepts which improve our understanding of social phenomena in natural, rather than experimental settings (Pope and Mays 1995). Quantitative research, on the other hand, is concerned with quantification and numerical analysis and is often seen in conjunction with empirical research. To fully appreciate how each may be applied to the same topic and using oral precancer as an example, a quantitative study may seek to discover *how many* referrals are made from primary to secondary care (Brocklehurst, Baker and Speight 2009b), whereas a qualitative study may seek to determine *why* the referrals were made by exploring the rationale behind these referral decisions (Brocklehurst, Baker and Speight 2009a).

This project is divided into two studies: study A involving individuals who have been diagnosed with oral precancer and study B involving clinicians (OMFS consultants) involved in the care of patients with oral precancer. Initially study B was to be a quantitative survey seeking to determine current management strategies undertaken by UK based OMFS consultants. The intention was to compare this to historical data to determine if management strategies are changing over time. However, following the patient study (study A), I felt that a more logical approach would be to investigate the clinicians' perspective of areas of oral precancer management using the areas highlighted by the patient study group as a basis for the investigation. Therefore, ultimately, both studies were qualitative in design, utilising semi-structured interviews to gather data.

Although historically used primarily in the social sciences, qualitative techniques, and in particular qualitative interviewing, have been shown to play a valuable role in health

care research and as a result are now becoming more common place (Pope and Mays 1995; Britten 1995; Gilbert 2008). Although qualitative interviews are the most common method of qualitative data collection in the medical sciences, it is worth mentioning that many other forms of data collection exist in qualitative research. Alongside interviewing, these primarily include: observation, participation and analysing documents and material culture (Marshall and Rossman 2006).

4.6 Qualitative interviewing

I felt that for the purposes of this research semi-structured in-depth interviews would be the most appropriate form of data collection. (Lewis and Ritchie 2003) (Lowes and Gill 2006). Specifically, I felt that this particular method would be best suited to achieving the research aims, namely exploring patients' and professionals' subjective experiences and views of oral premalignancy and the underlying understanding and beliefs that contribute to the formation of these views. I will now go on to discuss this research method in more detail.

Kahn and Cannel describe qualitative interviewing as a 'conversation with a purpose' (p.149) (Kahn and Cannell 1957). While the interview may be organized to some degree (in that the interviewer has in mind a broad framework of objectives, i.e. areas they wish to cover) it is not intended to be a formal interaction, being largely shaped by the responses of the interviewee. This is important in that the purpose of the interview is to explore the participant's reality, their experience of a particular phenomenon and how they make sense of it. Unlike many conversations in the clinical context (which as a dentist I had previously been more familiar with) open ended questioning is favoured so that these experiences can be explored.

In general terms, qualitative interviews may be semi-structured or unstructured. Structured interviews may also be conducted but these constitute a quantitative method of interviewing and by their nature do not allow for the exploration of a topic in the way that the other interviewing methods do. Unstructured interviews, on the other hand, are much less predetermined and largely informed by the response of the participant (Pope and Mays 2006). As previously mentioned, the interviews conducted for my research were semi-structured. This was a decision made to ensure that specific areas of interest relative to the study objectives were explored with the participants. The semi-structured interview is guided, to some extent, by a pre-prepared interview schedule or topic guide.

This allows the interviewer to cover anticipated areas of interest with all participants, but is evolving in its nature in that new unanticipated subject areas may be added to the guide as the study progresses. In this way it was possible to ensure that the objectives of the study are met by focusing the discussion on defined areas, whilst also being flexible enough to explore additional areas of importance to the participants. The topic guides for both studies were therefore informed by the aims and objectives of the study as well as by a review of the literature. The initial areas selected for enquiry following this process are shown in Table 9.

Study A	Study B
Individuals' understanding of oral precancer	Delivery of a diagnosis
Experience of treatment	Decisions relating to disease management
Life impact	Approach to behaviour change
Behaviour change	

Table 9. Initial topics selected for inclusion in topic guides

These preliminary subject areas were then further developed to produce the interview topic guides, which were used at the start of the interview process and were modified as the studies progressed to include emerging topics. These topic guides may be found in appendices G and H.

As well as considering how best to guide the interview content by designing a topic guide to focus the discussion, a number of other factors associated with the interview process were taken into account as part of the study planning process. These included:

- The interview style
- Interview location
- Interviewing sensitively
- The influence of the interviewer on the interview
- The power dynamic within the interview
- Issues associated with interviewing colleagues

I looked specifically at each of these factors as I felt that they had the potential to influence the success of the interview process and therefore the quality of the data generated. Each of the factors and their relevance will now be discussed in detail.

4.6.1 The interview style

It was important for me to consider that although I was used to ‘interviewing’ patients as part of a clinical assessment, the necessary skills involved in qualitative interviewing are very different (McNair, Taft and Hegarty 2008). Where clinical assessment interviews are often conducted with the purpose of gathering specific information necessary to work towards a diagnosis (in other words deductive), qualitative interviews seek to discover the framework of meanings an interviewee ascribes to a particular experience. The researcher needs to remain open to the possibility that the concepts and variables that emerge may be very different from those that might have been predicted at the outset (Britten 1995) (This certainly proved to be true in my case. Specific examples will be given as the data is discussed in later sections). In order to acquire the necessary skills, interview training was carried out prior to the recruitment phase of the project with the Health Experiences Research Group at the University of Oxford. Following this training, and to ensure consistency, I conducted all the interviews. This ensured that themes emerging from the interviews could be taken from one interview to the next in a seamless manner.

Furthermore each transcript, as well as being analysed from the point of view of achieving the research aims, was also examined to assess the interview technique. Despite having an awareness of potential common problems encountered during a qualitative interview, such as avoiding awkward questions, jumping from one subject to the next and the potential for interviewee or interviewer ‘stage fright’ (Field and Morse 1989), it was possible for me to see from the transcripts the difficulties I was encountering which helped me to correct them for subsequent interviews. For example, initially I found I was approaching the interviews using much too superficial an approach, moving on from topics too quickly and as a consequence failing to explore each topic in much detail. I also noticed that in response to the difficulty I felt with broaching sensitive subjects I was failing to examine these areas with any great depth. Reviewing the interviews in this way from the beginning alongside secondary review by

supervisors, allowed me to refine my technique and conduct better, more meaningful interviews.

4.6.2 Interview location

For reasons which will become clear, when considering the relevance of the interview location, the patient and professional studies will be considered separately. With regard to the patient study, a decision was made to conduct all the interviews face-to-face, however, as the interview location is known to affect the content of the interview (Elwood and Martin 2000; McDowell 1998) the participants were invited to choose a location comfortable for them. A choice was therefore given between an interview in their own home or an interview at the hospital they attended for their oral precancer. At each hospital site a room was identified which was non-clinical and away from the clinic they usually attended. Giving participants this option was feasible for the patient group not least because all the participants were located locally, within a maximum commute of 1 hour and 30 minutes from my base. Given this choice, the majority (19) of the patient participants chose to be interviewed in their own home, with the remainder (9) interviewed in the hospital.

As I was interviewing in participant's homes it was important to address the issue of interviewer safety. To this end, standard protocol was applied in that colleagues were informed of my whereabouts when I was conducting my fieldwork and arrangements were made so that should I not make contact following the estimated interview time, efforts would be made to contact me and failing that the authorities alerted.

The professional based interviews were conducted with a specifically selected group of individuals throughout the UK. Due to the varying location of the study participants, carrying out face-to-face interviews, similar to those undertaken with the patient group, with all participants was not feasible. The approach taken for this group was instead a combination of face-to-face and telephone interviews. Where possible it was felt that face-to-face interviews offered benefits that telephone interviews did not, particularly in terms of non-verbal communication. However, the practicalities of travelling around the country ruled this out as a viable option. Therefore, where distance, or participant preference, prohibited a face-to-face interview, telephone interviews were conducted as

an alternative. This resulted in 2 face-to-face interviews and 9 telephone interviews being carried out with the professional group.

Although telephone interviews have previously been considered most useful for a structured interview format (Fontana and Frey 1994), Sturges and Hanrahan have suggested that there are a number of instances where telephone in-depth interviews offer advantages over those conducted face-to-face. Specifically, where sensitive topics are being explored or where the respondents are members of hard to reach groups (Sturges and Hanrahan 2004). There are also the additional benefits of the interviews being of reduced risk to the researcher as well as being less costly to conduct. Importantly, Sturges and Hanrahan, in their study comparing telephone and face-to-face interviews for the purposes of qualitative research, concluded by stating that the mode of the interview did not significantly affect the data they generated.

From my experience, however, where initially I felt that telephone interviews would be advantageous in that they may be seen as more convenient by the professional participants, in practice I found that because I had no control over the professional's interview location there were instances where the participant conducted the interview from a site which was less than ideal in that there were distractions or interruptions which I felt took the focus away from the interview process. An example of this would be a participant taking part in an interview from an operating theatre.

4.6.3 Interviewing sensitively

During the study design process, consideration had to be made to the potentially sensitive nature of the topic. Finding a single definition for what constitutes sensitive interviewing is difficult. Sieber and Stanley define sensitive interviewing as that in 'which there are potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research' (p.49) (Sieber and Stanley 1988). It may be argued, however, that where this broad definition is used, almost all interviews could be considered sensitive to some extent, or at least have the potential to be. Lee and Renzetti explored the concept of sensitive interviewing from the standpoint of interviewing for which a 'threat' is posed (Lee and Renzetti 1993). Defining sensitive interviewing in this way certainly provides a more explicit definition, which they classify in the following way:

Areas which are likely to be threatening:

- Where research intrudes into the private sphere or delves into some deeply personal experience;
- Where the study is concerned with deviance or social control;
- Where the study impinges on the vested interests of powerful persons or the exercise of coercion or domination; or
- Where the research deals with things that are sacred to those being studied that they do not wish profaned (Lee and Renzetti 1993)

Of course a subject which may be regarded as sensitive by one individual may not necessarily be considered so by another and indeed may vary widely across cultures and situations. For example, in the context of the patient based interviews I found that individuals who had previous or concomitant experience of life-threatening disease often appeared to experience oral precancer differently from individuals who had little or no previous serious disease experience, in that their accounts appeared to show that their oral precancer had impacted on their lives less significantly than those without other disease experience. In spite of this, however, I felt that the subject of oral precancer, had the potential to be considered a sensitive topic, particularly with the patient group, and gave due consideration to this. It seemed to me that the experience of disease and its associated treatments is, for some at least, likely to be a private, deeply personal or emotive experience and therefore threatening. Interestingly though, work by Lowes and Gill exploring the effect of being interviewed on an emotive subject (Lowes and Gill 2006) has demonstrated the potentially beneficial effect of taking part in a qualitative research interview. They examine data from two studies which they consider to have the potential to elicit an emotional response. When determining feelings about taking part in the studies some interviewees expressed that where initially they felt anxious or uncertain, ultimately, none expressed regret or concern about taking part in the process. Indeed some went on to describe the interviews as ‘helpful’ or part of a ‘healing process’ (p.591)(Lowes and Gill 2006).

This notion of the qualitative research interview as a therapeutic process, in the context of health care research, has been expressed elsewhere in the literature (Moorecroft, Cantrill and Tully 2004). Lowes and Gill go on to comment that where the interviews

from their studies may have produced an emotional response they ‘did not cause distress, but were a medium through which participants expressed their distress’ (p.593) (Lowes and Gill 2006). Despite this finding I felt that it was important to consider that the principal purpose of the interview was not one of therapy, and although not necessarily an unwelcome outcome I was aware that should interviewees seek therapy, I was not in a position to provide it. As a result of this, adjustments were made to the set up of the patient study. Specifically, the environment in which the interview took place was carefully considered, as outlined in the preceding section, in order to allow the participant to feel as comfortable as possible when discussing such a potentially emotive subject. In addition, arrangements were put in place to allow referral of the participant to additional medical or psychological services should the need arise.

4.6.4 The influence of the interviewer

The nature of the interview process is such that the data produced may be affected by the person collecting it. That is to say that the interviewer, as an integral part of the interaction, has the potential to influence the data collected, for example, by the nature of their background. In my case I am a clinician but, in the context of this research, I am also a postgraduate student. I felt strongly that the way I chose to present myself was likely to influence my data.

Prior to interviewing the patient participants, particular attention was given to the possible influence of my professional background on the interview process. Whilst coming from a clinical background and having had previous experience of working on similar clinics from those from which the patient participants were recruited (in a different hospital) I felt it was important that I presented myself as a ‘researcher’ and not a ‘clinician’. This was of particular importance as I was looking to explore, in depth, the experiences of the individual patients including those experiences in a health care environment (which by its very nature will involve relationships with health care professionals and their influence on experience of care). As the patient based study focused on the experience of disease and care I decided that presenting myself as a clinician would potentially discourage participants from speaking frankly, specifically with regard to negative clinical experiences.

This particular dilemma has been explored in a paper by Richards and Emslie, in which they consider the impact of the professional background of two researchers on their in-depth interviews on the subject of heart disease (Richards and Emslie 2000). In this case one researcher was a doctor, a general practitioner (GP), and the other a sociologist. Where the authors noted some features of the interview process were common to both, there were also role specific interview characteristics that became apparent. For the GP these took the form of the interviewees asking or assuming medical knowledge. And for the sociologist, where the professional role appeared less well defined, time was taken by the interviewees to place the researcher. Ultimately they concluded that ‘who the respondents think you are affects what you have been told’ (p.75). With this in mind I decided that, for the patient based interviews, I would present myself as a researcher. I felt that this approach would be more likely to allow respondents to talk freely about their medical care without feeling restricted by my clinical background. From a moral point of view, however, I made the decision that if asked directly; I would have to reveal that I was also a qualified dentist, even though this may influence the data.

The significance of my choice to present myself as a researcher, I think, was highlighted when a participant discussed the difference between the dynamic of the interview with me compared to that of the relationship he had with the clinician responsible for his care. He then described how the nature of the relationship with the clinician prevented him from asking for further information about his condition. I wondered if I would have been party to this disclosure if the participant had viewed me as a member of the clinical team.

4.6.5 Interview dynamics

The same participant mentioned above went on to suggest that the reason he experienced difficulty asking for further information was as a result of a power imbalance between the two. This manifested as a desire not to look stupid in front of the more knowledgeable consultant. The relationship between the interviewer and the interviewee is a key component of the in-depth interview and power imbalances within this relationship are therefore likely to influence outcome. Just as the dynamics of the doctor-patient relationship in the context of a medical consultation may influence their outcome.

The balance of power between the two individuals in a qualitative interview is often seen as imbalanced in the favour of the researcher, in terms of the researcher defining the situation, introducing the topics and guiding the interview (Lowes and Gill 2006). However, when the researcher is asking the interviewee for an account of their personal experiences and opinions then perhaps they should be considered the expert and therefore in a more powerful position. In line with this concept, Colbourne and Sque suggest that accepting the role of interviewee may cause participants to feel empowered, allowing them to communicate in a way not normally available to them and in doing so could explain why participants are often happy to answer questions on difficult or emotive topics (Colbourne and Sque 2005).

With this in mind, I addressed the issue of power during the interview process by taking care to try and make the participants feel comfortable with me prior to beginning the interview. For example by chatting informally before the start of the interview and by explaining to participants that it was *their* experiences I was interested in, in a bid to create a power dynamic in which I was not seen as being in total control. In practice, when conducting the patient interviews I noticed that the majority did in fact appear to feel empowered. In particular I noticed that participants were often keen to tell their stories regularly stating that they were eager to pass on information about their experiences to others, suggesting that as a consequence of their experiences they had assumed an expert role on the topic.

Power relationships may be different again, when interviewing colleagues. As I chose to interview senior colleagues, and by virtue of my disclosed status as a Clinical Fellow I felt that the power dynamic of interview had the potential to differ from that of the patient interviews. Indeed, my decision to disclose my status as a Clinical Fellow during study B enabled the professional participants to easily establish my status as a junior colleague. I felt, however, that there was little to be gained by presenting myself as a stand alone researcher to this group as some would already know me from other settings. In the context of the clinical environment I am of a lower rank compared to the professional interviewees and I wondered whether this would affect the interview power dynamic.

On reflection, following the clinician interviews I felt that predominantly, although not exclusively, the professional interviewees sought to establish the balance of power in their favour. This was accomplished largely by efforts aimed at controlling the interview process, for example by veering the conversation away from topics I raised, by seeking to test my knowledge on clinical subjects or by displaying expert knowledge not directly related to the research questions.

4.6.6 Interviewing colleagues

As well as considering specific issues relating to the interview dynamic when interviewing the professional participants, I felt that as a clinician undertaking the role of a researcher there may be other specific issues surrounding the interviewing of colleagues. Chew-Graham et al., examined the effect of interviewing colleagues in two studies based in General Medical Practice (GMP). Through their work they noted the potential for the interviewer to be seen as fulfilling one of four roles: researcher, confidant, expert or judge. They went on to comment that although being interviewed by a fellow professional will have an impact on the data generated from the interview, this is not a problem in itself, rather a factor that needs to be acknowledged and considered when analysing the data (Chew-Graham, May and Perry 2002).

This is reiterated by Coar and Sim who argue that interviewing colleagues brings up particular methodological issues (Coar and Sim 2006). In their work, again with General Practitioners, they identified the following points which they felt were significant and potentially important:

- The notion that the interviewee may feel that the interview is a test of knowledge
- The concept that notions of professional identity appear to underlie the dynamics of the interview process

Although these studies raise interesting points, in both cases the interviewee and the interviewer were GPs, and were therefore peers. As a result of this they may be considered equals and I wondered if the issues identified above would therefore be applicable to my study. With this in mind I looked to the literature concerning elite interviewing, as I felt that this may be more representative of my situation.

Study participants may be considered elite when they are seen to be located at the top of any stratification system. In the case of study B; the participants are all high status medical professionals which I felt may be considered elite. Specific issues surrounding elite interviewing have been examined in the literature. Broadly speaking, difficulties have been suggested around gate keeping, the ability of the elite to manipulate the interview process and indeed the dissemination of the results.

I spent some time considering the significance of elite interviewing in relation to the interviews I was to conduct with surgeons for study B. Picking up on the issue of gatekeepers, I found that I often had difficulty contacting the participants directly in that the contact details they provided were often that of their secretary. This sometimes made arranging a suitable time for interview difficult, involving several attempts before an interview time could be finalised. I wondered whether not having direct access to this participant group lead to 2 of the sample dropping out. Additionally, I also felt that being an elite in is a notion intrinsically linked with power and as previously mentioned this manifested in the context of the interview process as the professional participants' seeking to control the interview. Ultimately, I approached this by trying to establish a rapport with the interviewee and by waiting until I felt that the interviewee was comfortable with me before broaching more difficult subject with them, which proved successful in a number of cases.

4.7 Sampling

Having established the proposed interview format, the next stage in the study planning process was the development of the sampling strategy. In broad terms, the approach taken to sampling varies according to the research paradigm under which the research method falls. As the approach undertaken for this study was qualitative, the sampling method chosen was that of purposive or criterion based sampling which is a form of non-probability sampling. Sampling differs between quantitative and qualitative studies in that quantitative studies tend to employ probability sampling, whereas qualitative studies employ non-probability sampling. The differences between the two will now be briefly outlined.

With probability sampling, the aim is to produce a statistically representative sample, with each member of the defined population being of equal chance of being selected.

With non- probability sampling, on the other hand, participants are selected on the basis of their individual characteristics. The purpose of this is twofold: firstly this approach allows the sample to be tailored to ensure that the chosen subject under investigation is explored in detail and secondly, this method also ensures diversity by deliberately enabling the inclusion wide range of participants (Mays and Pope 1995). In other words, the aim with this approach is not to represent the general population, but to select individuals who are likely to have experienced the phenomenon under investigation so that the social processes involved may be better understood (Silverman 2000). With this in mind, several variables were considered prior to sampling for both the patient and professional participant studies. For the purposes of study A, the patient study, all study participants were required to have been diagnosed with oral precancer as this was central to the research question. A number of other potentially relevant factors were also considered and taken into account when designing a sampling strategy (Table 10).

Variable	Details
Gender	Male Female
Age	18 - 40 years 40 + years
Risk factors	Smoker Drinker Smoker and drinker Never smoker and never drinker
Management	No active treatment (patient under regular review) Currently receiving treatment Previous treatment received - no further disease diagnosed since treated Previous treatment received - further disease diagnosed following treatment
Location	Newcastle Sunderland

Table 10. Patient study sample group variables

I will now briefly discuss each variable and the reasoning behind its inclusion in the table.

- Gender - Oral precancer is known to occur in both males and females, however, it is well recognised that males and females respond to illness in different ways (Scambler 2003). For this reason the sample sought to include both genders in order to explore if men and women experience oral precancer differently.
- Age - Although oral precancer is primarily a disease of individuals over the age of 40, I felt it may be possible that younger patients may respond to illness in a different way compared to older patients. As a result of this, as an ideal, I aimed to recruit and include patients under the age of 40 in my sample group.
- Risk factors - The known risk factors for oral precancer are the same as those for oral cancer: namely smoking tobacco and drinking alcohol. Because eliminating these factors may improve disease outcome, part of any oral precancer management strategy is likely to involve an element of smoking or alcohol cessation advice. For this reason, the sampling strategy included sampling patients who had active risk factors as well as those who did not in a bid to determine the impact of this on their experiences of disease.
- Management – Alongside the elimination of risk factors, management of oral precancer is typically divided into those patients who are treated surgically and those who are treated conservatively. I felt that the way a patient's disease was managed was likely to have an impact on their experience of it. Experience of disease management is of particular interest in this group given the lack of agreed protocols from within the specialty. From the literature elsewhere it has been highlighted that patient experience of surgical treatment can often be a daunting experience. However, it has also been demonstrated that conservative management options too can have a significant life impact. For example, some patients in a study by Donovan et al., interpreted 'watchful waiting' to mean watch 'while I die' (Donovan et al., 2002).
- Location - I thought carefully about the potential significance of the nature of the clinics the sample group attended. For this reason I chose to sample from two outpatient clinics. This included clinics at two geographical locations. Ideally the geographical research area would have been widened further but due to limitations of the project particularly in terms of time constraints, travel and financial implications an achievable restriction was placed on the location of the participants

to involve those attending clinics in Newcastle and Sunderland. As well as differing locations, each of the clinics was set up in a different way: one of the clinics being a dedicated oral potential malignancy clinic and the other a mixed oral and maxillofacial clinic where people with a range of head and neck pathology may present. I felt that these factors had the potential to influence experience of disease.

Alongside the sampling framework, which I felt would enable a breadth of views to be obtained from the group sampled; a conscious decision was made to seek out ‘deviant’ or extreme cases. In other words patients for whom there may be the potential to disprove or challenge current analytical thoughts. In the case of oral precancer there exists a small group of patients who experience multifocal areas of disease. I felt that, if possible, recruiting at least one of these patients would be desirable as they represent an unusual manifestation of the disease process and fortunately I was able to achieve this goal. The make-up of the study group recruited according to the sampling framework may be found in appendix J.

For the study B, the professional based study, a similar approach to sampling was taken compared to that of study A. The criteria considered in the process are documented in Table 11. Again, this approach was employed to ensure a breadth of views.

Criteria	Details
Gender	Male Female
Designation	Consultant
Specialty	Oral and Maxillofacial Surgery
Location	Variety of locations, UK wide
Working environment	Teaching hospital, large regional unit, district general hospital

Table 11. Professional group sample criteria

The rationale behind the criteria included will now be explained:

- Gender – Although the vast majority of OMFS consultants are male, it was hoped that it would be possible to recruit female participants too in order to explore the

experience of managing oral precancer patients from the perspective of both genders, however, in the end, none were recruited.

- Designation/Specialty - While I recognise that there will be professionals other than OMFS consultants involved in the care of oral precancer patients I made the conscious decision to focus my study on this professional group. I felt that since my patient study involved patients under the care of OMFS consultants, and that since I used the information gained from the first study to inform this one, that consistency would be maintained. I felt that interviewing consultants in particular would ensure that, as the individuals had completed their professional training, participants would be more likely to have developed firm personal views on the topic which, perhaps, junior trainees would not. It is also more likely that these individuals have involvement in the set up and organisation of the clinics that the precancer patients attend.
- Location/Working environment – The location or the working environment may potentially affect the clinical set up, particularly in terms of the staff (and/or students) involved in the clinic, the mix of cases seen and the associated services offered. I wished to examine what participants felt the significance of this was and if they were involved in the set up and organisation of the clinics, what relevance they felt their choices had to the management of the oral precancer patient.

The make-up of the group of participants for study B with respect to the sampling criteria is documented in appendix J. Although the sampling criteria for both studies were designed to ensure a breadth of views were obtained, it is acknowledged that there may be possible bias in the self-selecting nature of these groups. For example, in the professional group it is possible that those choosing to participate in the study have a particular interest in precancerous lesions.

The final consideration in the sampling process is that of sample size. This is another area in which probability and non-probability sampling differs. Unlike probability sampling, in which sample sizes are determined by statistical testing, in non-probability sampling, sampling is linked to data saturation which is the time at which further interviewing generates no new additional themes (the generation of themes will be further explained in the discussion on data analysis). In other words, once data saturation occurs the sample is complete and only then is the final sample size determined. For the purposes of this research, data saturation was seen to occur at 16

interviews for area 1 of the patient study, 12 interviews for area 2 and 11 interviews for the professional study, which is in line with the literature (Guest, Bunce and Johnson 2006).

4.8 Recruitment

The patient cohorts were recruited from outpatient OMFS clinics in both Newcastle and Sunderland. As outlined in a previous section, I had made the decision to present myself as a researcher during the patient interviews, therefore, to avoid potential participants associating me with the clinic I decided not to be actively involved at the recruitment stage. Instead, at each clinic a lead consultant was identified to co-ordinate the recruitment process. This involved identifying suitable participants, providing a verbal explanation of the study along with an information leaflets and reply slip. If, following this, a patient wished to participate the reply slip was filled in. Using the information provided on the reply slip, I contacted each potential participant following a 7 day cooling off period.

In practical terms, not being directly involved in the recruitment process made the process more difficult, recruitment was slower than anticipated and despite arranging meetings to identify and manage difficulties progress was slow. Ultimately I applied for an amendment to the ethical approval to enable me to modify the recruitment process to include recruitment via post. This was accepted and recruitment continued successfully following this amendment. However, the process took 18 months in total to complete.

In terms of the professional study, potential participants were identified using a database of registered OMFS consultants on the British Association of Oral and Maxillofacial Surgeons (BAOMS) website. This provided information pertaining to gender, designation, geographical location and working environment to be established in line with the sampling criteria. Recruitment was carried out via post. Potential participants were provided with a study information leaflet, including researcher contact details should further information be required, and a reply slip. Once a reply slip was received participants were contacted to arrange a suitable time for interview.

Although the recruitment process for the professional study was different to that of the patient study, problems were also encountered. Specifically the need to obtain research and development (R&D) approval from each NHS trust associated with each individual participant resulted in considerable delay. Another problem involved the addition of gatekeepers, which had not been relevant to the patient group. In particular the professional participants always gave their secretaries contact details rather than their own. This sometimes resulted in difficulty arranging a suitable time for an interview to take place and in 2 cases, despite multiple attempts; it was not possible to set up an interview at all.

4.9 Ethics

Following the planning process approval must be sought from the National Research Ethics service (NRES) before the study can commence. NRES is part of the Health Research Authority, its role being to ‘safeguard the rights, safety, dignity and wellbeing of people participating in research’ (NRES). To this end, I felt that the main ethical issues associated with the studies were:

- Confidentiality
- Consent/ Coercion
- Emotional distress

I addressed these issues by: ensuring confidentiality was maintained throughout the project including the anonymisation of data (including changing the participants names), by gaining written informed consent from each participant, by leaving a cooling off period between recruitment and the interview process, by making participants aware that they were free to withdraw at any time and by ensuring arrangements were in place to deal with any undue emotional distress caused by participation in the project.

Following review of the submitted approval documents, within which these issues were addressed, and a subsequent committee meeting, ethical approval was granted by County Durham & Tees Valley 2 REC (Reference number 08/H0908/77) (Appendix B). Later, as the project progressed, two substantial amendments were made and approved (Appendices C and D). The first related to change of the design of professional study from quantitative to qualitative and the second was to allow postal recruitment as well as face-to-face recruitment in the patient based study.

Approval was also sought, and gained, from the research and development (R&D) department of each NHS site involved in the research. This, unfortunately, led to considerable delay. Particularly in relation to study B which required approval from 12 individual R&D departments. Funding was obtained in the form of a small research grant from the British Association of Oral and Maxillofacial Surgeons and was used towards the cost of the work.

4.10 Pilot interviews

Prior to beginning each of the studies in earnest pilot interviews were conducted. The process involved recruiting, setting up and undertaking an interview with a participant from each group. The main purpose of these pilots was to test the suitability of the topic guide. However, they also allowed me to identify any practical issues with the proposed study set up as well as allowing me to practice and develop my interviewing technique.

4.11 Analysis

I chose to analyse the data using thematic analysis, which is an approach used widely across several disciplines (Rapley 2010). Thematic analysis is a process by which commonalities within the data are identified, reviewed and refined. This process allows the researcher to not only richly describe the data but also may enable them to look for patterns which can help to examine or establish the underlying meanings behind the data content. Where some claim that thematic analysis is merely a *component* of other types of qualitative data analysis (Ryan and Bernard 2000), Braun and Clark argue that, as a widely used and flexible analytical process, it should be considered a research method in its own right (Braun and Clarke 2006). They go on to state that, in terms of qualitative data analysis, it is not so much the label applied to the analysis that is important, but that the process itself is clearly stated and justified. For this reason I will now go on to outline the steps involved in thematic analysis (Table 12).

Phase	Description of the process
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4. Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts relating the analysis back to the research question and the literature, producing a scholarly report of the analysis

Table 12. Phases of thematic analysis

I began analysis of the interview data at an early stage of data collection, using thematic analysis based on the 'constant comparative method' (Glaser 1965). This is an inductive, data driven style of analysis. By analysing the transcribed interviews as soon as they are produced, interesting features can be noted (or coded) immediately. This has the benefit that unanticipated issues arising from the early interviews may be incorporated and explored with later interviewees. In this way the interviews are not limited to exploring areas that the researcher thinks are important (anticipated themes) but are also free to explore other topics raised by the participants (emergent themes) (Ziebland and McPherson 2006).

Prior to coding, the first step in the analysis of the data involved transcription of the digital recordings. The transcriptions were carried out by a professional transcription company and then checked through alongside the original audio recordings to ensure accuracy. Checking each recording in this way began the analytical process by, importantly, initiating familiarity with the data. Once this process was completed initial coding could begin. Coding involves carefully examining the transcripts, then selecting and labelling sections of dialogue. Labelling a piece of data in this way provides, at a basic level, a method of indexing so that sections of data may be retrieved at a later date. On a deeper level, coding is an important basis for the next stage of thematic analysis, which involves collating codes, identifying patterns and considering relationships between codes so that common themes may be identified.

Where traditionally this process was carried out by physically highlighting text on the printed out transcripts, cutting the sections out and grouping them together, computer packages have now been developed to aid this process. It is important to note, however, that the packages do not undertake the analysis. Rather they act as an electronic filing cabinet, allowing the researcher to group together sections of text into electronic files rather than paper based files. Since I had used neither method before I undertook training in both the traditional and electronic methods of data analysis. Ultimately I found that I felt more involved with the data if I used the traditional approach so this was the approach I employed throughout both studies.

Once these themes had been assigned, I employed a technique outlined by Ziebland and McPherson to summarise the data (Ziebland and McPherson 2006). Essentially they describe a process by which one large summary document is produced. This document displays the themes identified in a map style format. This approach allows relationships between themes to be explored and patterns identified visually. By including the respondent's identification tag alongside each code it also enables the researcher to look for patterns between individuals grouped around specific themes as well as between themes themselves. As initial themes were developed, transcripts were then re-analysed to ensure the validity of the initial themes. By continually reviewing the data set, it was possible to ensure that no potentially significant information was overlooked. This process continued until new interviews failed to produce any new themes, that is when data saturation was seen to occur. In order to better illustrate this process, and taking

the patient interviews in study A as an example, Figure 1 indicates the initial themes identified from the coded interviews:

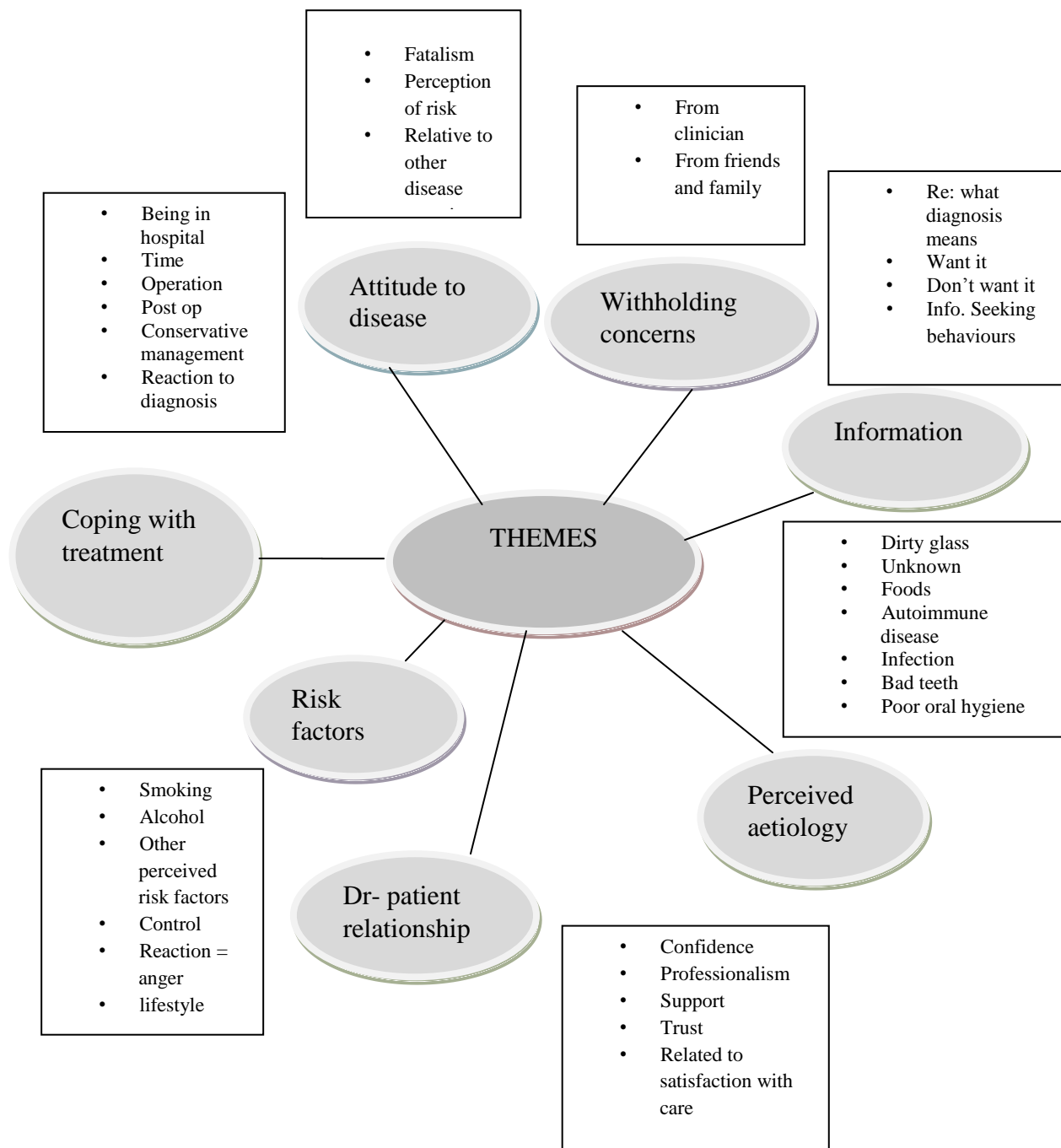


Figure 1. Initial themes and their associated codes

It has been suggested that a potential problem with thematic analysis is a failure to analyse the data at all (Braun and Clarke 2006). It is potentially possible that data may be superficially coded but the researcher fails to make sense of the data by searching for depth and meaning within it. I was aware that as a novice researcher this was a potential pitfall. Therefore, in order to avoid this I regularly discussed my findings with my qualitative supervisor as I sought to develop and refine codes and themes. These discussions helped greatly when initially attempting to make sense of the data. Another activity which I found particularly helpful was attending a data analysis session from

another project within the institute. It was useful for me to observe senior colleagues work with a data set and explain the approach taken when merging codes into larger themes then later, refining and searching for patterns and relationships between those themes.

4.12 Limitations of chosen method

As with all research methods, as well as particular strengths, the limitations of the chosen methods should be also be considered before a final decision is made with regard to the method undertaken. In terms of qualitative interview based data collection and analysis, the following limitations were considered:

- Generalisability

Due to the nature of the sampling process (purposive), it may not be possible to generalise or apply the results of the research to other settings. However, the ability to transfer results to other groups is said to be enhanced by ensuring a breadth of views in the sample and by providing an adequate description of the research context (Malterud 2001), both of which have been taken into account and outlined earlier in the chapter.

- Influence of the researcher

The influence of the researcher on the data must be considered. This may be as a result of personal biases (for example professional status, see section 4.6.4) or through the skills of the researcher (in particular how experienced they are in relation to the research method, see section 4.6.1). The potential for such bias has been outlined so that the reader may interpret the results with these possible influences in mind.

- Time consuming

Qualitative research is an often time consuming process, both in terms of data collection (particularly where participants are interviewed in their own homes) as well as the time taken to undertake the analysis itself. However, being prepared to give time to the research allows the researcher to gain an insight into a previously under investigated area.

In summary, this chapter has considered not only the method but the underlying methodology associated with the project design. It has examined a number of the, sometimes complex, considerations made prior to the start of the interview process and has concluded by describing the approach to data analysis. Accordingly, the next chapters will discuss the results of the analysis, beginning with Study A, the patient based study.

Chapter 5. Patient Results and Discussion: The patient journey

5.1 Introduction

The following section comprises the results and discussion of the patient based study. It is organised in chronological order, that is, the order in which the patient experiences their disease from initial discovery of symptoms (if experienced) through to diagnosis and management of the condition and, where relevant, the ongoing effects of living with oral precancer. I believe that organising the chapter in this way provides a clearer narrative, allowing me to see opportunities within this pathway where interventions may take place. Therefore, using this structure as a basis for discussion, the results will be explored with particular reference to the following themes:

- Perceived disease aetiology
- Information provision/needs
- The doctor-patient relationship
- Precancer associated risk factors
- Attitude to disease
- Experience of treatment/disease management
- Withholding concerns

As it is possible for a single theme to emerge at more than one stage of the patient's journey, where relevant, themes will be discussed multiple times and within the appropriate sections. The discussion begins at the stage of the journey prior to the individual's initial visit to a health care professional.

To aid the discussion quotes from the participants will be used to illustrate points made. At times the interviewers questions will be given alongside the interviewees responses, this is to allow the reader to appreciate the context in which the responses were provided. Although a breadth of responses are presented, it was not possible to include data from each participant. Of the 28 patient participants, 3 were not included in the

discussion. This was as a result of additional oral disease or general health problems which influenced their responses.

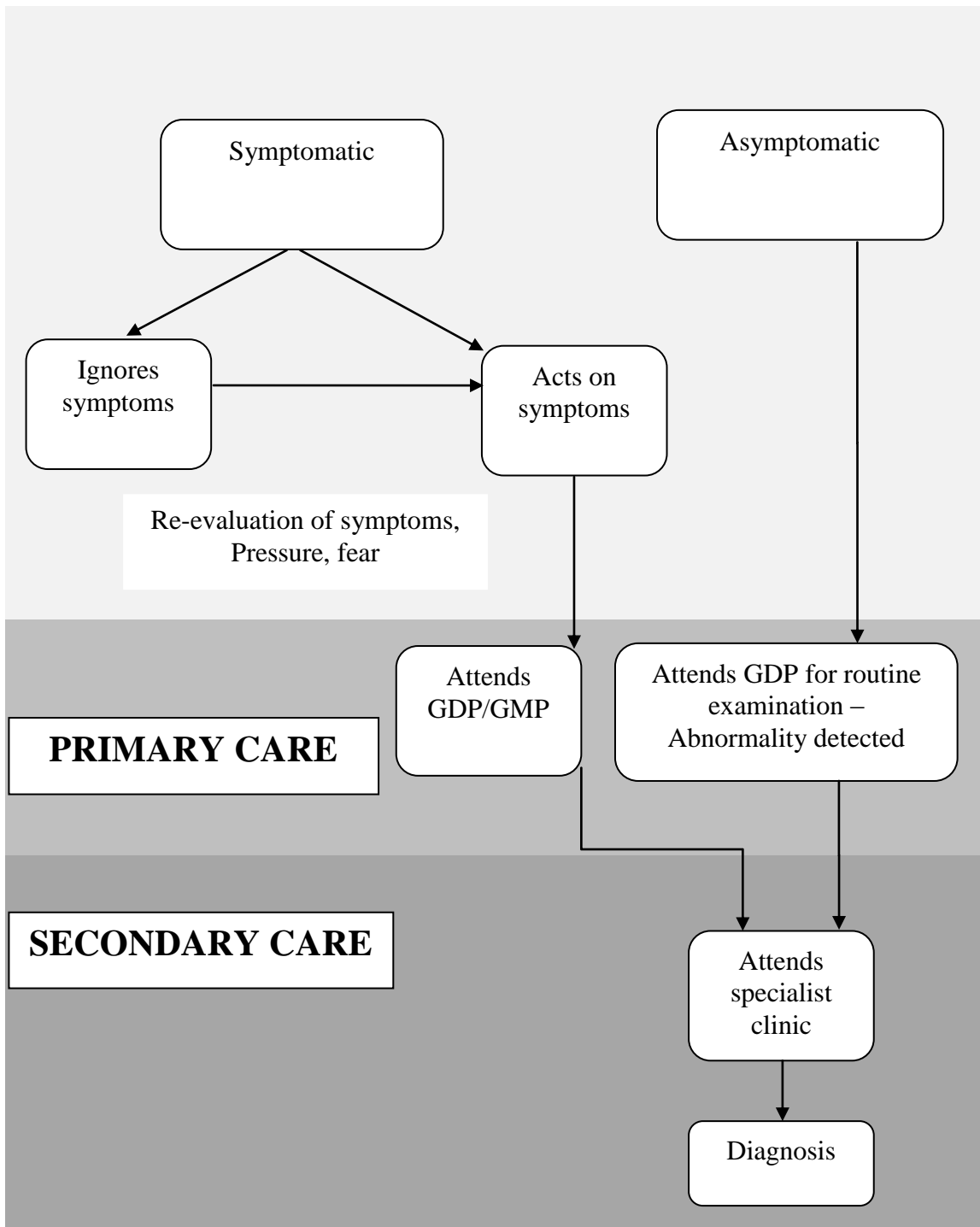


Figure 2. Route to diagnosis – patient pathway

5.2 Pre-diagnosis – An account of participants help seeking behaviour

The patient's disease journey begins with the discovery that there is an abnormality present in the mouth. This discovery is made either by the individual themselves or by a health care professional, most commonly the General Dental Practitioner (GDP). At this early stage it is possible to divide the study group into two, those for whom

symptoms alerted them to the abnormality and those without symptoms. Although, in the long run, both groups end up in specialist care, the route and therefore the experiences of each group at this stage are very different. Figure 2 is constructed to provide a visual illustration of this journey for both patient groups. It can be seen from Figure 2 that once an abnormality has been detected and acted upon a pathway follows which ultimately leads to a diagnosis. However, the precise route and duration of this pathway will be largely dependent on the presence or absence of symptoms and, where symptoms are present, the actions taken upon their discovery. With this in mind, the data will now be discussed from the point of view of the symptomatic individual and will begin by exploring their health seeking behaviours.

5.2.1 Health seeking behaviour – the symptomatic patient

Symptomatic individuals who seek medical help quickly are more likely to be diagnosed and managed rapidly. This is particularly relevant when it is considered that some of the signs and symptoms of oral precancer are the same as oral cancer, a disease that if treated at an early stage may not only result in a higher chance of survival for the patient but could be less of a financial burden on health care services. Yet, examination of the data revealed that the experience of oral symptoms often did not result in prompt health seeking behaviour. A participant, for example, was aware of the presence of oral lesions, however, she attends her dentist for treatment following trauma, which she sees as a more urgent problem:

I got these lumps in my mouth and I was seeing my dentist (for something else) and he said oh, I think you should go to the hospital about this so he made an appointment.

Betsy (Age 74, Participant 9, Area 2)

Her account suggests that although she is aware of an abnormality in her mouth, for some reason this in itself is not enough to prompt her to seek medical help. In light of this, the data was analysed with a view to determining the factors that may affect health seeking behaviour in the symptomatic patient.

Whilst it is certainly the case that symptoms have a bearing on many people visiting a health care professional, assuming that individuals seek medical advice as a direct response to the initial discovery of signs or symptoms does not reflect the true, somewhat individual, complexity of this process. As an example, this study participant

recalls that he noticed a white patch but states that he did not discuss it with the dentist, perhaps feeling reassured by the dentist's apparent failure to pick up on it at an earlier stage:

I: And when your dentist was referring you to the dental hospital were you surprised that was happening?

IV: Well actually I'd been to the dentist a few times before that and he'd never mentioned owt but I noticed it about a year before that.

I: Oh, so you'd seen it yourself before?

IV: Aye, but I didn't think nowt of it¹

Bob (Age 48, Participant 10, Area1)

Looking at the dental literature, in general, there is little specific information in relation to what factors prompt people to seek care in oral health. This is perhaps surprising given that the experience of oral symptoms in the general population, 'toothache' in particular, is not an uncommon occurrence (Pau, Croucher and Marcenes 2000) with the 1998 adult dental health survey finding that 51% of dentate adults surveyed reported that they had been affected in some way by their oral health (Nuttall et al., 2001). Examination of the sparse available literature, however, suggests that there may be numerous, varied reasons that act as a barrier to an individual seeking health care advice or treatment once signs or symptoms of disease have been recognised (Fox 2010). Looking specifically at oral signs and symptoms in relation to care seeking in oral cancer, (which as explained, are sometimes similar to those in oral precancer) the literature confirms that where symptoms do have a role to play, their presence alone is not always sufficient to warrant a visit to a health care professional (Scott et al., 2009). In particular, a study by Scott et al., demonstrated that up to 30% of patients delay seeking help for up to three months following self-discovery of the symptoms of oral cancer (Scott et al., 2009), a finding replicated by my patient study group.

As well as quantifying patient delay in oral cancer, Scott et al.,'s study also went on to explore delaying and motivating factors in health related care seeking with this patient group. Table 13 summarises their findings:

¹ In the context of the quotes used thought out this document, the letter 'I' will be used to indicate the interviewer and the letters 'IV' the interviewee

Triggers to seeking care	Barriers to seeking care
Change in symptoms	Beliefs regarding oral symptoms
Persistence of symptoms	Factors relating to the health care professional
Pain	Factors relating to circumstance
Presence of another reason for visit	
Desire an early diagnosis	
Need to resolve uncertainty	
Worry/concern over symptoms	
Dislike of symptoms	
Advice of significant others	

Table 13. Triggers and barriers to care seeking in patients with potentially malignant oral symptoms (Adapted from Scot et al., 2009)

As a number of commonalities appear to be shared between this and the study group, a number of these factors will be explored alongside the study data.

5.2.2 Barriers and triggers to seeking care in the symptomatic oral precancer patient

With reference to barriers to seeking care, this participant also spoke of his delay seeking help for his oral symptoms:

I mean I hate the dentist, I hate anybody touching my mouth, anything like that, so it was a case of it had been left and left and the pain had basically got that bad that as I say I was at work, me and the kid I worked with at the time, and I said ‘listen just get us there [to the emergency dental clinic] and you’ll have to drive us’.

Andy (Age38, Patient participant 11, Area 1)

In contrast to the previous patient, Bob, who was regularly attending a general dental practitioner, the participant above, Andy, attended a dental emergency clinic for acute dental pain, where mucosal abnormalities were observed as an incidental finding. Although his symptoms were unrelated to his oral precancer, his experience is significant in that it highlights a delay seeking help for oral symptoms, he describes that it is only when the pain is persistent and changes in severity that care is sought. As well as Scott et al.’s study, parallels may also be drawn between this behaviour and the

findings of Pau et al. Through their work they sought to explore care seeking behaviours in patients with 'toothache'. In relation to toothache, a positive relationship was demonstrated between the intensity of the toothache pain experienced and the likelihood that an individual will seek health care services (Pau, Croucher and Marcenés 2000).

Another interesting finding demonstrated by Andy's passage is the influence that his perception of the dentist has in delaying him seeking care. As it is often the dentist who is involved in the process of recognising signs of oral precancer, it can be seen that for individuals with dental anxiety and signs or symptoms of oral precancer, a significant barrier to accessing appropriate services exists, resulting in increased delays and potentially more advanced disease in this patient group. This finding is also seen in the dental literature. For example Schuller et al., reported that patients with higher levels of dental anxiety visited the dentist less frequently than those with low dental anxiety and experienced more extensive disease (Schuller, Willumsen and Holst 2003). Armfield et al., take this concept further by examining the influence of dental fear on oral health and service utilisation using the model of 'the vicious cycle of dental fear' (Armfield, Stewart and Spencer 2007). They use this model to analyse their data with a focus on dental fear and its relationship to dental visiting patterns. They sum up by concluding that for individuals with high levels of dental fear, delay seeking treatment is greater than for those with low levels of dental fear. This in turn leads to more extensive dental problems and erratic symptom driven attendance patterns which serve only to exacerbate the individual's fear and reinforce care avoidance patterns. Applying this to precancer patients it may be seen that barriers to seeking care for their oral precancer may be influenced by previous experiences of dental treatment.

Continuing with a focus on barriers to care seeking in the symptomatic individual, the patient study data also demonstrates that beliefs regarding oral symptoms could influence a person's decision to seek treatment, a finding also discovered in research by Anderson and Thomas investigating why people seek emergency dental care (Anderson and Thomas 2003). They found that an individual's past experience of oral symptoms could result in that person attributing their current symptoms to other, sometimes less significant oral conditions which may be amenable to self-care.

The findings of Anderson and Thomas's study are emphasised when considering one of the major themes to arise from the data; that of patients' perceived aetiology of their oral condition, where symptoms were commonly misinterpreted as being attributable to more frequently occurring, less serious oral conditions such as oral ulceration, trauma, burns from hot food or drink or symptoms of dental origin, 'toothache'.

The Sunday morning when I woke up, I'd been out the night before to the pub for a drink with the wife and woke up the next morning and felt my tongue was just a bit sort of rough round the edges if you like. It just had this sort of feeling to it. And it was only when I sort of looked in the mirror, the bathroom mirror, and looked at my tongue and I saw this what appeared to be like a sort of white area and it was very sort of rough to touch and it sort of threw me a bit because it wasn't there the day before and then all of a sudden it was there the following morning, which I found very strange. And at first I thought it might have been due to a drink I'd had at the pub, it may have been a dirty glass and it may have been an infection of some description that I picked up from having a drink in the pub out of a glass.

James (Age 61, Patient participant 4, Area 1)

It started with a tiny little white patch on the roof of my mouth which to be honest I thought I had just burnt it because I always drink black coffee and it used to be very, very hot. I thought I had just scolded it.

Lily (Age 58, Patient participant 12, Area 1)

The disadvantage of attributing symptoms to minor oral disease is that patients' are more likely to believe that they may be self-resolving or responsive to self-treatment. However, it has been shown that in patients with symptoms of oral premalignancy, if these symptoms fail to resolve individuals may then undergo a process of symptom re-appraisal. In some cases this prompts health seeking behaviour, but in others alternative coping strategies are adopted instead, leading to further delay (Scott et al., 2006), a finding also seen within the patient study data:

It wasn't a question of being frightened of what it was, I think that might apply to some people...it was just; oh this is bloody awkward, I wish it were...oh I'll buy some more pastels or I'll put some more isolating fluid or whatever they call it and its just to get to that thought; wait a minute, I've been doing this six months.

Frank (Age 63, Patient participant 11, Area 2)

Another common thread passing through the data was the general belief that a lack of pain meant a lack of significance even when other oral changes were present:

I didn't attach much importance to it...I didn't think it was anything because there was no pain, could hardly see anything and I didn't really worry about it
Archie (Age 72, Patient participant 3, Area 1)

This was a finding again explored by Scott et al, in another study investigating delay in patients presenting with potentially malignant oral symptoms. They found that patients with both benign and malignant disease often delayed seeking treatment, but contrary to other studies involving health seeking for oral symptoms, they found that magnitude or type of symptom did not impact on patient delay (Scott, McGurk and Grunfeld 2008).

Further analysis of the data also demonstrates that beliefs relating to oral symptoms were sometimes guided by knowledge of oral precancer or indeed oral cancer itself.

I mean I'd never really heard, thought or heard much about mouth cancer... I'd never really been aware of mouth cancer, never really thought about it. I know the dentist examined for it as part of this annual check-up but the consequences... hadn't been aware of them.

Archie (Age 72, Patient participant 3, Area 1)

This is significant when we consider that Dubayova et al., have found that knowledge is an important factor for decision making, stating that those with knowledge of specific medical conditions and their associated symptoms are more likely to present to health care providers, seeking treatment, should symptoms occur (Dubayova et al., 2010). However, the above patient's account highlights the notion that public knowledge of oral cancer is poor. A finding supported by a survey commissioned by the Health Education Authority aiming to determine public awareness and knowledge of oral cancer in the UK, which demonstrated that oral cancer was one of the least well known cancers compared to those affecting other body sites, with only 56% of the survey participants being aware of it (Warnakulasuriya et al., 1999).

Given this lack of awareness of oral cancer in the general public previous knowledge of oral cancer and precancer was also explored with the study group:

They didn't know exactly what it was because I don't know myself to be honest.
Betty (Age 80, Patient participant 2, Area 1)
Talking about discussing her condition with her family

It was observed that a lack of awareness of oral cancer and precancer affected not only the individual's ability to seek care, but also impacted at later stages of the disease journey, as seen above, where Betty had difficulty explaining her disease to her family.

As well as the experience of previous oral disease, patients' experience of other illness was also seen to influence their response to oral symptoms. This is a phenomenon which is not exclusive to oral precancer patients. Looking at the wider literature, a pattern of delay in people with previous disease is repeated throughout a number of medical disciplines. For example, studies involving patients with breast cancer show that women who have previously experienced benign forms of breast cancer delay longer in comparison to women without a history of benign disease (Caplan and Helzlsouer 1992).

Where the study referenced above demonstrated that those with a history of benign disease delayed seeking help, examination of the data revealed that those with history of malignant disease (at other body sites), often reacted by assuming that an oral lesion was likely to be malignant too:

I: So when the dentist suggested referring you to hospital, what did you think at that point?

IV: I had a panic... because I have I've had a couple of histories of cancer, but survived.

I: So was that your first thought then... that there might be a cancer in your mouth?

IV: Oh yeah

Wilma (Age 64, patient participant 7, Area 2)

Furthermore, this reaction did not appear to occur exclusively in those with a personal experience of cancer. Where patients had experience of someone close to them having or experiencing cancer, the association between their oral condition and cancer was made more readily:

I was very, very worried. I had a member of staff whose daughter had had quite serious mouth problems, cancer of the mouth, and she'd obviously been very troubled and very worried, you know, she had a grandchild and I supported her through that. So I was really very worried, I didn't think...I was hoping it wasn't as serious as all that and you look for reassuring things....

Jackie (Age 51, Patient participant 13, Area 1)

As well as physical health, the impact of mental health can affect symptom appraisal and health seeking behaviours. In addition to the well documented influence of depression and anxiety disorders causing delay in patient presentation (Kugaya et al., 2000), the influence of stress has been shown to affect patient interpretation of signs or symptoms of illness with individuals having a tendency to attribute these to the stress rather than to the presence of an illness, resulting in delayed care seeking (Cameron, Leventhal and Leventhal 1995). Although stress was mentioned as a subtheme, the study data did not appear to support stress as a factor influencing presentation, rather the influence of stress appeared when participants reflected on their perceived aetiology of their condition:

IV: it may possibly have been stress related...

I: Is that something that was mentioned?

IV: I'm only thinking that myself. That possibly it could have been stress related....not that I'm always stressed but I seem to be always stressed, but I'm not as stressed as I was back then.

James (Age 61, Patient participant 4, Area 1)

Returning to Dubayova et al.'s paper, they also suggest that psychological factors may impact on patients' health seeking behaviour. Specifically, they state fear or anxiety has a significant effect on patient behaviour, particularly in relation to seeking treatment. Through their systematic review they concluded that an individual's fears of discovering the cause of their symptoms, as well as fear about the consequences of diagnosis and treatment, were often associated with delay seeking help.

Fear of the cause of the signs or symptoms alongside fear of the consequences of diagnosis and treatment were evident in the study participants' accounts, however, these fears did not cause delay seeking help. Instead, concerns of this nature were usually apparent at a later stage of the disease journey. Dubayova et al., go on to state that fear can be a motivating as well as a delaying factor in seeking help, dependant on the cause of the fear and the way people react to it. In particular, they noted that where patients react to their initial discovery of symptoms with panic or alarm this may prompt that individual to seek help very quickly.

With this in mind, looking at the patient data, when this participant discovers a white patch in his mouth he is prompted to seek treatment from his GP immediately, and when the wait for referral to a specialist is expected to take three months he describes

how he felt the need to seek private health care in order to speed up the referral process. He later explains his fear in relation to oral cancer and its consequences:

IV: it wasn't going away and it was there and the GP had said you know she was alarmed sufficiently to want us to see a specialist

I: Had she mentioned what she thought it might be or what she was worried about?

IV: Well she didn't say it might be cancerous but by inference I mean she was saying that.

I: So it's a long time to wait then with that hanging over you really isn't it?

IV: Yeah because frankly the idea of cancer on the tongue worries me more than prostate cancer.

I: Why is that?

IV: I can't imagine what life would be like if you can't talk

Bert (Age 72, Patient participant 8, Area 1)

Given that interpretation of symptoms varies with the individual, it is not surprising that contrasting response to a single factor may occur. This highlights the fact that patient perception is an individual process and is dependent on individual appraisal and interpretation of symptoms.

Alongside the patient's personal evaluation of symptoms, they may also seek help with interpretation through non-professional sources, typically friends or family (Anderson and Thomas 2003). However, the lay information gained from these sources will not necessarily correspond with that of medical professionals and may also result in delay in presentation. On the other hand, Rozniatowski et al., report a positive relationship between high involvement of a spouse or partner and early presentation in head and neck cancer (Rozniatowski et al., 2005). They found that close interpersonal relationships appeared central to facilitating patients in recognising the significance of their symptoms.

One of the male study participants described his experience of discovering lumps in his mouth, initially his thoughts turned to the possible causes:

Well I couldn't think of anything else that would grow like that in your mouth like. I suppose it's possible to get a wart in your mouth I don't know but I just thought what am I going to do now? ...you just think well at the time there was a lot of cancer going around and things like that and that's what it could be.

Arnold (Age 71, Patient participant 6, Area 1)

When asked about information he shared with his wife he reveals his wife's reaction when he told her about his oral lesions:

It was right on the end when I took to the dentist, I told the wife like and she seen it and she... blew her top like, you know

Arnold (Age 71, Patient participant 6, Area 1)

These data appear to suggest that although this participant was aware of a change in his mouth it wasn't until his wife had seen and reacted to the lumps that he sought medical attention.

Rozniatowski's team also reported that for those living alone, lacking stable family situations, there appeared to be a correlation with longer periods of delay. Where it was not possible to make that association on the basis of the study results, there was certainly evidence of the impact of a stable relationship on health behaviours within the data set:

As I say I was living by myself, [then] I met my partner that I'm with now. You still have your good times, I mean, well, all the times are good if you like, a lot better than they were, but ...I've settled down a lot more, where you would never see me drinking a cup of coffee put it that way you know (laughs). If I was by myself I would have been in the pub so now I'm at home and that's it you know.....just life and growing up...whereas when you're living by yourself you've got to – I mean the only priority you've got is yourself if you like, whereas obviously if you're in a relationship there's a lot of people to consider

Andy (Age 38, Patient participant 11, Study 1)

Moving on from the influence of friends and family, the final consideration in health seeking behaviour for the symptomatic individual is the influence of the health care professional. The influence of the dentist specifically has been briefly covered earlier in this section when fear of the dentist was mentioned as a barrier to seeking help, however, there are other factors involving the dentist or other health care professional which may too be of relevance.

Smith et al.'s review in relation to patient delay in cancer presentation explored individuals' help seeking experiences in patients with several types of cancer. They focused on fear, describing two distinct forms of fear that may impact on individual behaviour: fear of cancer and fear of embarrassment (Smith, Pope and Botha 2005). Where fear of cancer has also already been discussed, fear of embarrassment has not.

Fear of embarrassment has long been echoed in the work of others (Aitken-Swan and Paterson 1955) where there appears often to be a feeling of reluctance by patients to seek advice for seemingly trivial symptoms. Although this did not come through in the patient data at the initial presentation stage, fear of embarrassment was discussed in relation to a reluctance to ask questions during consultations with secondary care clinicians:

I don't know if I'm just blooming stupid or what but it's all over my head what they tell you.

Phil (Age 58, Patient participant 15, Area 1)

In the case above, a reluctance to ask questions about his diagnosis results in the patient seeking further information elsewhere. This issue will be further discussed in later sections.

A further potential barrier to seeking treatment may be access to a health care professional. Simply getting to a hospital in order to access services may prove difficult and even once help is sought, can remain a significant problem for some:

IV: I had to continue going to the clinics with us still smoking to keep an eye on it, which was very difficult because I've either had to get a friend to go with us or I've had to get me son to take us because I haven't been able to... because its three buses to hospital A

I: Is it? So it's quite far way.

IV: ...from here. And I just can't travel that far with taking panic attacks and that. So it was quite difficult.

Brenda (Age 53, Patient participant 7, Area 1)

She later comes back to this as if to re-emphasise the importance the issue of access is for her:

That's the only thing about travelling so far. I just wish services were local rather than having to go so far for treatment. I just wish there was like a local surgery just for people who were having check-ups. I mean I know people have to go over there for any treatment, but I just wish there was probably a local surgery for... just for check-ups and things

Brenda (Age 53, Patient participant 7, Area 1)

This section has demonstrated that for symptomatic patients with oral precancer, a complex process surrounds the period between symptom discovery and presentation to a

health care professional. This will centre on the patients appraisal of their symptoms and may be influenced by factors such as: past experience of disease (both in general and oral disease specifically), knowledge of oral disease and information gleaned from friends and family. Other than symptom appraisal factors including dental anxiety and difficulty accessing services may prevent or delay patients seeking help.

5.2.3 Health seeking behaviour – the asymptomatic patient

However, one of the key features of oral precancer is that it is often asymptomatic in its presentation. This was reinforced through the patient narratives, during which mucosal abnormalities were frequently observed during a routine dental check-up or on presentation at the dentist for another reason:

I went to the dentist, just for my normal check-up and he said I'm concerned about, it was down behind my lower teeth at the back, behind your gums, behind your teeth, and he said I had this white, I've forgotten the name of it...eluci something or other

Molly (Age 82, Patient participant 10, Area 2)

I only visit the dentist once a year for a routine check-up and he does a quick oral examination, that's it usually. Until this year in, sorry, last year, in June he noticed a white patch on the base of my mouth

Archie (Age 72, Patient participant 3, Area 1)

Well I went to see for some dentures to start with, and the dentist says, there, well if they fit alright, leave them, just leave them and I said oh alright, but she says how about this on your tongue, and I knew nothing about it

Beryl (Age 77, Patient participant 4, Area 2)

As symptoms are often central to an individual's understanding of what illness is, a lack of symptoms can later lead to difficulty when it comes to patients understanding and making sense of their illness. In some cases, asymptomatic conditions may lead patients struggling with how to define their state due to a lack of a perceived clarity over being 'ill' or 'healthy' and a feeling that they don't legitimately fit into either category. (Kavanagh and Broom 1998). Issues surrounding confusion with their disease will be explored in a later section.

5.2.4 Transition from primary to secondary care – all patient groups

Following presentation, either through self-directed health care seeking or via a visit to another health care professional, the next stage in the process is referral of the patient from primary to secondary care, the most common route being via the GDP to an outpatient oral and maxillofacial department.

The significance of this transition on patient experience has been noted in the wider literature, where even the referral itself can be seen as unsettling, particularly if patients are inadequately informed about the reason for referral (Jackson et al., 2006). Also coupled with this transition phase, Preston et al., outlined the importance of progress in association with the journey from primary to secondary care (Preston et al., 1999). Following their study they concluded progression through the health care system may signify not only progress towards recovery but, for those with chronic conditions especially, adjustment to an altered health state.

In the UK, targets set by the Department of Health now state that patients' who are referred for consultant led treatment should be seen for treatment within 18 weeks and those with suspected cancer should be referred urgently and should expect to be seen by a specialist within 2 weeks (DoH 2012b). Furthermore, legislation has now made these targets a legal right (2006). Where the drive behind these targets originates with a desire to diagnose and treat patients at an early stage in their disease, it is important too, to consider the psychological effect of waiting, as demonstrated by this patient:

So for the initial couple of weeks while I waited for the appointment I got meself really worried, really worried about it

Brenda (Age 53, Patient participant 7, Area 1)

A study investigating the '2-week rule' in suspected breast carcinoma demonstrated the significant distress experienced by this patient group during this wait. However, whilst patients were unaware of the 2-week initiative they stated that they valued a quick referral to provide assurances that they did not have cancer (Cornford, Harley and Oswald 2004).

The influence of speed during the transition from primary to secondary care was discussed with the patient study groups. Where there was a feeling, as with the

suspected breast cancer group, of a quick referral being important in terms of alleviating anxiety there was also a sense of the duration of the wait indicating the seriousness of their undiagnosed condition. It became apparent that participants felt short referral times indicated urgency and therefore a potentially more serious diagnosis:

I think the length of time always helps you, because you think well if it had been that dire they would have had you in immediately. Maybe that might not be right. Maybe there's just a big waiting list. But you keep thinking that don't you?

Molly (Age 82, patient participant 10, Area 2)

I think the thing was, because they didn't see it straight away, I didn't think it was that serious. It couldn't have been that serious or they would have done something quicker.

Aida (Age 65, patient participant 8, Area 2)

In some cases, even the need for referral itself involving specialist opinion was enough to prompt feelings of anxiety:

IV: She said but I would like you to go to the dental hospital. And it just all started from there. She said you've got what we call white patches

I: Right

IV: And I thought oh god, you know

Betty (Age 80, Patient participant Area 1)

The GP said 'I'll have to send you to see a specialist' so I thought...well quite often you think 'Oh it could be something nasty' you know

Bert (Age 72, Patient participant 8, Area 1)

Once the referral has been made, the individual then makes the transition from primary to secondary care, where their journey continues. The following section of this chapter will therefore go on to focus on the patients initial experiences of secondary care, including their first encounter with the doctor, their experience of the hospital environment and their reaction to the need for further investigations (biopsy).

5.3 Initial consultation

5.3.1 Beginning of the doctor-patient relationship

The transition from primary to secondary care heralds the beginning of the relationship between the patient and the hospital practitioner. At this initial stage this relationship

may not be as established as the one with the primary care practitioner and may therefore be viewed as more impersonal and of potentially limited duration. This may impact on the confidence of the patient and have a negative influence on patient experience at this juvenile stage of the relationship.

Where the idea of attending a hospital was, for many, an anxiety provoking experience, one factor that appeared to benefit patients at the initial consultation stage was that of the notion of the secondary care clinician, usually a consultant, as an expert.

He just knew the ropes, didn't he? And that made me feel quite... it gave me a confidence to keep going back... Yeah, it was essential to see somebody that had obviously a deep understanding of his job.

Wilma (Age 64, Patient participant 7, Area 2)

However, this concept of the consultant as the expert appeared to be of particular importance to those patients' who later recognised in themselves the desire to almost remove themselves from the decision making process:

IV: I put myself in the hands of the professionals, they know what to do

I: So did you have any questions at the time for any of the doctors or people that you saw?

IV: Not really, no. I just went and got the treatment and got an examination whatever they wanted.

Arnold (Age 71, Patient participant 6, Area 1)

At the initial consultation stage the significance of free communication between patient and doctor is a crucial one. Specific barriers at this stage appeared to include the power dynamic between the patient and their doctor within the consultation.

This power dynamic sometimes appeared imbalanced, the power resting with the doctor. This resulted in difficulty requesting further information from the consultant (usually due to a fear of embarrassment) and subsequently puts up a barrier to the patient expressing concerns or asking questions about their disease:

I think looking back, I mean if I was at ease as I am with you I could have said hang on a minute, just go over it again, I think its professionalism...I don't want him to think that this stupid boy here, hang on, what do you mean by...I felt as if I was belittling myself, probably wrong, well it would have been, he's a smashing fella but you don't want to look stupid.

Phil (Age 58, Patient participant 15, Area 1)

As well as creating the potential for uncertainty with regard to their diagnosis, this difficulty in communication may lead to patients feeling a lack of involvement in their care. This situation could be seen as being at odds with the government white paper 'equity and excellence. Liberating the NHS' which states that the intention is that patients are put at the heart of the NHS (DoH 2010).

As patients progressed in their journey through secondary care, continuity in relation to the individual seeing the same clinician is seen as important. Further it is put forward that the 'continuity could facilitate the progress of the treatment' (p.19) (Preston et al., 1999) due to the professional having sufficient background and knowledge of the case (Preston et al., 1999). Examining the accounts of the patients in this study it can certainly be seen that consistency in terms of seeing the same health care professional is preferred:

My only concern about going there is that, yes, most of the time I have seen Mr. X, and other times – and I know they're all doctors and they've got a job to do, but I mean sometimes I see different people and when you're seeing different people they're not exactly up on what's happening. I mean they're only going off notes, and I think personally it would be better if you were seeing the same person all the time, and they're going to have a look at your mouth and see exactly if there's any changes without reading the notes, because they've seen it before, they know exactly...

Andy (Age 38, Patient participant 11, Area 1)

Furthermore, patients express concern or panic when access to a specific individual is not possible, even when the person seen as an alternative behaves in a professional and satisfactory manner:

It's better to see the same person. But I do get in a panic if I don't see him. It was like when I didn't see him in the clinic because you just expect he is going to be there. When he wasn't there and I saw Mr Y and Mr Y was lovely, don't get me wrong, he was really lovely, but you just think, it was like being left at school for the first time by your mother, I thought this isn't right.

Lily (Age 58, Patient participant 12, Area 1)

The significance of a good relationship between the health professional and the patient was seen throughout the course of the patient journey. Patients' opinions of their clinicians became central with themes relating to faith, trust and confidence in their

clinicians presenting strongly throughout all stages of diagnosis, management and follow-up.

5.3.2 Impact of the environment

As well as the impact of the clinician on a patient's experience of care, the hospital environment itself may also have an impact. Although not an especially prominent theme, for some the experience of being in a hospital setting was an anxiety provoking experience in itself:

I don't like going to the hospital, it's horrible. I don't like any of it but I'm pleased we've got it.

Wilma (Age 64, Participant 7, Area 2)

Where Wilma demonstrates a general dislike of the hospital environment, the following participants find the maxillofacial outpatient clinic itself a difficult environment to be in, directly relating the impact of the surroundings to their personal situation:

People are on top of each other. People who are poorly and worried and goodness knows what, they want space around them, they want air to breathe, you're all sitting here like sardines and it was very much like that...it was like the black hole of Calcutta, you were on top of each other all the time. And there were some quite nasty disfiguration cases sitting around which sort of took your breath away...it certainly made me uneasy...your eyes were drawn to it. I think the only down side was, the worry was, that dear me, could I end up like that?

Frank (Age 63, Participant 11, Area 2)

When I was in the clinic, I used to get frightened seeing some of them, you know...there was half their faces missing and...you know deformed, like, lumps of their jaws taken away, and you think, that could be you pal, you know. And you do tend to; I think I do tend to be a bit more careful, that's why I check it all the time you know, this little thing... I don't know, there probably is different, but you think bloody hell... I mean I've still got my face, some of these poor guys I've see, women, men, they don't have that...it does tend to frighten you...as far as I'm concerned I've been lucky.

Mark (Age 62, Participant 5, Area 2)

Interestingly, although participants from both study areas commented generally on the effect of the waiting room environment, only those from area two spoke specifically about the effect of sharing a waiting room with others with facial disfigurement, making

them consider their own situation and the likelihood of their own disease resulting in a similar outcome. The difference in findings between the study groups may be explained by examining the differences in the set-up of the individual clinics in each area. Where area one has a dedicated dysplasia clinic, area two does not and patients are seen on a mixed maxillofacial outpatient clinic. As a result it is much more likely that precancer patients from area two will come into contact with patients who have obvious signs of facial surgery or disfigurement than those seen in area one.

5.3.3 Inference of the need for biopsy

Moving on from the impact of the hospital environment and the clinician involved, one final significant aspect of the initial consultation itself will now be considered; biopsy of the lesion. This aspect of the patient journey will occasionally take place at the initial consultation visit, although it is more usual that it is mentioned at this time and the patient returns for this investigative procedure. For some patients even the suggested need for a biopsy to establish a diagnosis was enough for the individual to make the assumption that they had cancer:

IV: When they just mentioned about the white patches [I thought] ‘ah nay bother, they’ll just go away’...and obviously when I’m going to a biopsy I’m thinking ‘hold on, they’re not that sure about that’, so it was worrying if you like, and I don’t know, I think you get yourself a bit down and depressed with things like that don’t you, but as they say life goes on and you’ve got to get on with things. Cope with things the best you can, simple as that. That’s what life is isn’t it.

I: When they mentioned to you, when you had to have a biopsy, what did you start thinking about at that stage

IV: Basically cancer. You do don’t you? I mean have I? Haven’t I? Have I got it? Have I not? And if I have got it, how bad is it?

Andy (Age 38, Patient participant 11, Area 1)

Where the patient above demonstrates that they associate biopsy with a serious diagnosis, this theme was not confined purely to the initial consultation stage and was often also seen as a significant event for those patients who were monitored long term:

If I did have another biopsy that means it must be getting worse

Chris (Age 65, Participant 6, Area 2)

Where you might suppose that, being a minor investigative procedure, a biopsy may be considered innocuous by a patient; this was often not the case. Patients frequently

described the biopsy itself as an unpleasant and at times disturbing procedure even prompting some to adhere to modification of lifestyle factors primarily to ensure further biopsies were not carried out:

I: And what was having the biopsy like?

IV: It was horrible. They took a piece out, the back of the teeth, and, of course, it was awful. Not very nice at all.

Aida (Age 65, Patient participant 8, Area 2)

Patients who were dissatisfied with their biopsies occasionally complained that the person they were seen by was less experienced than expected and this seemed to have a negative impact on their experiences as Wilma explains when asked about her experience of having a biopsy:

[the experience was] quite poor actually...I suspect it was probably one of the first he'd done and he was dead anxious...he kept complaining about my inquisitive tongue... And he said 'if I've got to do another one, I'll put you to sleep.' And I said 'oh you wont'...I did survive, but I was in for ages.

Wilma (Age 64, Patient participant 7, Area 2)

The notion of faith in the clinician's abilities is a common thread throughout the course of the patient journey and will be discussed further at each relevant stage. Where a lack of faith existed, patients spoke negatively about individuals:

I think I saw three different... maybe they were Dr Xs minions, anyway I saw these people...oh dear, really, they weren't all that... impressive.

Betty (Age 80, Patient participant 2, Area 1)

However, like the experience of disease, it would appear that biopsy itself is an entirely subjective experience. Where for one person it is a disturbing, anxiety provoking encounter, for others it is something that is easily tolerated and quickly forgotten:

I: And how did you find having the biopsy?

IV: Oh, it was champion. It was just a wee nick that was all, it wasn't painful or nothing like that.

Beryl (Age 77, Patient participant 4, Area 2)

Following the biopsy there is a delay, during which the tissue sample is processed, before the results of the investigation become available. During this time patients reported experiencing a period of worry or stress in association with this wait:

The worst time is the waiting really...the last thing you want is to have this worry on the back of your mind all the time.

Archie (Age 72, Participant 3, Area 1)

In keeping with these findings Risberg et al., investigated the psychological impact of diagnostic delay on patients with suspected malignancy, noting a positive correlation between total diagnostic delay and psychological distress (Risberg et al., 1996). Poole et al., broke the process down further examining specifically anxiety associated with what they termed the peri-diagnostic interval, that is the interval between a diagnostic investigative procedure and receiving a definitive diagnosis. They found that for those who demonstrated anxiety this was sustained throughout the period between the procedure and the results (Poole et al., 1999). A factor which has been suggested by some to be a reason in itself to minimise such diagnostic delays (Neal and Allgar 2005). Interestingly, Poole et al., also found that where patients believed the outcome of their investigation would be a cancer diagnosis, the patient went through a 'preparatory period' during which they psychologically readied themselves for the prospect of a life with cancer.

5.3 Diagnosis

Following biopsy, a diagnosis is usually made, or confirmed. It is at this point that the patient will be given a label to apply to their oral lesion, which is something they are often seeking:

And of course naturally you're keen to know what it was...what it actually is

James (Age 61, Patient participant 4, Area 1)

Although an explanation of the diagnosis will be provided at this stage, this does not mean that it will be understood or interpreted in the way the professional providing the explanation intended. There will be a number of factors which influence interpretation of diagnosis, which will now be discussed:

5.4.1 Understanding the diagnosis - the role of communication and patient response

When considering how patients' make sense of their diagnosis it is worth initially taking into account the terminology used during the diagnosis. Lerner et al., discuss the importance of the terminology used in medical communication in their paper concerning patients' understanding of common medical terms (Lerner et al., 2000). They found that even frequently used medical terminology is often poorly understood by patients. As an example, 78% of their sample group did not recognise that broken bone and fractured bone were analogous terms. This highlights the importance of the wording used when providing medical explanations to patients.

In this study, the patients from both sample groups described their recollection of the terms used by their clinicians when delivering their diagnosis. Descriptions such as white patch, unstable cells, abnormal cells, hot spots, dysplasia, leukoplakia and precancer were the terms most commonly recalled by patients. Although frequently able to remember the label which had been given, and in some cases, speak authoritatively regarding this label, upon further questioning it often became clear that patients accepted the label without a true understanding of its meaning or consequences:

IV: There were some unstable cells
I: And what do they mean by unstable cells
IV: I don't know. Pass.

James (Age 61, Patient participant 4, Area 1)

Furthermore, there often appeared to be a reluctance to seek clarification where a lack of understanding existed:

I didn't really ask I don't think I knew what it meant

Dot (Age 61, Patient participant 5, Area 1)

The significance of this lack of understanding as a consequence of terminology used is discussed in a small body of work within the field of cervical precancer. This work has revealed that patients with the diagnosis of cervical precancer are frequently confused by the terminology used by medical professionals. This, in turn, can lead to misinterpretation of the diagnosis given. Kavanagh and Broom discuss the relevance of patient understanding in patients with abnormal cervical smear test results (Kavanagh and Broom 1997). They note that the use of terms like abnormal and precancer can

result in the patient believing that they in fact, have cancer. Something that was sometimes seen with the study group:

Basically it was cancerous cells, that's what they are.

*Andy (Age 38, Patient participant 11, Area 1)
Discussing his interpretation of his diagnosis*

As well as the direct effect of the confusion caused by difficulty interpreting terminology, there is also the potential for further misinterpretation when such terms are used by patients to seek further information. A specific example of this was seen when patients used terms such as white patch to seek further information via the internet. This will be explored in more detail in a later section.

As well as providing a label to apply to their disease, the conversation during which the diagnosis of precancer is delivered may also involve a discussion regarding risk. The diagnosis of a potentially malignant disorder carries with it risk, specifically the risk that the lesion will transform into an oral malignancy. Living with this risk will be discussed in a later section, however, as a component of delivering the diagnosis, the health professional will, on occasion, use statistics as an aid to convey this risk:

...he said eight out of ten times its cancer

Chris (Age 65, Patient participant 6, Area 2)

Although the patient data often made reference to the use of statistical information, the values recalled by the participants were never the same. Perhaps this is because communicating risk to patients is an inherently difficult task. The subject of risk communication has been explored extensively in the literature. For example, Bogardus et al., discuss potential difficulties encountered when discussing risk with patients (Bogardus, Holmboe and Jekel 1999). They begin with a quote from a patient considering risks of prostate surgery to illustrate the point: "You tell me the chance of becoming incontinent from this surgery is 5%. What does that mean? If I get it, its 100% for me, right?" (p. 1037).

Following their discussion of the challenges associated with risk communication including the difficulty surrounding interpretation of numerical data, they put forward a proposal for effective risk communication. They identify three primary formats via

which risk may be presented to patients: qualitative, quantitative and graphic, and suggest that the more recently adopted approach of presenting information graphically may help to overcome difficulties some patients have with interpreting quantitative data.

The efficacy of risk communication is also explored in a paper by Lipkus. In it he details the following potential effects of effective risk communication: engagement in recommended behaviour, paying attention to the message, acquisition of factual knowledge, effects on emotions, judging perceived risk and evaluation of the message (Lipkus 2007). Given the wide ranging potential effects it is important that methods other than quantitative approaches to risk communication are considered as effective risk communication needs to be tailored according to the individual needs.

Following delivery of the diagnosis, there were primarily two opposing responses noted: one of relief and the other of distress:

Once they said, after the biopsy, it's not cancerous; I thought that will do me
Ted (Age 69, Patient participant 12, Area 2)

[When] he said everything was okay, it's a relief and you don't realise until you come and you... the feeling of joy you get
Graeme (Age 43, Patient participant 14, Area 1)

For those who were worried about the possibility of cancer, they were often looking for what was frequently termed a 'negative' result. Once the diagnosis was given, as long as it was not cancer, this was seen as a positive. It appeared that patients were more likely to be distressed by the results of biopsy where they associated their results directly with cancer:

Then I got the news, devastating news really, that they'd only just caught in time what appeared to be a very unstable lesion. More or less precancerous.
Archie (Age 72, Patient participant 3, Area 1)

When they said it was like a precancer, I just went, you know, down, you know, I was pretty down
Mark (Age 62, Patient participant 5, Area 2)

This anxiety appeared heightened where the participant had been unconcerned prior to the investigation.

Looking again at the cervical precancer literature Karasz et al., demonstrated that patient response to the diagnosis of an abnormal cervical smear test is shaped by what they term the individuals illness representation (Karasz, McKee and Roybal 2003). They explain that each participant's illness representation is composed of their beliefs surrounding illness, which are frequently informed by a combination of biomedical and folk models of illness. Applying this to the distress experienced by some cervical precancer patients following their diagnosis, they noted that individuals who perceived themselves as being at risk, for example due to persistent symptoms, experienced significant distress, whereas those who did not feel personally at risk, for example as a result of no family history of cervical precancer, were unconcerned by the test results. In this way it can be seen that the reaction to diagnosis will be shaped not only by the way in which the doctor chooses to present the diagnosis but is also determined by the preconceptions of the patient which will vary with each individual.

This section has considered the diagnosis of oral precancer from the patient perspective with a focus on interpretation of the terminology used by the doctor to describe their disease, the risk associated with the diagnosis and the factors influencing an individual's response to this information. I will now go on to consider how the patient participants addressed their information needs following diagnosis, specifically by considering the role of their doctor, friends and family and internet as further sources of information.

5.4.2 Patient Information needs – seeking additional information

As discussed, alongside the diagnosis, the clinician will provide the patient with information about their disease. Where for some this is all they require, for others there is a need for further information, largely as a means of understanding their diagnosis.

When considering information sources at this stage of the patient journey, an obvious source of further information would be the health professional delivering the diagnosis. Indeed studies would suggest that medical professionals are often viewed as the most important information resource (Norum et al., 2003). However, accessing information in this way does not always appear to be straightforward. When considering utilising

the health professional as a source of further information, it is impossible to exclude the significance of the relationship between the patient and the health care professional (usually the doctor). This relationship has been explored in the literature over a number of years.

Historical work by Parsons examined this relationship when he examined the sick role (Parsons 1951). This role described the roles and obligations of the patient and doctor and can be viewed largely as a similar relationship to that of parent and child. The nature of this relationship means that there is a power imbalance in favour of the doctor. Demonstrated here by this participant who categorises her clinician as an ‘authority figure’:

IV: ...mind you, by the that time I was in floods of tears.

I: Why was that?

IV: I'm a weeper. Some people are. I just weep. I'm sure it's something to do with authority figures.

Wilma (Age 64, Patient participant 7, Area 2)

Over time, however, the literature has demonstrated a change in the doctor-patient relationship with some patients looking to adopt a more ‘active’ role (Hack, Degner and Dyck 1994). In their study investigating the information needs of breast cancer patients, Hack et al., suggest that so called active patients not only look for greater levels of information in relation to their diagnosis but also expect a greater role in treatment decisions. Decisions surrounding treatment will be considered in a later section. Continuing to focus on patients’ information needs, Raspe et al., explored this topic, finding that patients fall into one of three categories: those who do not wish any detailed information, those who would like to know more but do not ask and those who ask and succeed in obtaining further information.

Looking at the patient data, it is interesting to note that many of the patients fell into the category of patient who do not wish any detailed information, and instead are keen to maintain a passive role, for example this patient describes how he actively avoids seeking further information about his disease, when asked about information seeking habits he replies:

I just never bothered, I thought they know what they're doing, I just let them get on with it...I just let the professionals get on with it and trust them, yeah.
Mark (Age 62, Participant 5, Area 2)

Furthermore, it would appear that as a result of a desire to maintain a passive role and need to 'put their faith' in the doctor, a barrier to accessing further information is created.

The doctors get paid to diagnose, they know what the score is
Bob (Age 48, Participant 10, Area 1) discussing why he did not feel the need to seek any further information about his condition.

I'm just one of these people that go along and leave it up to the doctors to tell me what's happening.

Wilma (Age 64, Participant 7, Area 2)

Wilma also explains how at one review appointment the doctor she saw mentioned a possible need for surgery; she then describes how she reacts to this new information:

Well, obviously, head in the sand, let's not talk about it if we don't need to

Wilma (Age 64, Participant 7, Area 2)

For patients like Wilma, clearly it may be challenging for professionals to encourage patient involvement in care, which has been demonstrated to have a positive effect on quality of life and experience of disease (Hack et al., 2006).

For those patients adopting a more active role, it was seen that although some felt that they wanted additional information, barriers existed which made accessing this information from the doctor difficult:

I suppose it's the North East, you're supposed to be a hunky, brutey man and not have concerns. Get on with it.

Frank (Age 63, Patient 11, Area 2)

For example, Frank seems to suggest that asking questions may translate as showing weakness. Other barriers including feeling ridiculous and feeling that the doctor is short of time have also been put forward as specific barriers in the literature. However, even for those who were able to ask for and obtain additional verbal information, there was an acknowledgment that understanding or taking in this extra information at the diagnosis stage, could be difficult:

People don't always hear, as I'm sure you know, people don't always hear what's being said to them.

Jackie (Age 51, Patient participant 13, Area 1)

Where many patients recognised that retaining information was difficult, some put forward potential solutions to this problem:

I know it would take loads of work, but if they could write it out and send it back to you so then you could, then you would probably remember. But that's maybe just me, that I don't take it all in.

Aida (Age 65, Participant 8, Area 2)

Looking again at work carried out with patients diagnosed with cervical precancer, parallels may be drawn with their patients and my patient study group (Kavanagh and Broom 1997). Patients in their study also recognised that additional information provided at the time of diagnosis may not be absorbed. They reported this is as a direct result of either distress following the diagnosis or the technical language used. Factors which were also common to my study data.

After professionals, friends and family are the next common source of medical information (Norum et al., 2003), with some taking the process a step further:

My wife and I compared tongues...

Phil (Age 58, Patient participant 15, Area 1)

Describing the action he took following his dentists discovery of a white patch on his tongue

My sisters an ex nurse, and I take it down to her and I say right, put this into English for me please...I like to know

Beryl (Age 77, Patient participant 4, Area 2)

This quote also reiterates the point that medical terminology can prove somewhat inaccessible to patients, to some it is seen as a different language requiring translation.

As well as family and friends, the internet was mentioned by some as a source of further information, as in this case, following delivery of the diagnosis:

When I got home I looked it up on the internet... [I found] all sorts of information, the people most likely to get it and pictures and what have you... I didn't even know the name, I just said it was a lesion, unstable white lesion, unstable white cells, a lesion.

Arnold (Age 71, Participant 6, Area 1)

As well as demonstrating that some patients use the internet as a resource, this participant also highlights the importance of the choice of search term used when accessing this resource. A paper by Alcaide-Raya et al., on internet use, sought to examine the quality of information available in relation to potentially malignant disorders (Alcaide-Raya, Hughes and Warnakulasuriya 2010). They conclude by stating that the information available is of satisfactory quality. It is important to note that their study relies on the use of medical terminology when conducting the search. However, it has been discussed that patients are often given lay labels for their disease, such as white patch or unstable cells. An internet search via popular search engines using terms such as these will reveal less specific, confusing and at times alarming, information. Something that was picked up by one of the participants:

The trouble with the internet though is you can end up more worried, you've just got to be really careful. It's like reading medical books isn't it, you can read them and think oh my god and by the time you've convinced yourself you've got Blackwater fever or something, you know what I mean? You've just got to be so careful.

Jackie (Age 51, Patient participant 13, Area 1)

I just put in white patch and dear me, grotesque

Phil (Age 58, Patient participant 15, Area 1)

Whilst there was evidence of internet use amongst the participants, this was certainly not a source explored by the majority of the study group. One possible explanation for this may be found in the work of Norum et al., who, when examining internet use by oncology patients, found that internet use as a source of medical information was positively correlated with young age (Norum et al., 2003). As oral precancer is most commonly seen in older patients perhaps the internet will prove to be a more significant source of information for future patient groups.

5.4.3 Influence of others at the time of diagnosis

Moving away from information needs, the significance of other people at the diagnosis stage will be explored by first considering briefly the role of the doctor and then discussing the importance of friends and family.

Although the influence of the professional at the time of diagnosis has been explored in relation to communication and information seeking, it is also important to state that there was a general feeling put forward by the study group that the experience of the professional delivering the diagnosis was important. This notion appeared to feed into participant feelings that confidence, trust or faith in the doctor is significant and if a lack of any of these factors was present there was a significant negative impact on the doctor-patient relationship. The perception of being seen by people at the core was important. The consultant was frequently considered as being at the core of the medical team and as a result was often seen as being the expert which, in turn, inspired confidence and trust:

Well I suppose if you're not seeing the top man it means that you're not terribly important

Molly (Age 82, Participant 10, Area 2)

This concept will be examined further in a later section.

As well as the influence of the patient's clinician throughout their disease journey, participants chose to involve friends and family to varying degrees. Interestingly though, when attending the outpatient clinic, although a number of participants discussed their desire to bring someone with them for support, it was not uncommon for the person accompanying the patient to stay in the waiting room. In this way it appeared that these patients appreciated having someone with them as a personal support (indeed bringing someone along was always viewed as positive), but also preferred to keep the interaction between themselves and their clinician private:

I just like to go in myself, I can talk easier that way, you see, and then when I come out, they say, what's he say, what's he been doing, and then of course I repeat it to them and they know what's been going on...and everybody's informed

Beryl (Age 77, Patient participant 4, Area 2)

One possible explanation for this behaviour may be found when participants' accounts are further explored. In doing so it was observed that participants often chose to modify the information they provided to their friends and family:

I minimised it, I minimised how worried I was because, well you don't do that to your family do you so I said luckily they've identified these things really early because I go to the dentist every six months and therefore, I'm sure everything with be fine

Jackie (Age 51, Patient participant 13, Area 1)

Similarly this participant described how he found it really comforting to have his daughter with him at the hospital (although she didn't go into the consultation itself), despite this he also goes onto describe how he chooses to withhold some of the details surrounding his diagnosis from her:

IV: Actually the lads that I work with know more than my kids. I've had quite a lot of support from them, it's a big help.

I: So you're quite happy to discuss it with people at work

IV: Yeah, strangers

I: Do you think it's easier that way

IV: Well you don't want the family to worry. At least I didn't.

Mark (Age 62, Participant 5, Area 2)

In this way there appears to be a desire, by some patients, to maintain control over the nature of the information passed on to friends and particularly family in a bid to protect them from what is seen as potentially upsetting information. Unfortunately, the literature would suggest that shielding information from loved ones in this way, known as protective buffering, may ultimately lead to increased levels of distress over time (Suls et al., 1997).

5.5 Management

Once a diagnosis has been established a treatment plan is formulated. This will usually involve advice regarding removal of risk factors, if present, alongside either surgical or conservative management. The patient's experience of each of these aspects will now be discussed beginning with issues surrounding risk factors.

5.5.1 Risk factors associated with oral precancer

There is an established link between smoking and drinking alcohol and the genesis of oral cancer and precancer. As a result, efforts aimed at reducing or eliminating the presence of these risk factors often forms part of a patient's treatment plan. One of the potential barriers in this process occurs where patients appear not to accept the significance of the risk factors put forward by their clinician. Where this occurs it is not necessarily because patients do not hear the message (that tobacco and alcohol may be implicated in their disease), but more that their views of disease aetiology, or their lay beliefs surrounding illness, may not be consistent with that of the health professional putting forward the risk factors. If we use the data to consider patient perception of disease aetiology for example, it can be seen that study participants frequently attributed their oral lesions to a number of different factors:

Well personally I thought it was the inhalers that gave me it

Dot (Age 61, Participant 5, Area 1)

I believe myself the thing was caused first by my bad teeth because I had... I hated dentists and I didn't want to go and they were rotting and they were jagged and were catching my gum and you know the side of my mouth and I think that. I thought that's what had caused it like

Arnold (Age 71, Participant 6, Area 1)

At the beginning when I saw these white patches, I thought it was the toothpaste I was using. I thought it could be that.

Violet (Age 90, Participant 2, Area 2)

It can therefore be appreciated that if patients assign the cause of their disease to reasons other than known risk factors, the motivation to modify these health related behaviours is reduced and this can therefore be a barrier to following treatment plans.

A clear explanation of disease aetiology was not always present within each of the patient accounts and when discussing the potential causes of their condition, patients frequently reported the cause of their disease as unknown. This was seen to occur even when patients were aware that professionals were implicating smoking and drinking in their disease process:

Well it's like a lot of the doctors blame smoking for everything don't they, no disrespect or anything but I just think it's the easy option really, you know but I do believe a lot of doctors and people do blame smoking for a lot of things, I think there's other things that contribute

Gladys (Age 62, Participant 1, Area 1)

It doesn't matter what you go into hospital for... they ask you how much you drink...and do you smoke? And it doesn't matter.

Betty (Age 80, Patient participant 2, Area 1)

This response is perhaps not surprising when we consider the work of Lowry and Craven. They examined awareness of oral cancer within a cohort of smokers and drinkers. Through this work they demonstrated that there was a dramatic lack of perceived association between drinking alcohol, smoking tobacco and an increased risk of oral cancer development, despite these two factors being the primary causative agents (Lowry and Craven 1999).

This participant later goes on to describe her reaction to a clinician questioning her about her alcohol consumption:

And I did have a little bit of a do with a Mr Z. I don't drink any more than anyone else. And I said my husband and I used to have what we called our nightcap, we had a nightcap at night before we went to bed and I mentioned this and he said how much alcohol did you have? And I said well I suppose we had one sort of drink. And he said but how big was the drink? And he went on and on about the alcohol. And I'm afraid at the finish I said, look if you're trying to say I'm an alcoholic I'm not...I wasn't having that. So I ended that conversation. But just in case alcohol had anything to do with it I haven't had one single drink since then.

Betty (Age 80, Participant 2, Area 1)

The participant in this case demonstrates a reaction of anger when being questioned about her alcohol intake. It appears that she accepts alcohol as a risk factor because she chooses to modify this behaviour; however, this is not what she literately reports. Instead it is likely that she feels a sense of guilt that she may have contributed to her oral condition and is reluctant to accept it.

This reaction may be explained if we consider the role of stigma and disease with particular regard to self-inflicted conditions. Cancer in general is often considered a stigmatised disease, but if we take the example of lung cancer where there is frequently a strongly perceived association with smoking the stigma may not only be associated

with the disease but also with the notion that the sufferer has caused the disease through their actions. A qualitative study by Chapple, Ziebland and McPherson explored this topic. Through their work they found that although the majority of patients acknowledged the stigma associated with their cancer and smoking habit, some sought to resist blame and associated stigmatisation by attributing alternative factors such as diesel fumes, carbon monoxide, spray paint, asbestos, pollution, diet, stress, and bereavement to the cause of their disease (Chapple, Ziebland and McPherson 2004).

Within my patient study groups, smoking was by far the most widely discussed risk factor. As part of the discussions on smoking, the topic of smoking cessation was often brought up, usually because smoking cessation formed or was recommended as part of the patient's treatment plan. When talking about attempts at stopping their smoking habit, participants often started by drawing a distinction between smokers and health professionals:

So you always go and think oh god, here we go, smoking can be brought into it. In my experience, not everybody, but lots of people in the medical profession do have a sort of view, a sort of very strongly held view that why are these people smoking when it's so bad for their health so they feel very strongly about it. You can see why they can't understand it but then, you know, it's got to be a very addictive thing for you to spend that much money ruining your health, do you know what I mean?

Jackie (Age 51, Patient participant 13, Area 1)

As part of this process participants sometimes tried to ascertain my smoking status. Although the exact purpose of this was not clear from the discussion following these enquires it is hypothesised that the stigma associated with smoking and a potentially self-inflicted condition may have had a role to play.

When discussing attempts at behaviour change, it appeared that patients were more motivated to undertake a lifestyle change when they believed it would impact directly on their current situation:

I think I realised that Mr X wasn't saying to me you've got to give up smoking the way doctors, you know, go in with an ingrown toenail and they say you've got to give up smoking. I know they're coming from a health viewpoint but this was a very serious 'you've got to give up smoking' and it wasn't said nastily or exasperatedly or whatever, he just said it in a very serious manner. He said 'you really must give up smoking', you couldn't miss it and you knew it was meant for your benefit.

Jackie (Age 51, Patient participant 13, Area 1)

Where the patient above felt stopping smoking would have a direct effect on her prognosis in relation to her oral lesion, the following patient stopped smoking as a result of another motivating factor:

IV: I'll tell you what it was. I was having plastic surgery on my eyes, and they said that I need to stop smoking and that's what made me do it. I stopped just like that.

I: So was that a bit later on from the white patches?

IV: Huh-huh. Yes I think it was.

I: Did they say at the hospital, say that if you stopped smoking that would mean the white patches would go away?

IV: They said it would reduce the chances of it becoming cancerous.

Aida (Age 65, Patient participant 8, Area 2)

There were a number of participants in both study groups who continued to smoke following their precancer diagnosis. This was sometimes seen to occur even when a clear association between the patient's current disease, smoking status and potential progression to oral cancer were understood:

They basically said that eventually it would turn to cancer, it would. If I kept on smoking it would turn to cancer eventually...

Brenda (Age 53, Participant 7, Area 1)

In order to understand why Brenda and other participants continued to smoke despite the known association with cancer, the data was analysed with respect to barriers to smoking cessation. Other than the belief their disease is caused by another factor, as previously discussed, it became evident that a further significant barrier to smoking cessation existed where participants adopted a fatalistic approach to disease:

I've smoked since I was 14 you know: I'm 62 now... I've known people that don't smoke and they are in a hell of a sight worse state than me...and you know, you just; well you take your chances don't you, well I do anyway.

Mark (Age 62, Participant 5, Area 2)

He later goes on to describe in length the smoking cessation services he has accessed and reports a reduction in his smoking habit from 40 to 20 per day, however, when asked directly if he felt that he would eventually be able to give up smoking he answers:

Yeah, when I'm dead

Mark (Age 62, Participant 5, Area 2)

Thereby, making his true intentions clear. This point of view was seen in relation to alcohol consumption as well as tobacco smoking:

I don't think it does us any harm because I mean my father's ninety-four, [and he] has a whisky and orange every night.

Arnold (Age 71, Participant 6, Area 1)

Such attitudes have been defined in the literature as 'cancer fatalism' (Lewis et al., 1989), with one UK based study finding that 43% of the participants believed that whether a person developed cancer or not was a matter of chance and therefore was unavoidable (Warnakulasuriya et al., 1999). Cancer fatalism is a concept characterised by an individual believing that they have no influence over their health status, the likelihood of disease development being purely down to luck. It can therefore be seen that such an attitude poses particular difficulties when it comes to attempting to influence patients' risk factor related behaviours. Although behaviour change can be a challenging process much work has been carried out in relation to facilitating this process. To this end it has been suggested that the individual involved in facilitating this process can have a significant effect. Work by Lowry et al., has shown that the attitude of the health professional can be perceived by patients as a barrier to behaviour change, specifically a lack of enthusiasm. Their group found that social marketing can be used successfully to overcome this, and other barriers, to elicit smoking related behaviour change (Lowry et al., 2004).

5.5.2 Experience of treatment – surgery

Many of the study participants had undergone a surgical intervention on at least one occasion, usually involving either laser or scalpel excision. Earlier in the chapter the impact of the hospital environment during the transition phase from primary to secondary care was discussed and it was demonstrated that for some being in an outpatient department alone can be a daunting experience. When patients undergo surgical treatment the clinical environment changes again and they may face another new environment for the first time. For example, this patient recalls her experience of surgery where she had surgical treatment in a theatre environment under local rather than general anaesthetic:

It is quite scary. It's the first time I can remember being in a theatre, and you sort of stand there and look and there not going to like this but there was a lot of people and all in masks and goggles and goodness knows what, they looked as though they came from another planet to be honest. Mars comes to mind. And I just sort of thought oh, my god. And to be honest how I got through it I do not know. But I was told I did very well. But I didn't feel as though I coped very well. But I found it frightening. I did find it frightening.

Betty (Age 80, Participant 2, Area 1)

Where a number of patients' accounts echoed that of Betty, finding the experience of surgery frightening, for others the concerns were a little more trivial:

It was, like, what I looked like. I mean I had no teeth in, I had to take teeth out, I had the goggles and he wrapped us up so just me nose and eyes, I thought, my god, I hope nobody's watching, taking a photograph, what a sight.

Gladys (Age 63, Participant 1, Area 1)

However, fear of the surgery was not a universal experience:

I mean I've had so many operations especially when I had the leukaemia, I had four Hickman lines in so that was under general anaesthetic and I'd had the...eyes for Glaucoma before that under general anaesthetic...I mean by comparison the laser treatment was no big deal

Bert (Age 72, Patient participant 8, Area 1)

It can be seen here that Bert's anxiety levels are reduced apparently as a result of previous experience of illness. A theme also observed during other aspects of the patient journey.

Expectations of surgery were explored with the study groups where, at times, patient expectations did not match the surgery itself:

I actually just thought they were going to zap it with a laser beam...it wasn't until the day I come into hospital he explained to me that he was going to take a piece out and there was going to be a big black hole there.

Graeme (Age 43, Patient participant 14, Area 1)

This theme (meeting expectations) became more prominent when it came to investigating patients experiences of post-operative effects:

Afterwards I was quite shocked at how much they cut away actually. I thought I would just be a small patch. I didn't even expect any of my tongue to go, but he cut a lot off the tongue as well.

Archie (Age 72, Participant 3, Area 1)

And I thought oh, I'll just look in the mirror. And I lifted my tongue and I thought crikey me, where's my tongue gone?

James (Age 61, Participant 4, Area 1)

Now still, 18 months after, the tip of my tongue is still as dead as a dodo...I didn't know that was going to happen.

Betty (Age 80, Participant 2, Area 1)

These data suggest that there is a barrier in communication preventing these patients from fully appreciating the possible consequences of surgery. When the data were further explored, in comparison to communicating the diagnosis, it was found that explanations surrounding surgery were often provided by junior members of hospital staff. This is interesting when the professional data is also examined in relation communication. Where the vast majority of professionals stated that they felt it was important that a senior member of staff, usually a consultant, communicated a pre malignant diagnosis, this was not always found to be the case when it came to communicating the procedural details and consequences of surgery. Where it is not possible to establish a link on the basis of the data obtained, it is certainly concerning that patient expectations are not being met, particularly if we consider the following patient's account:

IV: I wish I'd known if it was going to turn cancerous then fair enough I would have had the operation, but without it, without knowing it was definitely going to turn cancerous I wish I hadn't had the operation.

I: Why is that?

IV: Because of the way my mouth is now

Ruby (Age 51, Participant 9, Area 1)

speaking about her regret at her decision to have surgery after being unexpectedly left with permanent paraesthesia in her tongue

Living with the potential side effects of surgery will be further explored in the final section of this chapter.

5.5.3 Experience of conservative management

An alternative to surgical treatment is that of conservative management, often preferred for patients who are considered to be at a low risk of malignant transformation.

Conservative management usually involves multiple visits to the hospital on a regular basis so that the oral lesion can be monitored for change. The way in which this option is presented to the patient is important. If we consider the previously discussed work by Donovan et al., involving patients with prostate cancer, the presentation of the option of watchful waiting was frequently interpreted by patients as no treatment leading some to believe clinicians would simply ‘watch while I die’ (p.768) (Donovan et al., 2002). The study went on to suggest that the terminology used when explaining the concept of conservative management is key. They found that by redefining the term ‘watchful waiting’ to ‘active monitoring’ a more proactive style of management was inferred, thereby inspiring greater confidence in this management option.

Going back to the patient data it was seen that although for many conservative management was a source of deep comfort, for others these visits were seen as an inconvenience. This appeared to be the case where ambiguity existed over the purpose of the visit and in such instances there appeared to be a sense of patients feeling lost:

I mean I had no idea what was going to happen, just went to find out. I must admit I was a bit sick of going up to the hospital every six months
Ruby (Age 51, Patient participant 9, Area 1)

Again, it appears that communication is central to patient understanding and acceptance of this option.

5.5 Review/post treatment phase

Following surgical management patients will subsequently attend a maxillofacial out-patient clinic for regular review. This will take a similar format to those who are being managed conservatively. In both cases the time between review appointments and the overall review period is variable and in the absence of any clear guidelines is dependent both on patient factors and clinician preference, but can last several years. As an extreme example, one participant in the study had been undergoing review for nine years. There are a number of themes associated with this review phase. In most cases these themes were evident in other areas of the patient journey. However, they will now be discussed with particular reference to this aspect of the patient experience.

5.6.1 Uncertainty

Uncertainty was a theme associated with many aspects of the patient journey. One of the uncertainties associated with precancer is the uncertain disease trajectory in that it is possible both that the disease may progress to cancer, but also that it may regress and resolve altogether. For example, at the diagnosis stage there was often a sense of relief seen in response to the results of the biopsy where cancer was not observed:

Well I mean there's always a doubt...you think it could be [cancer] but no, it turned out that wasn't so...it was [a relief] it's always a relief when you get good news

Gladys (Age 63, Participant 1, Area 1)

This relief may be partly explained if it is considered in terms of the participant being relieved or unburdened of their uncertainty over the looming diagnosis. The concept of wanting 'relief from uncertainty' is seen in other areas in medicine, for example in the case of conditions with a genetic predisposition where individuals undergo genetic testing to ascertain the likelihood of developing a specific disease (Williams et al., 1999). However, rather than responding with relief, this participant's reaction is more typical of the study group. Although, in common with the previous participant's account, she expresses that she is relieved that she has not been diagnosed with oral cancer, it is clear that her uncertainty in relation to the nature of her condition persists:

Worried about it, because it shouldn't be there should it. I'm worried about it. I don't know what it is. He said the two biopsies I had it wasn't nasty so I was relieved at that. But I just don't know what it is.

Glenda (Age 66, participant 1, Area 2)

It is often documented that uncertainty results in anxiety and as a result there has historically been a focus on 'anxiety reduction' in medicine in relation to diseases with uncertain outcomes (Brashers 2001). If we consider the work of Juraskova et al., it is clear that negative responses including anxiety are often seen for those who are diagnosed with cervical precancer (Juraskova et al., 2007). However, as Brashers states it is important to consider that individuals' cognitive responses to uncertainty are not uniform. Where it is certainly possible for some that uncertainty is an anxiety provoking experience, for others uncertainty can be positive in that it allows the individual to maintain hope, for example within this group a positive response to

precancer was seen in those who voiced hope that the oral precancer will regress. As this participant demonstrates:

Oh positive, without a doubt. It wasn't cancer. To me precancer... the earlier you catch it the better chance you have.

Frank (Age 63, Participant 11, Area 2)

Earlier, in the literature review, it was argued that oral precancer may be viewed as either an acute or chronic illness. This is significant when we look at uncertainty. For those with disease that is discovered, treated and resolved the uncertainty may be short lived, for example uncertainty associated with a surgical procedure:

I mean the main thing was getting put to sleep and frightened of not waking up...that was more of a worry than anything else

Bob (Age 48, Participant 10, Area 1)

As this participant demonstrates, his uncertainty is associated with surviving his operation which will clearly no longer exist following the treatment. However, for many oral precancer patients their management will not result in complete resolution of their condition and it is not unusual for these patients to undergo extensive periods of follow up (in either primary or secondary care). For these patients there was often uncertainty regarding the course of their disease:

IV: I think it will gradually go...just take its own time...leave it to its own course ...as long as they don't cut off a bit of my tongue

I: Did they mention to you that might happen

IV: No, [but] you never know.

Beryl (Age 77, Participant 4, Area 2)

Not only does this participant demonstrate her uncertainty with regard to disease outcome but she also voices unresolved concerns about possible future surgery.

For those with ongoing disease, the literature would suggest that the nature of the uncertainty can also be seen to vary over time particularly as individuals become accustomed to their disease state (Mishel 1999). Where this was not especially evident from the data in the way Mishel describes it, there was evidence of a change in the levels of uncertainty the individuals experienced as time elapsed. An unusual example

of this comes when we consider Violet's account. In this case she misinterprets information provided by her clinician at one of her review appointments, resulting in an increase in uncertainty. She had been attending an outpatient department for review over several years following a surgical intervention. She adopted a passive role throughout the course of her management, choosing to rely on the doctors in charge of her care as her sole source of information:

IV: Yes, white patches, it's all I remember. Yes, well of course it was all new to me then, I didn't understand it, but as the years have gone by well I've understood more about it.

I: What extra information have you picked up over the years about it?

IV: Well recently Dr X did mention cancer and that was the very first time, but I didn't think it was cancer that was the only thing.

I: So was he saying that you that you did have cancer in your mouth before?

IV: ...well yes, because he said the cancers returned sort of thing...

I: ...so how did you feel when that came up just quite a number of years later?

IV: Well I was just surprised really

Violet (Age 90, Patient participant 2, Area 2)

She later goes on to describe how she re-evaluates her past disease on the basis of this new information, stating that she believes now that she had a type of cancer that didn't spread and was therefore easier to treat. Examining Violet's transcript it could be argued that this process of re-evaluation resembles the process of biographical disruption described by Bury whereby an individual's inner biography is renegotiated following a significant event (Bury 1982).

For those whose treatment involved surgical intervention there were a number of possible side effects of surgery including pain, bleeding, paraesthesia, scarring or, less commonly, as the following participate demonstrate, xerostomia. Participants often reported uncertainty relating to the duration of these surgical side effects:

IV: you know, there's no saliva in the mouth and it just sort of sticks to everything

I: And is that going to come back?

IV: I'm not sure...I mean obviously it must vary from person to person, or where the actual treatment was, so I'm just waiting and holding on and keeping my fingers crossed

Mark (Age 62, Participant 5, Area 2)

This patient describes his experience of xerostomia, however, he appears unsure regarding its duration apparently relying on hope rather than seeking additional

information to provide clarity. Although the majority of patients who undergo surgical treatment for oral precancer report minimal adverse effects, even for those without any persistent undesirable post-operative side effects, there was still the potential for uncertainty when it came to disease recurrence:

I mean I knew nothing at the time what the success rate was, how many people it did come back. I still don't really know how many times people do have to come back, how often it reoccurs. When it reoccurs, does it lie dormant for another year or two. I don't know anything like that, even now.

Archie (Age 72, Participant 3, Area 1)

5.6.2 Fear

Linked with this often persistent uncertainty, some patients reported fear in relation to their disease. The topic of fear was examined as a significant factor earlier in this chapter when patients' initial seeking help behaviour was explored. At that early stage it was shown that fear could be either a motivating or delaying factor when it came to patients presenting to a health care professional.

When looking at fear during the review or post treatment phase, its possible effect on patient behaviour can again be seen. In some cases there was evidence of participants' fear that their disease may progress to cancer including the associated potential for extensive surgery and its consequences, including death. Examining the data further it could be seen that this fear often manifested in the individual avoiding seeking further information about their disease and its prognosis:

I: Did you go and look for any information yourself

IV: No, I didn't, no.

I: Was there a reason for that

IV: Frightened. Best ignore it.

Betsy (Age 74, Participant 9, Area 2)

On the other hand, a number of participants, reflecting on the potential consequences of disease progression to oral cancer reported a positive experience. These individuals described how they felt they were the lucky ones and were often grateful to the dentists or doctors involved in their care for the roles they played in avoiding a more serious, life threatening condition:

I was very grateful to the dentist for finding it and referring me on...and people say things about dentists and all that, but they do a good job really, when you think about it, they do a good job. So, I know I filled in a study for, the NHS often sends me studies out, I filled in a study about dentists and whether I thought they were good value for money or whatever. I said if they hadn't noticed that patch I probably would have got cancer.

Brenda (Age 53, Participant 7, Area 1)

The following participant is reminded of the potential for disease progression through her interactions with another patient in the waiting room at the outpatient clinic:

[in the waiting room] there was this gentleman there with his wife and I was a bit, because he had something wrong with his nose, like a cancer type thing, and I hadn't ever thought about this in my life, but he actually [had] a false nose. And it really shocked me, he lifted it off to show me. I mean I was a bit taken aback... and I thought oh, at the time I'm thinking oh, cancer in the mouth and the face must be dreadful, I remember thinking that...I kept thinking, oh you're lucky

Molly (Age 82, Participant 10, Area 2)

As well as the specific fear of cancer, some patients who had been treated by surgical intervention reported a fear of further treatment. This is perhaps surprising when we consider that the majority of professionals who participated in the second study stated that they felt surgical interventions for a patient with oral precancer to be minor particularly in comparison to the often more radical surgery required in many cases of oral cancer. While it is certainly true that, when comparing one with the other, surgery for precancer may be considered less radical with shorter recovery periods and less associated undesirable consequences than surgery for oral cancer, it must be also be considered that the individual patients will not have cancer surgery as a reference point. For example, this patient had opted for laser excision of her premalignant lesion as part of her overall treatment plan. However, she had been unsuccessful in reducing her risk factors (smoking). When another oral lesion was subsequently discovered she believed it occurred as a direct result of her continued smoking habit. She used her fear of further surgery as a motivating factor to successfully aid her smoking cessation efforts:

But I think what made me quit this time, I didn't, it didn't register when they said I had precancerous cells, it didn't really, it didn't really frighten me, but this time when he said the patch had come back, the thought of having the laser treatment again, that's been a big thing, because I don't think I could stand having the laser treatment again...but it's funny that how the thought of getting cancer didn't affect us but the thought of [further surgery did], that's because I'd had the laser treatment and I knew the pain involved, whereas I hadn't had the cancer.

Brenda (Age 53, Participant 7, Area 1)

5.6.3 Reassurance

The review/post treatment phase of management often involves sequential appointments at the same clinic. One of the most striking findings arising from the data when exploring the experiences of patients attending for review was that of the apparent therapeutic effect of the review appointment itself. In addition to this it appears that some patients become reliant on the review appointment reporting panic if it is changed or there is a possibility of discharge:

So I always feel quite good if I've got six months reprieve.

Lily (Age 58, Patient participant 12, Area 1)

I find it very reassuring. I find going very reassuring, I feel like, you know, passed again sort of thing so I find that very reassuring and knowing that things are ok.

Jackie (Age 51, Patient participant 13, Area 1)

The second participant here later goes further, and describes how she feels following a missed appointment:

IV: I didn't realise until I got the did not attend (letter) and I was absolutely mortified, that I'd wasted somebody's time... I was actually quite panicky. I tried ringing up and you can't get through, you really, really can't get through at all...

I: When you got panicky, why was that? You mentioned wasting time, was it because of that...

IV: It was because it wasn't being monitored. I was panicked as well, you know, I did feel awful that I'd missed an appointment and didn't know, so I even rang up the next day. But it wasn't being monitored, that really worried me.

Jackie (Age 51, Patient participant 13, Area 1)

What Jackie demonstrates is a dependence on the review appointment to satisfy her need to know her disease status. This finding is also seen in the work of Gibson et al., in their study examining regular dental attendance. They further go onto compare the behaviours of a regular dental attender (an individual who attends the dentist at six

monthly intervals for a dental ‘check-up’) to those with chronic illness, observing similarities between the two. In particular they state that dental patients ‘may take on the sick role and become dependent on the dentist for their dental health’ (Pg.10) (Gibson et al., 2000). This apparent dependence on a clinician will be examined further in the next section.

Although many of the participants interviewed reported a desire to maintain a regimen of regular review appointments as a means of reassurance, there were also a great number who were keen to progress towards discharge. It appeared that the significance of being discharged was that it was seen as an end of the disease process allowing the person to be released from the labels of both patient and precancer.

I think that I just have to go back one more time. I'm hoping I'll just have to go back one more time. And that would be me cleared altogether.

Betty (Age 80, Participant 2, Area 1)

For these patients there was no concern regarding future disease or disease progression and interestingly this desire for discharge was seen both in those with no ongoing disease or risk factors as well as those with persistent lesions and risk factors.

Previously when the patient data surrounding referral to secondary care was examined it was found that patients placed particular significance on the length of time between referral and consultation appointment, with a shorter wait indicating a more urgent problem. The influence of time is seen again when the data is examined with reference to the time left between review appointments, for example here the change from a two monthly to a three monthly review is viewed in a positive light:

He said we'll keep a very close [eye] on you anyway. The fact he's now made it three months is encouraging.

Archie (Age 72, Participant 3, Area 1)

This participant interprets a greater length between appointments as a signal that his condition is less serious and he is closer to being discharged, something which he also views as positive.

5.6.4 Influence of doctor-patient relationship at this stage

Throughout the patient journey in secondary care there was a strong sense of the importance of what was described as trust, faith or confidence in the doctor in charge of their care:

He was very reassuring. I had confidence in him which means a lot to a patient. My wife was happy with him too, he explained each time. Yeah, if the health service was staffed by a lot of Dr X's it would be very good

Frank (Age 63, Participant 11, Area 2)

This feeling of trust was often coupled by a belief that the clinician was being transparent:

Dr X, he'd obviously done a lot of it and seen a lot of it and I just put my faith in him really...I thought, well he's got to be genuine, he didn't try to make light of it which I would imagine some doctors do when you get something, trying to hide, but he came out with it straight away.

Archie (Age 72, Participant 3, Area 1)

The notion of having faith in the doctor in charge of your medical care is not a new concept (Becker and Maiman 1975) and is seen as being particularly important when it comes to communicating uncertain conditions such as precancer (Juraskova et al., 2007). However, the data suggested that where patients had established a rapport with a particular clinician and felt confident in their abilities, due to the nature of the repeated need for a review appointment, continuity in terms of seeing the same individual at each appointment was also desirable:

It's about the continuity of you know, that person, I'm sure people draw diagrams or measure it in some way, do you know what I mean, otherwise there'd be no bloody point. But it's also about seeing it and knowing you and you know he's seen it the last time and maybe opening the file refreshes their memory or whatever but I think that gives you confidence, that it is being seen and it is being taken very serious and I find that helpful.

Jackie (Age 51, Patient participant 13, Area 1)

Some patients go further, expressing distress at the thought of not having that continuity:

And I do worry because he knows the case so well. I just keep hoping, because I think he's possibly a lot younger than me, so I think well at least you'll not retire before I've...see I'm anxious about that, how sad is that? You think well if something happens and he moves away. I've told him I'll track him down

Lily (Age 58, Patient participant 12, Area 1)

This participant's account, like the next, also demonstrates an apparent dependence on a specific individual. Where this was seen it was always the consultant who was involved:

I'd be disappointed with somebody else...it's just I think you feel comfortable with a person, you can talk better to them and you just seem to understand what they are saying more.

Beryl (Age 77, Patient participant 4, Area 2)

Although the majority of patients expressed a preference to be seen by the same clinician, there were one or two patients for whom consistency did not appear to be of concern:

Well Dr X is in charge, but sometimes I do see other people. They do the same procedure... look in your mouth... make notes and two or three times I've had photographs taken, so they go by the notes.

Violet (Age 90, Participant 2, Area 2)

Going back to where an attachment with a particular clinician was observed, there was sometimes a feeling by the participants that they had personally let their clinician down when, following surgical treatment to remove a lesion, their disease returned:

I was going every six months for a check and then they found the patch had come back again. And I felt really terrible, I felt like I'd let Dr. X down...because I think like he did a very good job. And he was very, very nice to us and all that and then when the patch come back I just felt I'd totally let him down really...I wondered what he felt.

Brenda (Age 53, Participant 7, Area 1)

This section has focused on the factors affecting patients in the post-operative or review phase of their management. In doing so it has been possible to highlight the persistent uncertainty and fear that some patients describe in relation to their disease at this stage. In addition, it has also been possible to observe that where some patients report a need for discharge as a means of signifying the end of the disease process, others rely on the

review appointment for reassurance and comfort and in some cases are seen to become dependent on not only the review process itself but also the clinicians themselves.

5.7 Ongoing effect of diagnosis/living with precancer

This final section of the patient results and discussion chapter will focus on the ongoing effects of living with oral precancer which will be dependent on the patient's appraisal of their disease. As previous discussions have suggested, this is a multi-factorial process often involving patient factors (their knowledge, previous experiences), their social resources (typically the views of friends and family) and the influence of their health care professionals.

5.7.1 Attitude to disease

The individual's attitude to disease will be formed as part of the process of disease appraisal. The following themes demonstrate the attitudes the participants felt towards their disease:

- A devastating diagnosis
- View of oral precancer relative to other health related factors
- Attitude shaped by a fatalistic viewpoint
- Stigma felt in association with risk factors

Each of these factors will now be discussed in turn.

A number of participants found the diagnosis of oral precancer deeply distressing:

Then I got the devastating news really, that they'd only just caught in time what appeared to be a very unstable lesion.

Archie (Age 72, Participant 3, Area 1)

A finding which has long been demonstrated within the cervical precancer literature (Kavanagh and Broom 1997). Also consistent with the findings of this study, Kavanagh and Broom state that where associations with precancer and cancer were made, participants reported profound effects, particularly where the possibility of death was considered. This type of acute negative reaction was most frequently observed at the time of diagnosis. Where for some, the initial effects of devastation felt at the time of

diagnosis diminished over time, for others the ongoing negative effect of living with precancer was evident:

I remember having reflective moments at work when you suddenly come to put the pen down thinking what the devil am I doing here? ... I was on my own... there was more time to reflect at work than there was at home.

Frank (Age 63, Participant 11, Area 2)

Frank later goes onto reiterate this ongoing effect:

There were times I must admit you think oh dear, I'll stay in bed today. No doubt about that. I think having a caring wife...helps. Even if I didn't talk to her. But it helped, she was there. She knows. Just always being around and being helpful without telling me she was being helpful. Difficult for a single person I would think. More difficult. To go home and just have the four walls surrounding you, things closing in, too much time to think.

Frank (Age 63, Participant 11, Area 2)

As well as demonstrating the extent to which his disease affected his life, making him feel that he wanted to stay in bed, this quote also reveals the importance Frank attaches to the support of his wife as a means of helping him cope with this difficult diagnosis.

The impact of other significant factors and in particular the influence of other disease in the patients' lives has been discussed elsewhere in this chapter. When considering the ongoing effects of living with oral precancer, there was often a comparison drawn by participants between their oral disease and their experience of other disease. Patients frequently evaluated the significance of their oral precancer on the basis of previous or concurrent disease experience. Where their oral precancer was judged to be less significant than previous or current illness, the ongoing effects of living with oral precancer were less pronounced. For example, a number of patients reported personal experience of cancer. Where this was seen the precancer was evaluated as a lesser disease and the effect of it on the individual was less.

The impact of previous or ongoing illness was also seen in relation to associated hospital visits. Patients frequently compared surgical experiences between one disease and another. For some, even the experience of simply going to hospital was seen to be influenced by other disease experience:

Well as I said, I've been a diabetic since I was two years old, I've got 49 years behind us and I've been in and out of hospital for all sorts of things to do with that, so hospital holds no fear for me

Ruby (Age 51, Participant 9, Area 1)

The disease experience of others, particularly if they were close relationships, also impacted on the patient experience:

We've got a granddaughter...at the same time she was having trouble. And it was the dentist that told me that she was referring her to the hospital and she had a tumour. Had cancer.

Betsy (Age 74, Participant 9, Area 2)

This experience of oral cancer within the family resulted in Betsy having a higher degree of suspicion when it came to evaluating her own oral condition. Where she felt that she too may have cancer when it transpired she did not, she viewed the diagnosis in a positive light, counting herself lucky not to have been affected by the same devastating diagnosis as her granddaughter.

When exploring patients' attitude to their disease, a strong theme to emerge from the discussions was that of fatalism. A fatalistic attitude has already been covered when possible barriers to behaviour change were examined. The belief that illness occurs simply as a matter of chance was frequently put forward by the study participants. When discussed in the context of their attitude towards their illness this approach appeared to be strongly linked to the age of the participant. For example, the youngest participant, Andy, consistently demonstrated a fatalistic attitude towards his disease:

Life's for living at the end of the day and it's going to deal you out the cards that you're going to have

Andy (Age 38, Participant 11, Area 1)

However, where Andy saw his diagnosis as an opportunity to make the most of his life, others seemed to suggest their life was almost complete, with some expressing satisfaction in the life that they had experienced:

...and of course you see I'm old now, it doesn't really matter, so it's not as though I'm a young person... I've had my day

Violet (Age 90, Patient participant 2, Area 2)

God I'm 69, I've had a canny innings. I've seen my son grow up, my grandson, so I could go tomorrow...no I've had a canny life. I've had two heart attacks and a brain haemorrhage and an operation on my toe, so I think that I'm fortunate still to be here: He doesn't want us yet...

Ted (Age 69, Patient participant 12, Area 2)

Alongside fatalism, stigma was another factor which was seen to impact on an individual's ongoing attitude to their disease. The theme of stigma was most commonly seen in relation to participants' smoking habits. The vast majority of smoking patients were able to recall that their clinicians had advised them of the association between smoking and oral precancer. Alongside this there was, at times, evidence of a difficulty coping with the knowledge that their oral disease was in some way potentially self-inflicted. Where this has been discussed alongside the topic of smoking cessation, in addition, there was an undercurrent of shame present in some of the transcripts particularly for those who continued to smoke:

I don't know, having something in me mouth, I don't know, I feel like unclean somehow with something in me mouth. I don't know why it just...I tend to want to clean me teeth more, things like that. Because its something oral rather that like something on me arm...you know. That's the only thing I feel about it.

Brenda (Age 53, Patient participant 7, Area 1)

5.7.2 Withholding information/protecting family and friends

Where a supportive family unit can helpful during illness, it has been shown that there was often a need, especially initially, to withhold information from family and friends. This appeared to be related to the perceived relative severity of the oral condition:

I was really worried, I was really, really worried. I was so worried that I didn't mention it to my husband for some time, until I actually got the letter for the appointment, or to my daughter. That's usually indicative of how worried I am, if I'm not worried then I say such and such has happened or whatever but the more worried I am, the more I tend to keep things to myself. It's almost like that sort of thing if you mention it, it makes it more real.

Jackie (Age 51, Patient participant 13, Area 1)

As well as withholding information altogether, even when topics such as referral, diagnosis or treatment were discussed with loved ones, the information provided by the concerned individual was often tailored in an effort to play down the perceived seriousness of the situation:

I really told [my wife] very little...I liked to keep most things to myself during the course of what was going on. I don't know why. Yes, certainly the thought of I don't tell her she doesn't know, she doesn't have to worry. But then again you think well, there wasn't much to tell her for her not to worry about. But I don't know, I think most men are like that. Very inward, keep things to themselves. Until it all goes wrong and you break down and the poor woman has got to pick the pieces up.

Frank (Age 63, Participant 11, Area 2)

The same participant also describes the support he felt he got from his mother despite the fact that he chose to conceal his illness from her:

She was the most wonderful, lovely person but not sort of academically gifted. She had no idea. My dad did but he didn't say anything to her. I used to get a lot of support from my mum, my mum bless her, she didn't know but just by being there with her. She was always jolly and humorous and didn't know what was happening.

Frank (Age 63, Participant 11, Area 2)

Interestingly there was also evidence that patients' loved ones withheld their true feelings from the participants:

I did talk to me son and daughter about it and I think me daughter was very worried about it...they tend not to tell me very much. Me daughter, I've been told by other people she worries about us but she never tells me herself.

Brenda (Age 53, Participant 7, Area 1)

As discussed, shielding information from loved ones may also be termed 'protective buffering'. A study by Suls et al., examined coping strategies employed by men following myocardial infarction, they revealed that men employed this approach of protective buffering as a means of shielding information from their wives, but they also found that the men's wives likewise withheld information from their husbands. Whilst the intention of both groups was to protect the other, in the end the effect was instead the opposite leading to increased levels of distress over time (Suls et al., 1997).

5.7.3 Practical impact of precancer on everyday life

In terms of a practical impact on a person's day to day life, multiple participants reported a regular routine of self-checking the oral cavity:

I: Do you keep an eye on your mouth?

IV: Aye...every day...I check it every morning

Mark (Age 62, participant 5, Area 2)

I'm very conscious of what's happening in my mouth now. Obviously at one time – I brush my teeth a hell of a lot more, whereas sometimes it was once a day, now its three times a day, and the mouth wash and things like that...I mean I had an abscess not long ago behind one of my teeth... I went straight up to the hospital...I was genuinely quite panicky about it. I mean I didn't know it was an abscess.

Andy (Age 38, Participant 11, Area 1)

The impact of risk factor reduction (primarily smoking cessation) was ever present for a number of people for whom lesions persisted but attempts at risk factor reduction had failed. However, where the individual attributed their disease to other causes there were examples of unusual behaviour changes which, in some instances had a profound impact on that person's lifestyle:

And they couldn't really say why it had happened. Now I'd been putting it down to eating and drinking very hot things which I used to do...now I put cold water in everything...I don't eat, well, I try not to eat anything hot.

Lily (Age 58, Participant 12, Area 1)

Not only did this participant describe an extreme change to her eating habits she also, following an unpleasant surgical experience, took the decision to resign from her job:

It started to worry me that they were having to take supply nursery nurses in and that worried me because I know it's a more expensive route to take. And I thought it might be better if I didn't have that worry so I actually gave up work.

Lily (Age 58, Participant 12, Area 1)

Where this was not a typical example of the impact of oral precancer, it does demonstrate the powerful effect that this condition can have on an individual.

This chapter has explored the patient experience of oral precancer by following the patient through their disease journey, from the point at which initial signs or symptoms are discovered, through the diagnosis stage, management of their condition and the ongoing effects of living with oral precancer. The next chapter will go on to present and discuss the results of the clinician based study.

Chapter 6. The Clinician study: Results and discussion

The study based on clinical professionals' views and experiences formed the second phase of the overall project. Initially it was proposed that this study would take the form of a paper based postal questionnaire focusing on management choices in oral precancer. However, following the results of the patient based study it was decided that a qualitative approach would be necessary in order adequately to explore the complex decision making process involved in the management of oral precancer patients. In addition I thought it was important that themes uncovered in the patient study were fed into the professional study. As a result the areas of communication and behaviour change were specifically discussed with the professional group.

The next section presents and discusses the results following analysis of the clinicians' study data. It begins by discussing the intricacies of delivering a diagnosis of oral precancer and patients' information needs, it then goes on to outline the challenges faced when addressing risk factors and formulating treatment plans and finishes by examining a number of specific difficulties that may be encountered when managing the oral precancer patient. Although a range of views are presented, it is acknowledged that data from participants 8 and 11 account for a larger proportion of the presented data than the other participants. This may be because both are consultants who identify themselves as having a specific interest in the field of oral precancer. As both have developed and set up dedicated oral precancer clinics as well as active involvement in undertaking research in the area it is conceivable that they may have more developed ideas than the other participants.

6.1 Communicating with patients (delivering a diagnosis)

Communication was a prominent theme that ran throughout the interviews obtained from the professional study. Perhaps this is not surprising if the impact of good communication between the doctor and patient is considered. As Ong et al., have noted, good communication between the clinician and their patient can potentially influence patient understanding of their disease and shape the decisions patients make about investigative procedures and treatment. Furthermore, the success (or otherwise) of free

communication between clinician and patient has the power to impact the level of patient distress, satisfaction with care and compliance with treatment (Ong et al., 1995).

For the purposes of this section, communication will be discussed primarily in relation to the delivery of a diagnosis. Whilst good communication is important at every stage of the patient journey, the diagnosis stage has been chosen as the focus of this section as it contains a number of different relevant aspects of the communication process including: the significance of the terminology used during the consultation, the specific difficulties that may arise when communicating possible cancer risk to a patient and the desire to deliver a positive message.

6.1.1 Significance of the terminology used

When focusing on oral precancer diagnosis it is worth reconsidering how oral precancers are defined and how they are related to oral cancer, in this way the message that the study participants are trying to convey to their patients may be better understood. Briefly, oral precancers are not cancers but are lesions which are more likely to contain dysplastic changes (cytological and architectural changes in the epithelium) than normal oral tissues. Significantly, they are also statistically more likely to progress to oral cancer (squamous cell carcinoma) than normal tissue.

In order to begin to explore how clinicians communicate the concept of oral precancer to their patients, the clinician study group were asked to describe how they would approach discussing a precancer diagnosis with their patients. To this end, the participants often spoke of their choice of terminology and a desire to provide their patients with a clear message. Discussing their views, the participants tended to distinguish between lay and technical terminology with some using what they considered to be lay terminology alone whilst others opted for a combination of the two. For those who chose to use lay terminology only, there was often a belief that using technical language posed a barrier to patient understanding:

I think we don't actually talk about the term or mention 'dysplasia' much, because I think that's a difficult concept to grasp, or is that a bit patronising? But I think changes, 'changes in the cells' is a term that I would use rather than 'dysplasia'.

OMFS Cons 7

[I] just explain it in simple terms and just say that, you know, the cells are starting to misbehave...

OMFS Cons 9

IV: I just tell them they're unstable.

I: Right, ok. And do you give them any further information?

IV: No

OMFS Cons 6

Terms such as unstable cells, cells behaving badly, and abnormal cells were commonly used to explain the difficult concepts of oral precancer and dysplasia in a bid to provide explanations to patients that were unambiguous. However, the literature suggests that using non-medical terminology alone may lead to uncertainty surrounding a diagnosis. For example, Chapman et al., as part of a larger study, explored the effect of cancer euphemisms such as 'lesion', 'growth' and 'dark spot', on lay understanding of a cancer diagnosis (Chapman et al., 2003). They concluded that a substantial portion of their sample did not understand such terms. Confusing patients and creating barriers to their understanding of oral precancer was clearly not the intent of the study group:

It's absolutely crucial to be clear with patients what we're talking about

OMFS Cons 11

However, some participants had reservations that their chosen terminology was fit for purpose:

I do try and use what I think is lay terminology. Now obviously it's difficult, because sometimes even though you think you're using lay terminology, you can end up using language that people don't quite understand.

OMFS Cons 2

This participant makes an interesting point, where he states that he thinks that he is using lay vocabulary he also suggests that despite duly considering the language he uses he is not always able to assess if his chosen language has been understood. The ability to provide clear explanations of medical conditions in modern times is complicated by the frequent use of 'medical' terms in the media. However, whilst people may hear or read about medical terms they may not fully understand them. This is highlighted in the work of Chadha and Repanos who conducted a study exploring individuals' comprehension of a number of commonly employed medical terms used to describe 'lumps' (Chadha and Repanos 2006). Alongside comprehension they also investigated

the influence of each word on a person's level of anxiety. Among their findings they noted a significant misunderstanding of some of the terms used to describe lumps. Specifically, the word carcinoma was among the terms which were not well understood whereas the words malignant and tumour were reported as being the most threatening.

The concept of threatening or anxiety provoking language was examined further, for example when exploring the terminology used by the participant below:

I tend to avoid the word dysplasia, I tend to use precancer. Rachel, I assume, and maybe wrongly, that people understand what I'm talking about when I say precancer, I don't know.

OMFS Cons 10

Where this participant queries the effectiveness of the terminology he uses, in addition he chooses to use the word precancer. This is perhaps surprising when it is well documented that the word cancer is an anxiety provoking term. Indeed cancer has been described as 'the most feared of modern diseases' with some reporting that even the threat of such a diagnosis evokes a sense of fear (Clarke and Everest 2006). If we then look specifically at the term precancer, Kavanagh and Broom in their study exploring women's understanding of abnormal smear test results found that many of their participants mistook the word precancer for cancer, which, not only led to a misunderstanding of their diagnosis, but in turn also led some to thoughts of death and their own mortality (Kavanagh and Broom 1997).

Analysis of the data also revealed that in contrast to those who used either lay or medical terminology in isolation, some participants chose to use a combination of both lay and technical terms:

I do make a point of telling people what the proper term is, but then explaining what that means.

OMFS Cons 11

In many cases there was a definite reason for this:

Well I would explain that diagnosis as a precancer or potentially precancerous condition. If we're talking about dysplasia...the ones where you've got moderate or severe dysplasia, then I do explain that as being a precancerous condition that if left untreated or unmodified by lifestyle factors, it could well progress to the development of a cancer...I would use [the term dysplasia] but then explain what it meant, because the point is, a lot of patients I think want to go and look things up.

OMFS Cons 9

In the quote above the participant uses the diagnosis consultation as an opportunity to explain the link between oral precancer and cancer. However, it appeared that some participants were not as explicit in their explanations:

For more severe dysplasia I tend to, sort of, talk about cancer in waiting, that's probably a phrase I use quite a lot.

OMFS Cons 2

This participant is much more ambiguous in his explanation of the diagnosis using the phrase 'cancer in waiting' which could potentially be wrongly interpreted as a lesion in which cancer progression is inevitable rather than one in which there is a risk of future cancer development.

6.1.2 Desire to be positive

Where participants spent time outlining the association between precancer and cancer with their patients, the message was usually closely followed up by the accompanying information that the diagnosis presented an opportunity to reduce the likelihood of cancer occurring, on the proviso that tobacco use and alcohol consumption were discontinued. The concept of the diagnosis being an opportunity went alongside the frequently expressed desire to provide a positive message:

I tend to stick to more positive things like, as you smoke 20 cigarettes per day, if you reduce that, we know...that when people stopped smoking, two years later some of the genes revert to normal. Mutations do resolve...some genetic damage is repairable, so I focus on things like that.

OMFS Cons 11

This was, clearly, an easier approach to take where patients presented with modifiable risk factors:

It's very helpful, oddly, if they are a smoker because then we can start talking about, 'there are things we can do which might help reduce the risk'.

OMFS Cons 11

Conversely, participants often had difficulty providing a positive explanation of a patient's disease where they presented without any apparent modifiable risk factors:

There's nowhere to go really...if you've got something to give up then you perhaps reduce your risk status, if you've got nothing to give up, you're relying on your genetics and there's obviously a problem with them in the first place...yeah, they are more difficult to manage when there aren't any risk factors.

OMFS Cons 3

A desire for a positive message at the diagnosis stage was often seen alongside a need to minimise the potential for distress or anxiety:

What I try to do is to deliver a message that there's an important and significant problem here but not in a way that's overly...try not to be overly threatening or overly dramatic in giving that information.

OMFS Cons 8

First thing, I think, is always to say things in the positive because they are often frightened when they are at the clinic

OMFS Cons 11

This was approached in different ways by the participants, in some cases the risk of inducing anxiety was thought to be reduced by minimising the apparent severity of the situation:

I play it down...I would say 'there's showing some abnormal cells but it doesn't necessarily mean that it's going to give rise to anything of concern.

OMFS Cons 5

The above examples illustrate the types of conversation the consultant participants had with their patients in association with cancer risk which is an important, but inherently difficult, task as although the literature provides convincing evidence that precancerous lesions are more likely to progress to a malignant lesion than normal oral tissue, figures on the incidence of malignant transformation are not consistently reported within the existing literature base. This creates a situation which can be challenging to address with patients:

‘And it’s rather difficult’, although I often say we’re working on ways of trying to do this, ‘but it’s very difficult to predict to anybody what is going to happen to that patch’

OMFS Cons 8

Where the participant in the example above chooses to broach the fact that a precancer prognosis is somewhat uncertain, others expressed concern that focusing on potential cancer risk may well evoke feelings of fear or anxiety.

A balance has to be struck between telling them the gravity of the situation that they’re in and in some way providing them with a degree of risk assessment, but not making them very frightened or anxious.

OMFS Cons 11

6.1.3 Risk communication

The participant above introduces the concept of risk assessment. There is a great deal in the medical literature on the subject of risk assessment and corresponding risk communication, with a particular focus on communicating risk in a format that patients can understand. In general terms, information concerning risk may be provided in a quantitative (usually in the form of statistics), qualitative (usually using descriptors such as frequently or rarely) or graphic format (Bogardus, Holmboe and Jekel 1999).

Evidence of qualitative and graphic risk communication was limited within the clinician data set. On the other hand, providing risk information using numerical values was a popular topic of discussion from the participants:

I do sometimes give patients statistics. I think it depends personally, I think it depends on the patients...and I will say to patients, look I can give you a statistical thing, but actually at the end of the day, statistics don’t apply to individuals, they apply to populations, and if I tell you there’s a 90% chance of something not happening, and yet you happen to be in the 10% where it does happen, then the relevance to you is you know, sort of, what.

OMFS Cons 9

Although it was not always a practice that was favoured:

I don’t think [the use of statistics is] helpful at all...I don’t like quoting percentages to people because I can never remember them and anyway, in real terms, in terms of this, they’re pretty meaningless

OMFS Cons 8

I don't ever quote statistics to patients because I think they're very unhelpful...if they're ok in five years it didn't help them that four out of five people were dead and they're either completely alive or completely dead, so I hate it when medics and anybody starts quoting figures at people because they are meaningless.

OMFS Cons 3

This participant later takes it further by suggesting that clinicians may use statistics in situations where they may find personal difficulty synthesising risk information into a format which is accessible to patients:

I think sometimes clinicians hide behind it because I think... I hear some of the juniors quoting statistics at people and that's because they've been reading up for exams and they're sort of almost showing off their knowledge and actually I don't think it helps anybody and I think what the patient wants to know is how is this going to affect me.

OMFS Cons 3

This initial section has shown that communicating with patients is not always a straightforward task and, in particular, the results presented here have demonstrated that within the theme of communication, the terminology used in the process of delivering a diagnosis of oral precancer to a patient can often be seen as crucial, with the choice of the terminology having the potential to both produce uncertainty and impact on patient anxiety. In addition, the results discussed have explored the practicalities associated with communicating the increased risk of oral cancer with patients which, amongst other things, has also highlighted the desire of some to provide a positive message by outlining to patients the opportunity such a diagnosis presents to modify behaviour and reduce cancer risk.

6.2 Addressing patients' information needs

Patients with oral precancer will receive information about their condition at several stages of their disease journey. Such information will often be provided verbally by their clinician, and may include: a description of a diagnostic investigation, an explanation of their disease or a discussion of a treatment option. However, it should be appreciated that this is not the only source of information that will be accessed by patients.

When we consider ways of addressing patients' information needs it is impossible to do so without also considering communication. Where the doctor is an important source of

information, the literature demonstrates that patient information needs will not necessarily be met through verbal information alone and although it is always the case that some degree of information will be provided verbally by a clinician, it is acknowledged that patients will often look for additional sources, frequently finding them more accessible. Such alternatives include: other health care professionals, other individuals such as friends and family, other patients, persons associated with the patient's faith as well as various forms of media including the internet and written material (Rutten et al., 2005).

The challenge of addressing oral precancer patients' information needs was explored with the clinicians and is discussed in the following section. This includes the approaches and limitations of verbal information provision from a consultant; it also explores the use of other methods of conveying key information such as the provision of written material.

6.2.1 Approaches and limitations of verbal communication

When discussing their patients' information needs, some clinicians felt that many of their patients were satisfied purely with the information provided by them:

I don't think they do [look for further information]...I think people are probably used to talking about [precancer] in terms of cervical malignancies, sort of CIN², when people talk about the changes in the cervix, and I think people understand that concept because it's been around for a longer period of time.

OMFS Cons 7

This participant seems to be suggesting that the general public, and as he later clarifies, women in particular, are familiar with the concept of precancer as result of a greater public awareness of cervical precancer. This belief, however, is certainly at odds with the cervical precancer literature, which indicates that many women find cervical precancer a confusing and, as a result of an ambiguous diagnosis, often distressing disease (Kavanagh and Broom 1997) (Karasz, McKee and Roybal 2003).

However, in contrast to the previous participant's account, others recognised that some patients want additional information about their condition, with some clinicians going

² CIN = Cervical intraepithelial neoplasia (also commonly referred to as cervical precancer)

on to provide explanations of how they sought to address these needs. This often involved the use of alternative forms of media:

We've got printed leaflets...and we're also doing a survey on how many patients use the internet. I do talk about using the internet to get information with patients for a variety of things.

OMFS Cons 2

Quite often as well [as] writing to the GP, I'll write to the patient, and that letter will contain the right language, so if they are going to sit and Google it, they get the right answer.

OMFS Cons 11

Although the examples given above highlight that other sources of information may be provided or suggested, where patients do seek clarification relating to their disease an obvious source of further information may be the clinicians themselves. However, studies investigating patient participation during the clinical encounter (in the form of verbal communication) indicate patient involvement is low (Bensing et al., 2006). Other research suggests that patients may leave the clinical encounter without discussing all their pre-visit concerns, the so called 'unvoiced agenda' (Barry et al., 2000), which suggests that, for many patients, accessing information from their clinician alone may not satisfy all their information needs.

With this in mind, it was postulated that barriers may exist which prevent optimal communication between the clinician and the oral precancer patient. If we consider the concept of the 'unvoiced agenda', it has been reported that patients will often fail to ask their clinicians for the information they want, particularly, when the questions may reflect non-biomedical folk beliefs or negative feelings that patients have towards themselves. For example, negative feelings of guilt may act as a barrier when seeking information from a clinician if the patient feels they may have in some way contributed to the disease process through their behaviour (Karasz, McKee and Roybal 2003). This could certainly be applied to precancer patients who are smokers.

A further potential barrier to patient-doctor communication was considered, that of a possible power imbalance between the patient and the clinician. As Bryant et al., state, this is a complex aspect of the doctor-patient relationship which may encompass factors such as education, income, culture, gender causing those from different backgrounds to respond to someone in a position of authority in a number of different ways (Bryant,

Bednarski and Gafni 2006). The idea that patients may see such authority as a barrier to communication was discussed with the clinician group, for example with the participant below where he was asked if he felt intimidation was a barrier in doctor-patient communication:

I: Do you think that people are ever intimidated by health care professionals, in terms of finding it difficult to ask for further information?

IV: Almost certainly yes.

I: And how do you deal with that?

IV: It depends really. We obviously write to the referring practitioner and we'll tell patients if they want further information they can ask. Do we have a dedicated service where we have time to give formal counselling with nurse pracs and people like that? No we don't.

OMFS Cons 1

Where this participant states he is aware that patients may find it difficult to request additional information from their clinician, he also seems not to fully address this issue within his practice. For example, telling patients that they can ask for further information does not necessarily lift the barrier that prevented them from doing so in the first place.

6.2.2 Other approaches to communicating additional information

Accepting that patients may have information needs that cannot be met by their clinician alone, the provision of additional information or guidance towards accurate supplementary sources of information was further explored:

I: Do you specifically point them in the direction of any further information?

IV: No I don't actually...it's a very interesting thought and I think that it might be more valuable for us to develop a literature pamphlet with some sensible website address and things. I hadn't thought of that actually...it's a good area for some work. Because, of course, you don't know what, we live in an era where people, when they have a significant diagnosis, a lot of them will go straight on the website and, of course, it's a minefield. There are all sorts of things, usually American, and usually trying to flog something. So I think it's a good point actually.

OMFS Cons 8

Although this participant states that in his current practice he does not provide his patients with any supplementary information, on considering the matter further he mentions the two most common sources spoken about by the clinician group, namely pamphlets or leaflets and the internet.

Beginning with the internet, it became apparent that a number of the participants had reservations about suggesting their patients use the internet as reliable form of information on their disease and, as a result, it was often viewed in a negative light:

I know that quite a few of them do it and I actually warn them against it sometimes. I warn them in particular about if they Google for things worldwide and particularly in countries like North America, that information contains thereon, may not be accurate and I advise them that healthcare is a business particularly in countries like North America, so to be careful what they read.

OMFS Cons 11

The ones that have Googled, I find have frightened themselves...I don't find they come across helpful information easily.

OMFS Cons 10

IV: We don't recommend them [using the internet], because the information uncut is actually...can be alarming, misleading, so we don't recommend people go to the internet.

I: Would you say that explicitly to the patient

IV: No, only if they ask

OMFS Cons 1

It appeared that the negative attitude often expressed towards internet use may, at least in part, be attributed to a personal lack of knowledge on the nature of the information available on the web:

I'm not particularly aware of any resource that, you know, there is for people with pre-malignancy which is perhaps a gap in the market if you like, because, what I do always say to patients is look, you know, the internet is a great thing, you can learn an awful lot from it, but there's also an awful lot of unsubstantiated rubbish on it, so you need to be careful what you look at.

OMFS Cons 9

As well as the internet, the provision of supplemental written information was frequently discussed in relation to assisting the patient with access to further information on their condition. This took various formats from the provision of locally developed leaflets through to personalised correspondence which included the individual diagnosis and summary of the condition:

I mean, in cancer practice now it's a measure that we must offer them a copy of the letter to the GP, so they all get offered that anyway, but that's not necessarily a helpful letter for them, so I always offer them a letter to go with that, which carries explanation...this is what we talked about, this is what you had, this is the diagnosis, this is what we need to do; so that kind of thing is very helpful I think.

OMFS Cons 11

The concept of a summary letter personalised to each patient is not a new concept, and although not routinely carried out by the clinicians in this study, patient letters specifically designed to summarise key information tailored to the individual has been carried out elsewhere in medicine with apparently successful results (Hallowell 1998). In addition, it would seem, that written material on a patient's condition may be useful in enhancing patients' recall of the information provided to them during a consultation even when it is not in the format of a personalised letter (Chan et al., 2002).

Although this might suggest that written material would be of benefit to the majority of oral precancer patients, it is important that the impact of 'health literacy' is considered. Individuals with restricted health literacy are defined as being disadvantaged in their capacity to obtain, process and understand both written and verbal health related information (Davis et al., 2002). Health literacy is recognised as a potential barrier in the delivery of efficacious health care (Berkman et al., 2011) and may be associated with poorer interpretation of health messages. The impact of health literacy clearly has the potential to impact on more than just the patient's interpretation of a letter or leaflet, however, focusing on this format of information provision, the potential problems with providing leaflets or letters to oral precancer patients as a result of reduced literacy was something that was hinted at by one of the clinicians in the study:

I think that might be an area that I would like to work at but I'm still finding it hard. It's easier to explain to the patients and, ideally, relatives, when they're there but [I'm] aware that the average reading age for head and neck patients is about 11. So written information, you can never be sure what they are actually going to do it.

OMFS Cons 4

The patient above suggests that the average reading age of his precancer patients is a barrier to him producing supplemental information for them. He goes on to describe how he has had limited success in the past producing leaflets on treatment for oral cancer patients for the same reason. However, he finished by saying that if he felt that

ultimately it was something that would be of benefit to his oral precancer patients he would consider developing something for them. Other participants had less specific reasons for not providing written material to their patients:

Actually writing things down and having them, giving them information sheets, I don't do that...but it's probably because I just haven't got round to it, not because I feel strongly against it.

OMFS Cons 3

However, this participant demonstrates that even where resources were available, they were not always utilised:

We have a written information sheet which is in the clinic which was created some time ago...I haven't ever used it personally

OMFS Cons 5

Alongside the participants' discussion of the modalities of information provision, there was a sense, from some participants, that despite their best efforts, some precancer patients may not always fully comprehend their disease. At times, this appeared to leave the participants with a feeling of dissatisfaction/frustration.

I think you wonder about [patients holding back from asking questions] all the time and at every consultation. I always specifically ask, but clearly it doesn't make any difference...I don't know what else you can physically do because obviously we can only ask 'is there anything that you want to ask?' and if they don't feel they can, that's sad. But I don't know what I can do about that.

OMFS Cons 8

And I like to think that, you know, I'll put [the concept of oral precancer] across in words of one syllable, but yeah, I guess you never know what patients are taking in.

OMFS Cons 10

The results of this section have demonstrated that, at present, there are a number of limitations in the way information is provided to patients who have oral precancer. Where the clinician remained the primary source of information, it was acknowledged that other sources may be beneficial. Participants specifically spoke of the potential benefits of written information (leaflets or personalised correspondence); however, such resources were not always available or were yet to be developed. The internet was another alternative patient information source which generated a lot of discussion.

However, there was a lack of knowledge noted in relation to the availability of reliable web sites and, in some cases, a negative feeling towards patients seeking information via the internet out of fear of them discovering incorrect or distressing information.

6.3 Challenges associated with addressing risk factors

Another key area of discussion to arise from the clinician based data was that of broaching the subject of risk factors for oral precancer with patients. Such discussions focused on the approaches clinicians took when explaining the relevance of specific risk factors (specifically tobacco use and alcohol consumption) and the impact of these factors on disease genesis and progression.

Patient health related behaviours are significant in those with oral precancer specifically as the literature has demonstrated that there is an association with tobacco and alcohol use and the development of oral precancer, with tobacco use being more strongly implicated. Furthermore, these two factors are also the primary risk factors in oral cancer development and it is believed that an individual with oral precancer who continues to smoke and/or drink alcohol is at a greater risk of their disease developing into oral cancer. On the other hand, importantly, the literature has also indicated that some patients with oral precancer can achieve complete resolution of their lesion(s) if these habits are eliminated (Gupta et al., 1995), which in turn reduces their risk of oral cancer.

6.3.1 Smoking as a risk factor

Smoking is believed to be the most significant risk factor in oral precancer, with premalignant lesions occurring up to six times more frequently in smokers compared to non-smokers (Dietrich, Reichart and Scheifele 2004). However, smoking is clearly not only a risk factor for oral precancer but a leading cause of preventable mortality and morbidity in the UK (1988). This has long been recognised, and as a result of the government publication, 'Smoking Kills: A white paper on tobacco', major investment has resulted in a number of national initiatives including public awareness campaigns, a ban on tobacco advertising as well as the more recent smoking ban in enclosed public spaces. Yet, evidence would suggest that, in order to be effective, measures aimed at health related behaviour change need to be addressed at population and community

levels, using a combination of measures as described above, alongside a number of tobacco control initiatives (Ramseier et al., 2010).

One way in which clinicians and other health care professionals can play their part has been highlighted by the National Institute for Health and Clinical Excellence (NICE) in the form of guidance on brief interventions and referral for smoking cessation for patients who continue to smoke (NICE 2008). These guidelines outline the obligation health care professionals in the UK have, not only to enquire about patients' smoking habits but to offer intervention. This guidance recommends the use of brief interventions which are described as 'opportunistic advice, discussion, negotiation or encouragement'. The NICE guidance includes specific advice aimed at hospital clinicians (recommendation 5), stating that hospital clinicians should refer people who smoke onto an intensive support service as an ideal.

In addition to the NICE guidelines, the independent advisory panel, the NHS Future Forum, recently produced guidelines which, amongst other things, recommended that each healthcare professional should 'make every contact count' (DoH 2012a). Put simply, the guidelines state that every health care professional working within the NHS has a role to play in promoting the general public's mental and physical wellbeing. In practical terms this involves measures aimed at reducing the following 4 key health related risk factors: tobacco use, alcohol use, poor diet and a sedentary lifestyle. This reinforces the need to enquire and take action when patients present with any of the above risk factors.

6.3.2 Tackling the subject of risk factors with patients

In this study the clinician participants tended to introduce the concept of risk factors for oral precancer to their patients at a relatively early stage in the patient journey, often at the point of diagnosis. As in this case where the participant is describing his approach to communicating the significance of risk factors to his patients:

If it was a potentially malignant lesion or condition, there would be an explanation as to what that was [and] whether or not the patient was doing anything that might be contributing to this. There's the usual thing, obviously a lot of these people are or have been heavy smokers and if they are smokers, they get the smoking chat.

OMFS Cons 4

Alongside the explanation of the significance of risk factors to their disease, a natural progression was for the discussion to continue on to include advice on smoking cessation and particularly its role in the management of the patient's disease. To this end, the participants often described using a strategy of shared responsibility:

I generally say to them, look, well we can do our bit, but there's a contribution you have to make, being responsible for your own health in stopping poisoning the area which is causing these changes or likely to be causing these changes in the first place.

OMFS Cons 9

In some cases the onus of responsibility was placed primarily with the patient:

Really it's up to him to look at this, you know, what he's doing to the oral mucosa. I'll try and help. But you know I can't do anything about it. And so I don't take point of shouting at him or doing anything, they're all adults, they all know what they're doing is wrong.

OMFS Cons 11

Despite the perceived importance of smoking cessation in patients with oral precancer there were often difficulties reported when it came to discussing access to smoking cessation services. However, in some cases such services were never discussed:

I: Would you point them toward any support services yourself?

IV: Only if they ask

OMFS Cons 2

This approach, however, is clearly at odds with the national guidelines mentioned earlier which outlines the duty the clinician has to explain the presence of support services and outline what they offer (NICE 2008). Where support services were available, participants suggested accessing them was not always a straightforward process and was often reported as something that could not be fully addressed on the clinic:

In community care, smoking cessation is available...it's certainly not done in the clinic, other than, the very bland message that smoking is damaging your mucosa and you need to try and stop it. And that ultimately if you don't you're more at risk of getting a cancer...Do we engage in smoking cessation in the department? No.

OMFS Cons 2

For some this was principally as a direct result of funding issues:

What we do have is a hygienist who's been trained in smoking cessation, so she's a resource, but we fall into a familiar trap where the primary care trust refuse to pay for her time to do that...an enormous frustration since they're already in the building.

OMFS Cons 11

As a result of these and similar problems many participants advised their patients to contact their general practitioner (GP) rather than being able to provide assistance there and then. This is an unfortunate situation especially if it is considered that in smokers seeking help, the likelihood of success is greater in those with access to smoking cessation specialists (West, McNeill and Raw 2000).

Alongside difficulties encountered with access to services, participants often described the perception that patients were frequently resistant to the notion of changing their health behaviours (smoking and drinking):

[The patient says] I've tried before or x, y and z has just happened in my life...a lot of them seem to come up with excuses why they're smoking and why they're not ready to stop.

OMFS Cons 10

[some] people are quite resistant and quite reluctant to accept, even if they perhaps think internally that it's smoking, and they will look for other things like 'I remember my dentist was very rough with me one day 20 years ago and I think it all happened from there'. Or 'I had a friend next door who worked in a paint factory. I think it was the stuff he brought home.'

OMFS Cons 8

In the second example above, the participant seems to be describing a patient who does not accept or is unwilling to accept smoking as a potential cause of their disease. Where it is unlikely that a patient would not believe that smoking was detrimental to their health in general terms, there is evidence in the literature to suggest that some patients with oral precancer do not believe that their oral lesion(s) are related to their smoking habit (Bornstein et al., 2012). This may act as a barrier to smoking cessation, in that the patient may not be able to appreciate the specific potential benefit of smoking cessation. This is further illustrated in a study by Helgason et al, whose work demonstrated that patients who believe that they have disease or symptoms related to smoking are more likely to consider stopping smoking than those who do not (Helgason and Lund 2002).

In the previous two examples the participants describe how some of their patients provided an explanation or an excuse as to why they were not ready to give up smoking. However, clinicians also reported cases where patients made it quite clear that, to them, the benefits of stopping smoking did not outweigh the risk of continuing:

But a lot of people will say... 'there's no way I can stop smoking'. One lady... said to me 'Don't talk to me about smoking because I'm smoking 20 a day and I'm not going to stop. And do you have to have your clinic on a [specific day] because I play golf [that day] and it's golfing season'... so some people are very resolute in their views.

OMFS Cons 8

Regardless of the difficulties outlined above, smoking cessation was the main focus of risk factor discussions and, although discussed, it was reported that access to alcohol services were less well utilised. A possible explanation for this being provided by this participant:

You can access alcohol services, but it's much less common for us to do that with patients. I don't know, for some reason, it's something that we probably don't tackle as a group in the same way we might about smoking, and I suspect it's probably because we all think that smoking is the bigger factor than alcohol so, if you stop one, you'd be better off stopping the smoking.

OMFS Cons 9

Although studies indicate an association between oral precancer and tobacco use, in the past, the evidence implicating alcohol as an independent risk factor has not been as strong (Dietrich, Reichart and Scheifele 2004). This may explain why, in the management of oral precancer, often less time is devoted to providing alcohol cessation advice compared to smoking cessation advice. However, more recent work, including a prospective study by Maserejian et al., has demonstrated the role of alcohol as a risk factor for oral precancer both in conjunction with tobacco use as well as independently (Maserejian et al., 2006).

In relation to risk factors for oral precancer, tobacco use and alcohol consumption are the most significant. Where the study results revealed that both risk factors were usually discussed with patients, the focus of most discussions centred on smoking. Frustrations were expressed particularly where access to support services in the local area were limited or had been withdrawn. However, even where access to support

services was available personal frustration was suggested by some when describing groups of patients who were resistant to the idea of giving up a smoking habit.

6.4 Making treatment decisions

Once a diagnosis of oral precancer is made, a treatment plan will be formulated. As discussed in the previous section, this will usually involve a plan to eliminate known risk factors. In addition to this, decisions will also have to be made regarding active treatment of the disease. This is the focus of the following section.

6.4.1 Options available

Treating patients with oral precancer remains a complex and somewhat uncertain process which, despite extensive research, does not have specialty wide agreement when it comes to the most effective treatment options (Kanas et al., 2011). This was something the participants acknowledged:

It remains a subjective decision about intervention, I'm afraid... we're looking at ways of trying to make that more objective, trying to stratify people into what we would regard as being a high risk of malignant transformation and low risk; all that's complex

OMFS Cons 8

The literature reports a variety of possible options for the management of oral precancer (Lodi and Porter 2008), and while current opinion would generally favour scalpel or laser excision (van der Waal 2010), survey based data would indicate that clinicians employ a variety of strategies (Table 14). Closer inspection of the data, however, reveals that medical management of oral precancer in this country appears to be declining, with a significant decrease noted from data published in the late 1990s (Marley et al., 1998), (Marley et al., 1996) compared with more recent data (Kanas et al., 2011). This is perhaps due to a lack of strong evidence to support their use (Lodi et al., 2008).

Surgical	Medical	Other
Scalpel excision	Topical therapy – e.g. vitamin A and derivatives, steroids	Watchful waiting/conservative management
Laser excision	Systemic therapy - Steroids	Mixed methods (a combination of 2 or more options)
cryosurgery		

Table 14. Management options in oral precancer

Adapted from papers by Marley et al., 1996, 1998 and Kanatas 2011

6.4.2 Factors influencing treatment decisions

The vast majority of the professionals interviewed in this study indicated that the mainstay of their practice consisted of either intervention to remove the lesion surgically (through either scalpel or laser excision), or conservative management, involving regular review to monitor the lesion. In a bid to break down how the clinicians made difficult treatment decisions the rationale behind these choices was explored with the study group. Analysis of the data revealed that the participants' treatment decisions were influenced by:

- the degree of dysplasia within a lesion
- the clinical appearance of the lesion
- patient lifestyle (with respect to risk factors)
- reliability of follow up
- patient preference

The influence of the degree of dysplasia within a lesion was consistently mentioned by the clinicians as the primary consideration when making treatment decisions:

- I: and what helps you to guide these decisions
- IV: the degree of dysplasia...and then patient wish

OMFS Cons 10

Dysplasia and its role in treatment planning will, therefore, be examined first.

It has already been discussed as part of the literature review that dysplastic changes may be present within oral precancer and, that when examined histologically, the level of dysplasia is usually graded as mild, moderate, severe or carcinoma in situ. Recent studies have confirmed a significant increase in the rate of transformation from oral dysplasia to oral squamous cell carcinoma depending on the grade, with lesions exhibiting severe dysplasia or carcinoma in situ being considered considerably more likely to transform (Mehanna et al., 2009).

Significantly, Mehanna et al., also reported where surgical excision of these lesions will not eliminate all risk, it apparently decreases the risk of malignant transformation to less than half of those that are not excised, leading the authors to suggest surgical excision with long term follow up as an optimal treatment plan for patients with dysplastic lesions, particularly those with high grade lesions (equivalent to severe dysplasia or carcinoma in situ). With the participants and the literature placing such importance on the degree of dysplasia within a lesion it is worth revisiting how dysplasia is identified and graded and in particular considering the variability that may exist within this process.

In order to achieve an accurate diagnosis in oral precancer, histopathological assessment of a biopsy of the lesion is required; however, there are a number of variables within this process. Firstly, at the biopsy stage itself, it is important that an appropriate site is selected. This is because a single lesion may exhibit varying degrees of dysplasia within it. The location of the biopsy can be of particular significance to a small number of patients with widespread oral lesions. For these individuals multiple biopsies may be required, particularly as the rate of malignant transformation in this group appears to be higher than for those with single discrete lesion (Saito et al., 1999). The limitation of a diagnosis on the basis of a biopsy was recognised by the participants:

Well obviously I'm very aware that when you diagnose a patient, that first of all, your biopsy only represents the bits that you biopsied so I'm very keen to look at the rest of the lesion...if I look at something and say hang on that lesion doesn't look like it should, according to the report, it looks worse, I wouldn't believe the report, I'll send the patient for more biopsies. Sometimes you may even pick up an early invasive disease where the biopsy said dysplasia

OMFS Cons 4

A second limitation of dysplasia diagnosis is the dysplasia grading process, which is recognised as being somewhat challenging and complex (Poh et al., 2008). Judgements are made by a pathologist on the architectural and cytological changes in the epithelium according to established World Health Organisation (WHO) criteria, however, this remains a subjective process which has been shown to vary between pathologists (Karabulut et al., 1995). Perhaps as a result of these difficulties associated with dysplasia grading, participants often looked for other indicators to help them assess the likelihood of an individual lesion progressing to cancer. To this end, the participants frequently stated that they would use clinical appearance as a means of further assessing the significance of the patient's disease, regularly advising surgical intervention if the lesion appeared 'nastier' than the report suggested:

And if I personally think the lesion looks more significant than the biopsy would say, then I wouldn't just rely on the biopsy, I'd go ahead and do an excision.

OMFS Cons 7

Where the participant above states that he would excise a lesion based on the 'significance' of its clinical appearance, the literature allows us to examine in more detail what specific features of the clinical appearance increase the likelihood of malignant transformation. From their review of the literature, Napier and Speight, determined the following appearances as having a higher association with malignant transformation: non-homogenous or nodular leukoplakias and erythematous and verrucous lesions (Napier and Speight 2008).

Despite mentioning a number of influences during the treatment planning stage, including dysplasia grading and clinical appearance, it was clear from the data that in the absence of clear guidance, personal opinion concerning the most appropriate management for precancer patients had to be based on the individual's evaluation of the available evidence alongside personal experience of managing precancer patients. Perhaps because of the disparate nature of such evidence (and perhaps experience) participants' treatment recommendations to patients varied from unit to unit:

In terms of treatment I would usually say that we have a preference to actually remove these patches because it is difficult to predict what's going to happen to them.

OMFS Cons 8

If it's...carcinoma in situ...the most common treatment for that would be laser excision...we would not, generally speaking, offer intervention for patients with dysplastic lesions as such. The only caveat to that is, if there's severe dysplasia and the lesion clinically looks more than that, then we might be more inclined to offer laser excision.

OMFS Cons 1

As well as reiterating the earlier point that participants often considered the clinical appearance of precancerous lesions significant, the second participant here also states that he would only tend to recommend surgical treatment to patients whose lesions exhibit the most advanced cellular changes. This is in clear contrast to the first participant above who suggests a predilection towards surgery for the majority of his patients.

As well as differences of opinion relating to when to intervene surgically, the method of intervention too was variable:

I use KTP rather than CO2 [laser], but I always use a microscope, an operating microscope, ...I just feel more comfortable doing it that way, and it seems to make sense.

OMFS Cons 9

The point here is not so much that the participant has a different approach to the mechanics of his surgery, but that, in the absence of convincing evidence, he is carrying out surgery in this way because he feels more comfortable with it.

6.4.3 Influence of the doctor-patient relationship at this stage

Given the difficulties the participants expressed surrounding the factors considered when making treatment decisions it was felt that communicating information in relation to treatment choices to patients may be a difficult and complex task. The approach the participants took when aiding patients to make informed treatment decisions, including the significance of the doctor – patient relationship in this process, was therefore explored.

Throughout the patient journey (from initial consultation and beyond) a number of clinicians highlighted the effect their professional relationship with the patients had on a patient's management and indeed their overall experience of disease. The importance of this relationship was highlighted particularly when it came to negotiating treatment

decisions. In particular the need to inspire confidence through building up a positive rapport with patients was often discussed:

You want to bring them in, have them have confidence in me and our service, so that then they buy into our risk stratification, risk reduction mechanism.

OMFS Cons 11

For example, the quote above demonstrates that this participant felt that it was important that patients have confidence in clinicians responsible for their care as a means of inspiring confidence in their management philosophy. The participant below takes this further by suggesting that as the patient progresses through their disease journey, their relationship with their doctor may change, inspiring a deeper level of confidence or trust. He suggests that as a result the patient is more likely to follow the recommendations of their doctor, highlighting that the doctor –patient relationship is seen as a key factor in the patient decision making process:

And perhaps maybe because we've got to know each other better, there is perhaps more trust, more understanding, then the decision may change.

OMFS Cons 8

Talking about reasons for choosing to intervene surgically following a period of monitoring

This section has uncovered the influences involved in making treatment plans for oral precancer patients. It has been revealed that these decisions are variable dependent on the individual clinician, their interpretation of the available literature and their personal experience. Finally the results have touched on the influence of the relationship between the clinician and their patient when it comes to making treatment decisions, including the feeling by some participants that treatment decisions may change over time as a rapport is built up with the precancer patient.

6.5 Difficulties encountered when managing patients with oral precancer

The final section of this chapter will deal with a number of issues specific to managing oral precancer patients. It will begin by focusing on the strategy clinicians employed when reviewing their patients following treatment.

6.5.1 Management issues – How long to review and when to discharge

From a logistical point of view, participants frequently spoke of the difficulties faced when planning follow-up and discharge of oral precancer patients. When exploring patient review, the participant responses were variable. This is perhaps unsurprising when the lack of guidance is considered. One way participants found to overcome this difficulty was to approach an oral precancer patient review in a similar manner to that of the oral cancer patient, employing a programme of frequent review in the first instance, gradually increasing the duration between appointments before finally discharging, providing no further disease was evident at the five year mark.

However, this was not a universally employed strategy and, for some, discharging patients remained a contentious issue with a variety of factors apparently influencing the participant's decision to discharge a patient:

It's very difficult to be honest with you. I probably do it differently for every patient who comes through the door.

OMFS Cons 2

Where the above participant simply acknowledges that planning reviews and discharging precancer patients is difficult, the participant below states that he has no known mechanism for discharging them. This leaves patients in a constant cycle of review, potentially causing problems for outpatient clinics in that they may ultimately become saturated with these patients:

I have got, you know, a few dysplasia patients who have been coming once every six months and once every year, you know, for five or six years and you think, well what do I do with you. Watch this space. Sorry...I mean to be honest I have no mechanism for discharging them.

OMFS Cons 10

Looking to the literature for guidance, a relatively recent article by van der Waal recommends that because there is no reliable known predictor of malignant transformation in the oral precancer patient, nor evidence to suggest that surgical treatment removes transformation risk, lifelong follow up is recommended (van der Waal 2010). Mehanna et al., reiterate this by suggesting that due to the long term risk of malignant transformation, patients with oral dysplasia should be reviewed for

anything up to 20 years (Mehanna et al., 2009). This participant demonstrates that there is more than simply patient benefit to consider when planning review and discharge:

I mean there's a great pressure as you know, upon us all now to not keep seeing patients in secondary care so, it just upsets the balance for the Managers to get all worked up about.

OMFS Cons 9

I certainly used to then say bring them back in a year just to see what was going on but when we get to yearly reviews PCTs don't like that so we tend to boot them back in to practice

OMFS Cons 3

A number of participants reflected on their patients' fate following discharge from secondary care, with some expressing concern regarding the quality of the GDP that the patient would be referred back to. In some cases the perceived competence of the GDP was considered as a contributory factor in the decision making process:

It depends a lot on who they're registered with. If they're registered with one of the corporate dental practices and they're seeing a different dentist every time they go, then I might be less likely to discharge them back...I think it's quite important to be able to go back and see the same dentist time and time again.

OMFS Cons 7

This is an interesting point demonstrating that this consultant values consistency in terms of the patient seeing the same clinician, in this case the dentist, each time. This view however, was not upheld by all participants:

You know I consider them responsible dentists and if you're a dentist you're supposed to be a professional. And I don't distinguish, you know; I write them a letter, tell them, would they see them regularly. I don't think it's so much the dentist, it's the patient. Because they're the one who has to turn up.

OMFS Cons 6

This quote also reiterates an earlier made point that the participants feel that the patient has an obligation to take responsibility for their own health which, to some extent, must be demonstrated through their actions. For example by a willingness to modify risk factors, by attending their GDP for review following discharge from secondary care and ,in some cases, an obligation to carry out their own intra oral examinations:

I give them responsibility, I suppose, for checking it and obviously I would usually involve their GDP

OMFS Cons 4

6.5.2 Communicating transformation risk post treatment

Another area of specific difficulty in the management of the oral precancer patient was that of the persisting risk of malignant transformation which is known to persist even following surgical removal of a precancerous lesion.

The literature would suggest that, regardless of management strategy, there remains the risk that patients will potentially develop further precancerous or, indeed, cancerous lesions following treatment. I felt it was likely that participants would find this a difficult subject to broach:

I think that so much of the reason for doing what we do is designed to try and stop that happening, that one, I suppose, doesn't labour the point that 'Oh, by the way, you might get cancer anyway,' because it's not really the thought process at the time. So I don't know how you... I don't think I would like to introduce or underline that.

OMFS Cons 8

This is confirmed if we examine the account of the participant above. However, it appears that in finding this concept difficult he avoids, rather than broaches the subject with his patients. Although the following participant suggests that he does address this difficult area, he doesn't appear certain that his methods are effective:

I: Are patients aware, do you think, that there's still a possibility that changes might progress in their mouth even if they are treated?

IV: I think so. I mean; it's a balancing act, isn't it, between, you know, scaring the crap out of the patient and actually getting them to do something... and the problem is, what I generally say to patients is that I can't predict what's going to happen in the future, but you know, what we're aiming to do is to reduce the risk of them getting problems in the future.

OMFS Cons 9

The example above also highlights the desire the participants had to deliver a positive message in that the subject of further disease development is presented to patients as an opportunity. In other words, if patients have risk factors then an opportunity is presented to reduce these and therefore reduce the risk of further disease development. However, as discussed previously, there are a small group of patients with oral

precancer who present with no discernible risk factors and in such cases participants expressed an increased level of difficulty managing the situation.

6.5.3 Importance of clinical environment on patient experience and outcome

All participants recruited to the study were oral and maxillofacial surgeons who were responsible for the care of patients with oral precancer; however, there were some who stated a special interest in the area. This appeared to be of significance when it came to participants expressing their opinions on the importance of the clinical environment in which oral precancer patients were seen. Specifically the set-up of the outpatient clinic, where patients attended for their initial consultation and review appointments, was often viewed by those with a special interest in oral precancer as a key factor in patient management. Looking in more detail, data analysis revealed that there were a number of approaches to the set-up of the outpatient clinics the oral precancer patients attended. In general terms patients were seen either on a mixed general maxillofacial outpatient clinic or a dedicated oral precancer clinic:

We don't have a dedicated precancer or potentially malignant clinic, they're reviewed on general clinics

OMFS Cons 1

Our aim here has been to set up a clinic on the first [specific day] of every month and send out any patient with a diagnosis of dysplasia onto that.

OMFS Cons 11

Where dedicated clinics had been set up, participants felt strongly that there were clear advantages of providing care in this manner. These ideas tended to centre around the perception that such clinics allowed the clinician to focus on one particular disease process, and in doing so, not only provided a more efficient service for patients but also, potentially, improved patient outcome, as this participant explains:

the careful, co-ordinated, determined, continuing follow-up, clinical examination, re-examination, biopsy analysis of those patients to identify further disease or recurrent disease or hints of transformation at the earliest possible stage. And that's something that's come, I think, directly out of having a dedicated clinic where everything's concentrated.

OMFS Cons 8

The participant above is quite clear in his views of the benefits of having a dedicated precancer clinic. Although it was not within the scope of this study to determine the proportion of specialised versus general clinics in the UK, Kanatas et al.'s study examining the configuration of precancer clinics in the UK, reported that 41% of their respondents had designated specialist clinics in which the oral precancer patients were seen. It is difficult to suggest this is truly representative of current UK practice however, due to the fact this survey of UK based OMFS consultants only had a 56% response rate (Kanas et al., 2011). However, it is interesting to see the value such a high number of consultants place on providing a specialist service specific to oral precancer patients.

Returning to this study, for those participants who saw precancer patients on a generalised clinic, participants often stated that such a clinic was unnecessary because they 'wouldn't see enough of them' or because it was deemed impractical. Although some acknowledged that their management of patients may be altered due to the nature of their clinical set up:

Because it's not a dedicated pre-malignant lesions clinic, we probably don't [spend a lot of time discussing risk factors] although I'll mention it to patients, I probably don't spend as much time talking about it as I should

OMFS Cons 2

6.5.4 Importance of the clinician on patient experience

Alongside the importance, or lack of importance, given to the clinical set-up, participants frequently reported the perceived importance of the clinician the patients encountered at the outpatient clinic, which would not always be the participant themselves:

IV: It's a bit of a hit and miss whether they see me or not...we've got one associate specialist who will sometimes do it and there's an SpR³ who'll sometimes do it.

I: Do you think [who they present to] makes a difference?

IV: Yes.

OMFS Cons 11

In the example above the participant describes three different grades of clinician who may have contact with oral precancer patients. Later, this participant also expresses his

³ Specialist registrar: an individual who is undertaking advanced training in a specific discipline, in this case Oral and Maxillofacial surgery (OMFS).

Staff grade and Associate specialist – a 'middle grade' member of staff

belief that the specific clinician, rather than grade of clinician, encountered by the patient at this stage is significant. He goes on to explain that as the person with the most developed ideas in the department he would be in a better position to assess the patient and provide the most accurate and appropriate information where others would, more than likely, simply give a basic level of information to the patient before, ultimately, referring the patient on to him. Whilst this participant seems to suggest that it is important that patients within this area are seen by him because he is the local expert in this field, a number of other participants were less specific, stating the importance of the grade of the clinician rather than the individual, implying more senior staff were better suited to dealing with precancer patients, perhaps as a result of greater levels of training and experience:

IV: [oral precancer patients] would tend to be [seen by] myself, although we do have staff grades and associate specialists who parallel clinics with me. Some might end up on theirs; they wouldn't end up being seen by an SHO⁴.

I: What would be the reason for that?

IV: That's a very good question. I tend to sort of hoard this sort of thing myself, okay. I would be happy with SHOs reviewing obviously benign pathologies...giving the results, discharging the patients, but I would very much hope that everyone with dysplasia...would end up being seen by somebody senior.

OMFS Cons 10

The view that SHOs should, ideally, not be involved in the initial aspects of care of the precancer patient was a particularly prominent theme and seemed to be of particular significance at the initial stages of patient management:

IV: [oral precancer patients would be seen by] either me or one of the registrars but not an SHO

I: Is there a reason why they wouldn't be seen by an SHO?

IV: Because I would be very keen to make sure that things are maybe not missed, that they're all seen by people who understand the significance of these things, even if I don't see patients at every follow up, I want to be sure that we get the diagnosis and investigations right first time.

OMFS Cons 4

In particular, when it came to discussing the delivery of a diagnosis:

⁴ Senior house officer – a junior member of staff undergoing training in a specific specialty area. In OMFS SHOs often hold a dental degree only, in contrast to the SpR grade.

I: do you think it makes a difference who gives the diagnosis?

IV: I think it needs to be somebody reasonably senior

I: why is that?

IV: I think that the knowledge base of more junior staff these days, frankly, is not as good as it once was.

OMFS Cons 1

SHOs don't tend to see patients...they're quite often involved in the biopsies and things but in terms of decision making, absolutely not for them...they don't know what they're talking about.

OMFS Cons 3

The final section of this chapter has outlined some specific difficulties in the management of oral precancer patients. The contentious issue of when and for how long to review precancer patients has been explored, in doing so it has been revealed that although, in general, the literature would suggest long term review, in practice this is not always taking place nor is it always practical. The approaches the clinicians in the study took when it came to communicating cancer risk, even after treatment, has been briefly examined before finally looking at clinic organisation and the importance of the grade or experience of the clinicians involved in patient care. This uncovered the almost universal message within the clinician group that the initial management of oral precancer patients is best undertaken by those with a more comprehensive knowledge base, usually at a senior staff level.

Chapter 7. Conclusions from both studies with respect to the patient disease journey

The previous two chapters have examined the results of each study in isolation. The following section will bring together the results of both the patient and professional studies, with a view to identifying specific areas of the disease journey at which there may be the potential to make improvements in current practice.

As well as critically examining patients' experiences and understanding of oral precancer, analysis of the patient study data allowed their disease journey to be mapped. This journey is represented by Figure 3. This is presented as a theoretical care pathway because, at present, there is no formal pathway for oral precancer. Once mapped, this journey was then directly related to the clinician based study which allowed identification of the following specific areas where opportunities to modify current practice and potentially improve patient outcome exist:

- Communicating a diagnosis (including terminology used and risk communication)
- Information needs and means of provision (including barriers to obtaining and meeting needs)
- Behaviour change
- Management of oral precancer
- The influence of the clinician and the environment on patient experience

Each of these areas will now be reviewed from the viewpoints of both the patient and clinician. Following each discussion conclusions drawn from the study results will be made.

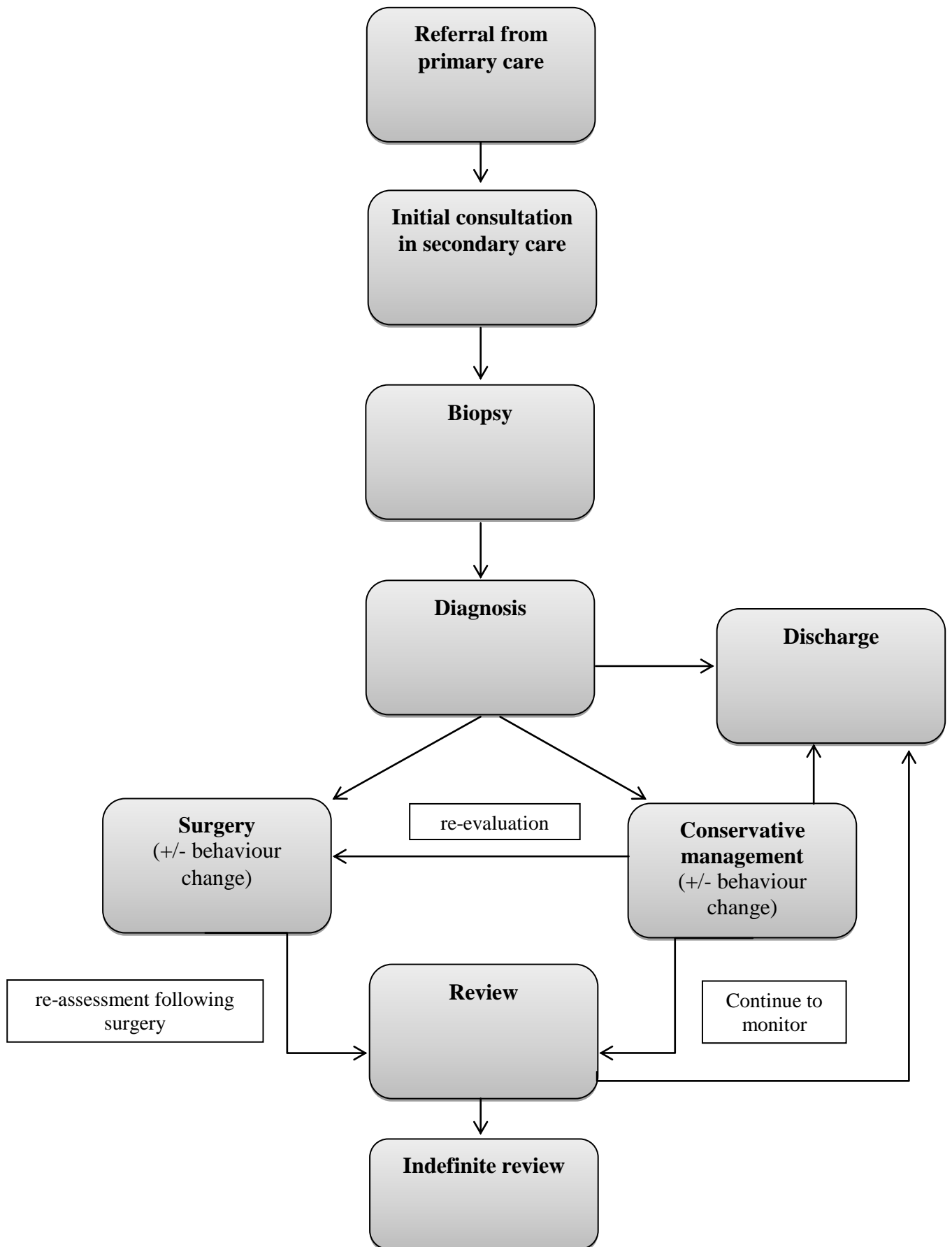


Figure 3. Oral precancer – the patient journey through care

7.1 Communicating a diagnosis

The diagnosis was the first aspect of the disease journey where difficulties in current practice were identified from both perspectives. Optimal communication at the diagnosis stage is important. Indeed, studies indicate that unsuccessful communication at this stage may potentially result in misinterpretation of the diagnosis and significant distress (Kavanagh and Broom 1997) (Gray et al., 2006). Within the topic of communicating a diagnosis two specific areas where there may be an opportunity to make positive changes were noted:

- The terminology used when communicating a diagnosis
- Efforts aimed at communicating risk

7.1.1 Choice of language

The results from the patient based study revealed that, for many people, communication of the diagnosis was an area that caused considerable confusion. This was influenced on some occasions by the choice of language used by the clinician. Specifically, confusion at the diagnosis stage led some patients to believe that they had oral cancer. This had the potential to leave the individual feeling ‘devastated’ by the diagnosis. In addition, the study results also indicated that even if patients did not believe they had cancer, the uncertainty of an unknown or misunderstood diagnosis could result in worry or distress. These findings are in line with data from studies involving individuals with cervical precancer (Bell et al., 1995; Gray et al., 2006; Kavanagh and Broom 1997). Furthermore, unclear terms used at the diagnosis stage were found to hinder patients’ efforts at seeking additional information in relation to their disease with a potential to impact on outcomes.

Focusing specifically on the terms clinicians used to describe their diagnosis, many patients remembered the label given, but when questioned further, were not able to convey an understanding of it. This fits in with work carried out by Kessels who explored patient recall of medical information. He states that between 40 -80% of information provided by health care professionals is forgotten immediately (Kessels 2003). In a bid to aid our understanding of why this occurs, Kessels further goes onto suggest that factors influencing patient recall may be divided into 3 categories:

- a) Clinician factors e.g. the use of medical jargon
- b) The mode in which the information is provided
- c) Patient factors e.g. age, level of anxiety and perceived importance of information

During this section I will focus on the influence of medical jargon and language used during a diagnosis alongside their importance. The latter two categories will be discussed in more detail in section 2 of this chapter.

The results obtained following analysis of the clinicians' accounts has revealed that providing patients with an explanation of oral precancer often includes the use of language that is considered accessible to the patient. However, the concept of accessibility appeared to vary between clinicians with some favouring the use of medical jargon only, others 'lay' terms only and finally others using a combination of the two. In all cases clinicians were seen to justify their choices on the basis of patient understanding, choosing a specific word or a collection of terms which they believe patients will understand. In instances where clinicians chose to use lay or non-medical terms, they explained this was because medical terminology is difficult for patients to understand. Yet the resulting 'lay' term was not always well understood by patients. For example, 'unstable cells' was a lay phrase used by some clinician participants. However, this was a phrase patient participants frequently remembered but were often unable to explain. In this way it can be seen that although the intention with using such terms is to aid understanding, there may well be a disparity between the doctor and the patient's perception of what constitutes 'everyday language' (Bourhis, Roth and Macqueen 1989).

One of the clinicians who provided his patients with both a medical term for their condition along with an associated lay explanation stated that he provided information in this way so that his patients would not only be able understand their diagnosis in simple terms but would also find it easier to seek further information on their disease (using the technical term) if they wished. This point becomes significant when the patient results are again considered. For example, some patients who reported that their disease was explained in lay terms only, using phrases such as 'white patch', stated an awareness that these terms were reserved for patient explanations only and were not the 'technical term' that doctors would use to describe their disease. However, when seeking additional information relating to their disease, the sole use of lay terminology

was sometimes seen as a barrier to obtaining useful information. In particular, using lay terminology as a search term on the internet sometimes provided alarming results. At the time of data analysis, I conducted an internet search using the phrase ‘white patch in the mouth’ and found, in particular, a number of misleading and potentially distressing images (2010). The results as a whole were wide ranging but most frequently pointed towards oral cancer. Conversely, studies indicate that if medical terms are used for internet based information seeking in oral precancer, the information obtained will be of satisfactory quality (Alcaide-Raya, Hughes and Warnakulasuriya 2010). Interestingly though, although some professionals acknowledged that patients may seek further information on their diagnosis from a secondary source, such as the internet, none of the professionals who took part in the study were aware of or had researched potential internet based sources of information for their patients.

7.1.2 Communicating risk

The second area of diagnosis communication to be compared between the two groups is that of risk communication. Communicating risk in oral precancer is complex. If we consider risk in oral precancer then, first and foremost, the increased risk of oral cancer development needs to be addressed (Warnakulasuriya, Johnson and Van der Waal 2007). However, we must also consider the risks of management (Goodson et al., 2012), both conservative and surgical, as well as the behavioural risk factors associated with oral precancer and cancer development (Jaber et al., 1999). Furthermore, if oral precancer is considered a chronic condition, which I would argue that for many people it is, then the risk of cancer development is persistent and, therefore, the psychological effects on the patient may be notable (the negative psychological effect of a precancer diagnosis and associated cancer risk has been demonstrated in the wider literature (Lerman et al., 1991)). In this section I will focus on communicating the risk of oral cancer development in a patient with oral precancer. I will compare the methods currently employed by the professional study group to communicate risk along with the reasons behind these to the patient accounts of how risk communication is received.

Analysis of the data from the clinicians in the study clearly demonstrated that they found risk a difficult area to communicate with their patients. This became apparent when the topic of risk was raised, with some participants having difficulty simply discussing the topic. Problems with communicating risk appeared to result from

uncertainty associated with both treatment effectiveness and future malignant transformation. Where professionals undertook discussions regarding risk, the data revealed a number of approaches: narrative explanation, statistical explanation, a combination of the two or not at all. When risk communication was approached from a purely verbal perspective, for example by using descriptive language to communicate risk, clinicians described two main approaches. Professionals either displayed a strong desire to provide a 'positive' message or alternatively a considered decision was made to overplay the risk. For those wishing to provide a positive message, some participants admitted that they would 'play down' the risk of cancer development. This was often seen where clinicians stated they were keen to avoid patient upset. On the other hand where a high risk of cancer development was communicated, for example by suggesting that oral cancer is a 'cancer in waiting', some participants felt that fear of cancer transformation could act as a motivating factor to change patient lifestyle. Using risk in this way (as a motivating factor) is acknowledged in the wider literature (Bottorff et al., 1998)

For those communicating risk statistically there was awareness that this was not always the most appropriate format for some patients (Garcia-Retamero and Dhimi 2011) and that, on an individual level, the value of using statistics to communicate risk was limited. This is, not least, because the ability to synthesise this type of numerical information is an inherently difficult task (Lipkus, Samsa and Rimer 2001). Rarely, professional participants admitted that risk of cancer transformation was not communicated to patients at all. Although the reasons for this were not explained explicitly, failing to discuss cancer risk appeared to be related to a clinicians desire to deliver a positive message as well as a personal discomfort with the notion of an uncertain prognosis and an inability to provide a curative treatment.

Where the clinician study data indicates that uncertainty can be difficult for professionals to deal with, the patient data found that uncertainty was, for some, distressing to live with. Furthermore, patient uncertainty associated specifically with the risk of cancer development was present at a number of stages throughout the patient's journey. Notably the diagnosis, management and review stages. Possibly as a result of interviewing the majority of patients towards the review stage of their disease journey, this was the stage at which uncertainty appeared most prominent. Patients often reported that they were uncertain of the risk of cancer development at this stage,

particularly where surgery had been undertaken. Specifically, patients were not always sure if surgery had removed the risk of cancer development. With some participants wrongly assuming they had been ‘cured’. In cases where patients recounted discussions surrounding risk, the recall was variable and often bore no resemblance to the medical literature.

Communicating a diagnosis - Conclusions:

- Clinicians are providing a diagnosis to their patients using variable approaches, often choosing specific terms on the basis of what they consider to be accessible to patients, but this is done in a completely subjective way with little or no supporting evidence.
- Some patients have difficulty making sense of their diagnosis; in some cases a precancer diagnosis was misinterpreted as cancer.
- Using lay terminology only to describe a diagnosis of oral precancer was found to hinder some patient attempts at information seeking in relation to their disease.
- Clinicians may find risk of malignant transformation a difficult area to communicate with oral precancer patients, with some opting not to discuss the topic altogether
- When discussed, clinicians may further confuse the message by either under or overplaying the risk
- Many patients are concerned about the risk of cancer development but are not clear what the risk is for them.

7.2 Further information needs and how information is provided

The point on the disease journey where patient participants reported the greatest need for information was immediately following their diagnosis. At this point, much of the information delivered about their disease was communicated verbally during a consultation. Unfortunately evidence suggests this is not always the most successful method (Thomson, Cunningham and Hunt 2001). Accordingly, I will now consider the patient and professional accounts from the point of view of verbal information exchange between the doctor and the patient. During these encounters a number of barriers to optimal information exchange were identified. These include; the patient’s ability to

comprehend and request further information and the doctor's ability and willingness to provide information.

7.2.1 Patient factors

The ability of a patient to retain information delivered during a consultation is important. As an example, Ley notes a well-informed patient is not only able to demonstrate a better understanding of their disease but is also more likely to adhere to treatment plans and express satisfaction with care (Ley 1979). However, the data from the patient study provides evidence that some oral precancer patients are not able to retain or comprehend the information provided to them by their doctor. This was explored in the previous section with reference to the use of medical jargon. The literature also puts forward two other factors that may influence patient recall: the mode in which the information is provided and patient factors (such as age, level of anxiety and perceived importance of the information) (Kessels 2003). I will now go on to examine these factors further with respect to the study data.

Evidence would suggest that written information is better remembered than verbal and leads to better treatment adherence (Kessels 2003). However, written information is not a format that all patients will find accessible, in particular those with low levels of literacy (Eaton and Holloway 1980). In the context of health care, health literacy is defined as: 'the capacity of an individual to obtain, interpret and understand basic health information and services in ways which are health-enhancing' (p.5) (Sihota and Lennard 2004). By considering this definition it can be appreciated that those individuals with poor health literacy may well be at a disadvantage when it comes to both obtaining and understanding information relating to their disease. Indeed studies have suggested that low health literacy is associated with a lack of understanding and use of preventative services, a lack of knowledge and decreased comprehension, poor compliance rates and poor self-reported health (Andrus and Roth 2002). Whilst it is not possible to say from the study data that patients are failing to request further information as a direct result of poor literacy or comprehension skills, given that low levels of literacy are common in the UK (with over half of the UK population displaying poor reading and comprehension skills (1997), it would be reasonable to acknowledge the likelihood that a proportion of oral precancer patients will fall into this bracket.

As well as health literacy acting as a barrier to patient understanding of medical information, the psychological literature has demonstrated that older people are more likely to have problems with memory and recall of medical information compared to their younger counterparts (Jansen et al., 2008). Specifically the volume of information has been identified as key feature in information recall, in that when a large volume of information is presented at one time, recall is likely to be reduced. This becomes relevant when we consider that, in the UK, oral precancers are more likely to affect older individuals (Napier and Speight 2008). Anxiety too has been shown to affect a patient's ability to recall information provided; for example MacLeod and Cohen report that anxious individuals are more likely to ascribe life-threatening interpretations to ambiguous statements made by the doctor (MacLeod and Cohen 1993). However, there is also evidence that this may be overcome by the provision of supplemental information (leaflets, audiotape etc.). As a number of the study participants report anxiety following their diagnosis, it is possible that the ability of some oral precancer patients to retain verbal information is affected by their anxiety. Furthermore, some participants reported finding the hospital environment anxiety provoking in its own right. Anxiety may also be of significance for those who consider a diagnosis of oral precancer bad news. This is because the literature suggests that some patients fail to hear further information following the delivery of bad news (Ptacek and Eberhardt 1996), something which was evident from the patient participant accounts.

As well as barriers to comprehending or retaining information, the patient study data revealed that for some individual's, barriers to seeking further information were also present. Specifically these barriers took the form of:

- A fear of embarrassment
- Adopting a passive role
- A fatalistic attitude

Each of these points will now be discussed.

Several participants from the patient study stated that they avoided asking for further information about their diagnosis so as not to appear 'stupid' in front of their doctor. This led some patients to go without additional information with others opting instead to go to the internet, family or friends, a behaviour that is seen elsewhere in the literature

(Ybarra and Suman 2006). Whilst seeking information in this way may well be a valid and useful experience for some, there was also evidence from the data that, for others, the information obtained was, at times, confusing, vast, difficult to comprehend and frightening.

By far the greatest barrier to information seeking, however, was that of the patient who stated that they preferred to adopt a passive role. Such patients frequently described a desire to put their trust in their doctor, abdicating any treatment decisions to them and correspondingly stating that they felt satisfied with the information provided by the doctor. This problem is significant when the white paper 'Equity and Excellence – Liberating the NHS' is examined. This document states that patients should be at the heart of the National Health Service, empowered by information and choice (DoH 2010). Clearly achieving this goal will be difficult to achieve where some patients choose to avoid both actively seeking information and participating in treatment decisions. The level of patient involvement put forward in this government document represents a shift in the dynamics of the doctor-patient encounter from a historically passive role to active involvement in their care. This active roll may be difficult for some patients to adopt and doctors should be aware and respond to this, for example by tailoring the consultation to the individuals preference (Brown et al., 2002). However, if patients can be encouraged to become more involved this, in turn, can have a positive impact (such as increased patient knowledge, satisfaction, adherence to treatment and improved outcomes) (Fraenkel and McGraw 2007).

As well as voicing a desire to maintain a passive role, a number of patients repeatedly communicated a belief that the development of their disease had been a matter of chance. This fatalistic attitude appeared to impact on their desire to actively seek further information about their disease. These patients qualified their decision by suggesting that there was little benefit to seeking additional information as the disease trajectory and outcome was essentially out of their hands. This is unfortunate as it may mean that patients with a fatalistic attitude are less likely to access positive information about their disease as well as feeling less able to influence disease outcome (for example by reducing risk factor behaviours) (Miles et al., 2008).

7.2.2 Clinician factors

Moving on from patient factors affecting information seeking, the results of the clinician study indicated that doctors employed a number of approaches when seeking to address patient's additional information needs. To this end, the majority of clinicians stated that they provided information verbally although, when questioned further, were often not sure of the success, or otherwise, of this approach. Other clinicians did not seek to address patients additional information needs at all, while the remainder provided supplemental written information, usually in the form of a personalised letter. The significance of personalising written information becomes clear when work such as that by Jones et al., is considered. Their study indicated that patients are more likely to find supplemental written information helpful when it is directly relevant to them (Jones et al., 2006). Moreover, the importance of accessible supplemental information has been recognised at governmental level (DoH 2006) and has prompted recommendations relating to the provision of 'information prescriptions', which are tailored specifically to the individual and include information that is relevant to them personally. However, although information prescriptions have been shown to be of benefit in other areas (D'Alessandro et al., 2004), providing this type of information for oral precancer patients may be more difficult due to the lack of robust evidence upon which these prescriptions should be based.

In addition to the details provided on the specific approaches to delivering supplemental information, some professionals indicated they felt the set-up of the clinic also impacted on this process. In particular some suggested that having a dedicated precancer clinic facilitates information provision by allowing the clinician to focus on one particular disease process. Although this is an interesting point it is not within the remit of this work to ascertain whether this is true and further work would be required to determine the relevance of clinical set up in relation to information provision.

Information needs and provision - Conclusions:

- Patients have varying preferences for supplemental information
- Barriers are present which either prevent patients comprehending or accessing further information

- Clinicians approaches to meeting their patients information needs are currently disparate and in some cases non-existent. This is a lost opportunity to address patients' needs

7.3 Behaviour change

Health related behaviour change (in this case primarily tobacco and alcohol cessation) was a further area in which problems with current practice were identified. Previous chapters have highlighted the importance of tobacco and alcohol use as risk factors in the development of oral precancer and oral cancer. In particular, the roles of smoking and, to a lesser extent, alcohol cessation in oral precancer management have been examined. The oral precancer literature stresses the importance of measures aimed at stopping or reducing tobacco and alcohol use in the management of oral precancer (Warnakulasuriya 2011). However, there is also evidence that despite intensive cessation measures many patients continue to use these substances (Hamadah, Hepburn and Thomson 2007; Poate and Warnakulasuriya 2006). As these risk factors are thought to be significant, it is vital to investigate how health related behaviour change in oral precancer is approached by professionals and received by patients. This discussion will focus primarily on smoking cessation. Although alcohol cessation was discussed with both study groups much less data was generated on the topic. In an effort to determine the reason for this, examination of the patient study results revealed that the majority of participants had no recollection of the topic having been discussed.

Looking first at the study of professionals, a number of the participants stated that they engaged less in measures aimed at alcohol cessation compared to smoking cessation. The justification often cited for this was the perception that alcohol use is less significantly associated with oral precancer and therefore efforts aimed at reducing risk factors would be better aimed at smoking cessation. Although the literature supports the concept of tobacco as the predominant risk factor in oral cancer and precancer development (Reichart 2001) it does not seem justified to omit efforts aimed at any other form of behaviour change, particularly where an increased risk of disease development has been noted (Maserejian et al., 2006). However, due to a lack of data, the rest of this section will be dedicated to exploring the topic of smoking cessation.

As the literature demonstrates that many patients with oral precancer continue to smoke following their diagnosis; it would seem that the effect of an oral precancer diagnosis is not necessarily powerful enough to elicit a change in risk factor behaviour. The study results will therefore now be examined both from the patient point of view in relation to barriers preventing engagement with smoking cessation as well from a professionals viewpoint, by exploring how clinicians advise patients on their health related behaviours and provide access to appropriate services.

7.3.1 Patients' experience of behaviour change

Examining the patient accounts revealed that there were a number of barriers to behaviour change, in particular: lay beliefs contradicting biomedical information, a fatalistic attitude and the influence of social norms.

The study results indicated that patients were more likely to engage in a behaviour change when they believed that the effects would be of direct benefit to them. In particular the impetus to stop or reduce smoking and drinking was often seen where patients believed that changing these behaviours would improve their oral precancer, reduce the chance of future oral cancer development or provide another positive lifestyle benefit. There were a number of examples, however, where participants made it clear that they attributed their oral lesions to a cause other than that put forward by their doctor, for example, as a result of previous dental treatment or following the use of a new medication. It can be appreciated, therefore, that where such beliefs exist, the motivation to change smoking or drinking behaviours may be limited. It was interesting to note from the professional data that a number of the clinicians also cited this as a barrier in tackling behaviour change with their patients. Other clinicians, however, dismissed the notion that some patients would not accept a link between oral precancer and smoking, stating that it is widely accepted in Western society that that smoking is detrimental to an individual's health. Whilst this may be true, it does not take into account the specific link that they are trying to infer between smoking and the patient's oral lesion.

Variations between lay and professional understandings of illness have been identified by many (Balshem 1991; Pill and Stott 1982; Popay et al., 1998). However, lay and professional understanding of disease processes may not necessarily be completely

distinct from one another. Factors such as, public health campaigns, experience of health care systems and free access to health related information can lead to a situation where 'lay beliefs' are informed in part by pre-existing knowledge of medical ideas and concepts (Shaw 2002). This may become important not only when patients seek to interpret and understand their illness but further may impact on their illness behaviour, including modification of behavioural risk factors such as smoking. Examples of the influence of lay understandings of oral precancer have been described in the previous chapters. For example, where one of the patient participants describes how she understands her disease to be the direct result of temperature of her food. Her description of her beliefs surrounding disease aetiology demonstrates both an awareness and a rejection of the biomedical explanation of her disease. Consequently her efforts at behaviour change are directed toward altering the temperature of her diet.

Moving on from the influence of lay understandings of disease aetiology and on to another potential barrier in health related behaviour change, it has been discussed that there were a number of patient participants who believed they had no influence on their disease course and should their lesion change it would be down to luck, fate, or God's will. It can be seen that such a fatalistic attitude could pose a significant barrier to engaging in behaviour change and this was demonstrated with the patient study cohort. This is of concern as studies have indicated that patients who adopt such a viewpoint are not only less likely to change behaviour but also may be more likely to have a poorer prognosis (Niederdeppe and Levy 2007). However, it should be noted that some studies have indicated that it may be possible to modify fatalistic attitudes following the implementation of an intervention (Powe and Weinrich 1999). The literature on fatalistic attitudes would further suggest that such beliefs are more prevalent in those from lower socioeconomic groups. As oral precancer patients are more likely to belong to such groups (Hashibe et al., 2003) this particular barrier to behaviour change may be relevant to the oral precancer patient.

In addition to a fatalistic viewpoint the potential relevance of a low socioeconomic status again becomes important when the influence of social norms as a barrier to behaviour change is considered. Accounts from the patient study revealed that many participants often looked to their immediate social environment as a means of gauging what constituted 'normal' behaviour. In the context of smoking and drinking alcohol participants often compared their behaviour to that of others from within their social

group. This information was then used to enable them to weigh up their perceived risk in continuing their damaging health behaviour. For example, some participants spoke of acquaintances who they felt smoke or drank more than them and compared their behaviour to that of their own as a means of suggesting that their behaviour, by comparison, was not significant or risky.

If we now go on to explore smoking specifically in a social context, the literature states that smoking is strongly associated with socioeconomic status, which in the UK (although not in other countries) equates to higher numbers of smokers in the lower socioeconomic groups (Pampel 2002). Furthermore, smokers from lower socioeconomic groups are less likely to respond to tobacco control messages (Frohlich et al., 2010). This disparity has been noted in the government guidance document 'Healthy lives, healthy people – a tobacco control plan for England' (Government 2011) which alongside other guidance, recommends that local areas are encouraged to provide tailored stop smoking services to those from high smoking prevalence groups (including those from socioeconomically disadvantaged communities). Because oral precancer patients may belong to such groups (Hashibe et al., 2003) it is important to consider why such messages are acted upon less often by individuals with low socioeconomic status. To this end, Frohlich et al., have hypothesised that this may be partly due to a 'mismatch' between, primarily, middle-class professionals delivering tobacco prevention messages to the lower income smoker (Frohlich et al., 2010). They further put forward the belief that persons from the target group (those from low socioeconomic groups) should perhaps be actively involved in the intervention process. A concept which is supported by others, specifically in the context of social marketing as a tool in smoking cessation (Hastings and McLean 2006).

7.3.2 Approaches to behaviour change employed by clinicians

The clinician based study results indicated that the majority of clinicians were discussing risk factors with patients, but with varying approaches. Best practice was seen where current guidelines were followed (DoH 2012a; NICE 2008) and included advice and encouragement to stop smoking alongside referral to specialist smoking cessation services. However, there was also evidence that smoking cessation advice was not always optimal. In some cases it was reported that engaging with smoking cessation was challenging because accessing services was difficult, for example in cases where

local smoking cessation clinics had been withdrawn. However, at other times clinicians stated that the responsibility to request access to services lay with the patient. In addition, it has also been discussed that the attitude, especially a lack of enthusiasm, of the professional has the potential to impact on a patient's likelihood to change their behaviour (Lowry et al., 2004). This is interesting if we consider the professional data, which demonstrated that in some cases little effort was put into messages about the benefits of behaviour change. Professionals sometimes qualified this behaviour on the basis of a lack of time.

Behaviour change - Conclusions:

- Patients accounts reveal a number of barriers which may prevent engagement with behaviour change, specifically these include:
 - Lay beliefs
 - A fatalistic attitude
 - Social norms
- When broaching behaviour change with their patients, clinicians appear to be much less likely to direct efforts towards alcohol cessation, compared to smoking cessation
- Clinicians report not always following current guidance on smoking cessation and in some cases are failing to advise patients of available services. This is a lost opportunity to improve health and to improve mortality and morbidity.

7.4 Management of oral precancer

It has been discussed that there are two main approaches to managing oral precancer: surgical removal or conservative management. By looking at both the patient and professional accounts of management together it is possible to examine how the patient participants experienced precancer management and compare this to how the professional participants made decisions about the most appropriate form of management for their patients. In this way, in future the decision making process may be better informed.

7.4.1 Patient experience

By beginning with those who underwent surgical treatment, analysis of the patient data revealed that patient experience of surgery is variable, ranging from those patients who report a distressing experience to those who cope well with the surgery. Focusing initially on surgery, it was clear to see from the data that this process included not only the surgery itself but also the lead up to the surgery, the experience of being in a hospital environment, the surgical intervention, as well as the post-operative phase, described by one participant as ‘the aftermath’.

As with other aspects of patient experience it is not possible to simply classify patients into those who coped well and those who did not. Instead it is important to examine the factors which influenced the patient experience of surgery, both positively and negatively. It is only by doing this that it may be possible to understand and, for some; potentially improve the patient experience of surgery. Analysis of these factors may also enable us to reconsider the consent and even the decision making process as a whole to ensure better, well informed choices and experience for all precancer patients.

Firstly, looking at those who coped well with surgery, the data demonstrated that a positive experience often appeared to correlate with patients for whom their expectations of surgery were met. In addition, where patients had undergone surgery for other medical conditions, they often appeared to cope better with their oral precancer surgery than those who had not. Interestingly, some patients who reported a poor experience of surgery stated that they would not have opted for surgery had they been aware of the nature of the treatment and/or its post-operative effects at the time. In some cases it appeared that a patient’s expectations were affected by their perception of a lack of pre-operative information. Further data analysis was able to show that some dissatisfied patients remembered the surgical information being provided to them just prior to the procedure and sometimes by someone other than their usual clinician. Moreover, it seemed that recall of the information provided at that time was not always particularly good.

As well as surgical management, the results and discussion of the patient study (chapter 5) outlined the format of conservative management alongside the patient experience of it. Conservative management essentially involves the patient attending an outpatient clinic for regular review of their lesion(s). This may also include regular biopsy and/or

photographs of the lesion depending on the clinic attended. It can be seen, therefore, that conservative management and review following surgery often take a similar format; however, the patient's experience will not necessarily be the same. One feature which was seen in the accounts of both patient groups was that they were not always sure why they were attending the clinic. Broadly, there were two main responses to the review appointment: some finding it profoundly reassuring, while others sought discharge. In both situations though there appeared to be reluctance to ask their clinician for clarity. As a result, uncertainty was a prominent theme at this stage.

Patients who felt reassured by their regular appointments often described a persistent fear of cancer, further treatment or sometimes even biopsy. Importantly, this fear was not always voiced at the appointment, thus eliminating a possible opportunity for reassurance or further information to be delivered by the patient's clinician. For those striving for discharge, there was often a view that discharge from the clinic was an indication of being 'cured', with some patients stating they were keen to get the 'all clear'. However, patient participants also frequently spoke of a lack of clear information on when or if they would be discharged. As a result, some patients looked for clues to assess the likelihood of discharge for themselves. For example, if the recall appointments were becoming less frequent this was seen as an indication that their disease was less severe and as a result these patients often felt reassured. This type of behaviour, where a patient looks for other indicators instead of asking the doctor directly for information has also been described in the cervical precancer literature (Martinez 2005).

7.4.2 Clinician experience

When examining the management of oral precancer from the perspective of the clinician study group it is helpful to remember that the existing evidence is not robust enough to definitively support one management option over another (Lodi et al., 2008). It is, therefore likely that this impacts on clinicians' treatment decisions. Indeed the results of the clinician study indicate that the decision making process surrounding treatment varied between participants with, for example, some participants indicating they would only offer surgery to patients whom they considered to have the most advanced disease. Further exploration of the decision making process revealed the factors taken into account by clinicians when making treatment decisions which included: the grade of

dysplasia within the lesion, the clinical appearance of the lesion, the reliability of follow up in general practice and patient preference, with the grade of dysplasia being the most frequently cited consideration.

In general terms, current literature on the subject of clinical decision making suggests that a decision making process involving both the clinician and the patient equally is the optimal model (Elwyn et al., 2010) and policy supports this (DoH 2010). Moreover, the advantages of the shared decision model previously discussed have been cited as: improved health outcomes, boost in patient satisfaction with services, increased knowledge and understanding of health status and increased adherence to a chosen treatment (Edwards and Elwyn 2009). However, the literature also acknowledges that this so called shared decision-making process, despite being considered the ideal, will not suit everyone (Deber et al., 2007). Indeed, there was some evidence from the clinician data that the decision making process was not always a truly shared decision, although the reasons for this were not clear.

As well as difficulties making treatment decisions, patient review and discharge was highlighted as another challenging area in oral precancer management. In particular, the clinicians often expressed concern that they had difficult decisions to make when it came to choosing when to review patients and when to discharge them particularly when deciding on an appropriate time for discharge. These decisions may be made particularly challenging when recent work suggesting review periods of up to 20 years or more is considered (Mehanna et al., 2009; van der Waal 2010). Furthermore, it was noted that the professionals who had become consultants more recently expressed greater uncertainty with regard to the duration patient review in particular.

Management of oral precancer – Conclusions:

- Patients experience of surgery is not uniform and may be influenced by a number of factors, including their experience of other disease and prior expectations of surgery
- Patients may view conservative management and review positively or negatively but in either case they are often associated with uncertainty
- Clinicians appear to consider the grade of dysplasia within a lesion particularly important when making decisions regarding treatment

- At present, there is limited evidence of shared decision making in oral precancer management

7.5 The influence of the clinician and the environment on patient experience

The previous four sections of this chapter have considered specific points along the patient journey at which there may currently be problems in current practice. The following section, however, will examine two factors which may influence a patient's experience throughout their journey through secondary care, namely the clinician and the clinical set up/environment.

7.5.1 The clinician – the significance of the individual

Not surprisingly the relationship between the precancer patient and the clinician or clinicians they came into contact with throughout their precancer journey often had an impact on their experience of their disease and treatment. When discussing this topic with the patient study group there were two key areas that were highlighted as important by the group:

- the significance of the individual at the time of diagnosis
- continuity of care in the post diagnosis phase

Analysis of the data with respect to the significance of the clinician delivering the diagnosis revealed that many patients desire to be seen by someone they perceive to be experienced and senior, usually a consultant. For some patients there was a dissatisfaction associated with being given a diagnosis by another member of staff. The advantages of being seen by a consultant from the patient point of view included: trust in the diagnosis, security that the appropriate action would be taken and feeling that they (the patient) mattered. This fits in with the work of Wittmann et al., who, in their study involving oesophageal and gastric cancer patients, found that of their sample a high percentage of patients felt that their diagnosis should be delivered by a consultant (77% of the study sample). Interestingly, only 5% of the junior doctors surveyed as part of the same study felt this was appropriate.

Furthermore, feelings of trust and confidence appeared to be fostered where there was continuity in terms of the clinician who saw the patient. For many patients the relevance of seeing the same clinician was that there was a belief that the person would be familiar with their case and, in particular, would be able to remember the appearance of their oral cavity and/or lesion which, in turn, would allow them to pick up any changes more readily. Interestingly, there was also evidence that, where a positive doctor-patient relationship had developed, some patients expressed that they would undergo procedures they found unpleasant because of the trust they had in their clinician and would therefore feel happy taking their advice as a result of the faith they put in their management decisions. On the other hand, where a lack of faith in the doctor existed, patients reported dissatisfaction with care. This was particularly, although not exclusively, evident at the biopsy stage where a perception that the clinician was inexperienced led to a loss of faith and an unpleasant experience.

Professionals, however, stated that precancer patients were often seen by a number of different individuals. There was a sense that although patients may prefer to be seen by a consultant, it was not always practical to ensure this happened at every visit. Instead, consultants often made it a priority to see an oral precancer patient at the diagnosis stage, as this was repeatedly deemed the most critical. There was an opinion that junior members of staff should not be involved in the diagnosis or review of the precancer patient due to their lack of knowledge or experience; however, they were frequently involved in the biopsy stage of management.

In terms of continuity of care, this was best achieved when dedicated clinics were set up. Using this approach meant that patients were more likely to see a particular individual on a regular basis. However, even when using this approach it was acknowledged that it would be difficult for the consultant specifically to spend time with each individual and that sometimes another member of the team would be involved in the patient's care. Some consultants felt that the benefit of establishing a positive relationship with their patients over time was that they were more likely to 'buy into' their management strategies. As noted above, this seemed to be happening in some cases.

7.5.2 The environment – the significance of the clinical set up

From the clinician point of view it has been discussed that there are two general approaches to organising clinics for precancer patients: by managing them on a specialised clinic or by incorporating them onto mixed outpatient clinics. The available literature would suggest, that in the UK, patients with oral precancer are frequently seen on specialist as opposed to generalist clinics (Kanas et al., 2011). When study participants from the clinician study stated that they had set up specialist clinics, there were clear ideas surrounding the benefit of organising a clinic in this particular way. Specifically, there was a perceived benefit to the clinician on focusing purely on one disease process during a clinic; this was thought to allow a consistent approach, with targeted messages, and on occasion, the use of new technologies and potential for patient involvement in research. When clinicians saw patients on mixed outpatient clinics the majority reported that this was satisfactory, however, some admitted that due to the disparate nature of the mixed clinics there was, at times, a tendency not to spend as much time focusing on health behaviour messages such as smoking cessation.

Compared to the clinician data the topic of clinical set up in the patient data was much less prominent. Where patients did complain about the clinical set up it was usually due to a dislike of being in a hospital environment or a lack of flexibility with appointment dates or times. On occasion, patients attending mixed clinics spoke of their shock when faced with others who had visible facial disfigurements but chose not to voice their concern with clinicians. On the other hand, patients reported satisfaction with the clinical set up when it was well organised and they were seen on time.

The influence of the clinician and the environment on patient experience -

Conclusions:

- Patients wish to be seen by a senior doctor (usually a consultant) at the time of their diagnosis and subsequently value continuity as part of their continuing care
- Clinicians reported that oral precancer patients will not always see a consultant or indeed the same clinician at each appointment
- Clinicians often feel that the organisation of the clinic may impact on patient experience, particularly in terms of delivering health messages

This chapter summarises the work of both studies. This is facilitated by the use of a map outlining an oral precancer patient journey through a health care system which enabled identification of four specific areas at which current practice may benefit from an intervention, namely: communicating a diagnosis, meeting patient information needs, facilitating behaviour change and decisions concerning treatment options. In addition the influence of the clinician and the clinical environment on patient experience (which is present at multiple stages of the patient journey) has also been described. The following chapter will go on to make final conclusions with respect to the studies aims and objectives as well as providing recommendations for changes in practice and future research.

Chapter 8. Summary, recommendations for practice and further work

8.1 .Summary

This work was conducted as a result of a perceived disparity in oral precancer patient care, a lack of research within the field of patient experience in oral precancer and a desire to improve the patient experience.

The aim of this project was, therefore, to investigate both the patient and professional experience of oral precancer with a view to identifying opportunities to improve patient care.

With this in mind, this thesis reports on two studies the first of which sought to examine critically patients' experiences of oral precancer with a view to:

1. Gaining an insight into the understanding patients have of their disease
2. Exploring what patients recall of the information they receive in relation to their disease and their views of the medium through which information was given
3. Exploring the impact of the diagnosis on the individual's life and health related behaviours
4. Exploring patients' views of their ongoing clinical management

The results of this study indicated that:

1. Patients' understanding of their disease is variable with some patients finding their diagnosis particularly difficult to make sense of. Specifically the terminology used is shown to impact patient understanding and subsequent information seeking.
2. Patients are often able to recall a term given to them to explain their diagnosis, but are not always able to make sense of it. Some patients are aware that they are not able to recall the entire conversation with their clinician, which is often the primary means of disease specific information delivery.
3. Being diagnosed with oral precancer does not produce a uniform response: for some individuals the diagnosis is devastating, for others the impact is less. The response appears to be dependent on a number of variables, in particular the influence of past or concomitant disease is noted.

4. The experience of oral precancer management varies and is dependent on a number of factors, including the mode of management. However, meeting expectations is a prominent theme at this stage.

The second study aimed to investigate oral precancer from the clinicians perspective, in particular the objectives of this study were:

1. To determine how the diagnosis of oral precancer is explained to a patient and to ascertain how concerns are addressed.
2. To determine if behaviour change, specifically modification of risk factors, is considered an important factor in the management of oral precancer and if so what action is taken to assist patients with this
3. To determine the how decisions are made relating to management options for patients with oral precancer.

The results of this study indicated that:

1. A diagnosis of oral precancer is often explained to a patient using terminology that the clinician feels the patient will understand and in many cases this involves the use of lay terms. At the time of diagnosis there may be concerns pertaining to the risk of malignant transformation which can be difficult to address and are, sometimes, avoided.
2. Efforts at health related behaviour change are concentrated around smoking cessation, however, current guidance is not always followed and in some cases, clinicians feel that it is the patient's responsibility to request access to services.
3. Decisions relating to management in oral precancer appeared to be complicated by a lack of clear clinical guidance and were often made primarily on the basis of the grade of dysplasia within a lesion.

In addition to the conclusions listed, the analysis of the studies allowed the patients journey through care to be mapped which enabled several points along the journey to be identified at which point there are problems with current practice. These will now be outlined in the next section: recommendations for practice and further work.

8.2 Recommendations for practice

8.2.1 Communicating a diagnosis of oral precancer

The results from both studies provide evidence that when deciding on an approach to communicating a diagnosis, particular attention should be paid to the terminology used. Clinicians should be aware that the choice of terms they use are likely to directly impact on patients understanding of their disease and that patients will not always interpret the diagnosis as clinicians intend. In addition, terms used to describe oral precancer at the diagnosis stage may be used by patients to seek further information and clinicians should consider this when deciding on the most appropriate language to use.

8.2.2 Addressing patients information needs

There is evidence that patients do not recall all of the information given to them verbally by their clinician and may require additional information about their disease. In addition, the patient study results also demonstrate that factors such as a fear of embarrassment, adopting a passive role and a fatalistic attitude can create difficulties pursuing additional information directly from their doctor. Clinicians should be aware of this and consider how best to support their patients' needs. In particular, there is need for high quality, accessible, reliable supplemental information resources.

8.2.3 Facilitating behaviour change

Tobacco use and in particular cigarette smoking is a risk factor for the development of both oral precancer and oral cancer. Clinicians should be ensuring that patients are aware of and have access to smoking cessation services. It may be helpful for clinicians take more decisive steps to encourage patients to engage more with smoking cessation, specifically by tailoring the message to the individual.

8.2.4 Making treatment decisions

Although decisions made regarding treatment options in oral precancer are difficult without clear evidence-based guidance, the patient study results indicate that managing patients' expectations is an important aspect of this stage of their disease journey and may help to improve patient satisfaction with care.

8.2.5 The doctor-patient relationship

Finally, throughout their journey, patients often appear to place importance on the relationship with their doctor placing a particular emphasis on trust in their clinician and consistency. It may be helpful for clinicians to be aware of this when organising clinics for oral precancer patients.

8.3 Further work

Clinicians often communicate a diagnosis of oral precancer using terminology they believe patients will understand but the evidence from this study suggests that the terminology used can be problematic. Further work needs to be done to unpick the meanings patients attach to particular words in order to determine which terms should be used during an oral precancer diagnosis. This would enable the development of clearer guidance for clinicians on the delivery of a precancer diagnosis.

The results of the clinician study suggest that clinicians often fail to facilitate further patient information seeking because either they do not have adequate resources directly available (for example leaflets on the clinic) or because they are not aware of potential resources (for example, appropriate internet based information). This may mean that such resources may need to be developed or identified. Clinicians should be able to direct patients to the best available resources for their patients in order to guide them toward meaningful additional information. This is of particular importance when it is considered that patients may not feel able to access further information from their clinician directly.

Many of the uncertainties in oral precancer stem from a lack of robust evidence, in particular in relation to likelihood of malignant change and effective treatments. Further work is required in relation to both predictors of malignant change and treatment effectiveness in order to allow the production of detailed national guidelines for clinicians. In this way treatment practices may be standardised and discussions surrounding risk of future disease may be easier.

8.4 Final summary

This thesis adds to the literature in that it explores and describes the experience of living with oral precancer and in doing so offers the reader a deeper understanding of the potential impact of an oral precancer diagnosis. It is intended to allow the reader to appreciate the factors that may prevent an individual with oral precancer from questioning or seeking further information from their clinician. Moreover, this work unpicks potential barriers to an individual fully engaging in treatment decisions or health related behaviour changes. In addition, this work highlights difficulties associated with managing oral precancer patients from the perspective of the clinician particularly where treatment decisions are based on a limited evidence base.

Appendices

Appendix A – Study protocol



PATIENT AND PROFESSIONAL VIEWS AND EXPERIENCE OF ORAL PRECANCER

Protocol

**Principal Investigator:
Miss Rachel Green**

Summary of protocol

This document outlines a project to investigate the patient's and professional's views and experience of oral precancer.

Contents

a) Introduction.....	2
b) Background.....	2
c) Aims and objectives.....	4
d) Method.....	5
e) Enrolment criteria.....	7
f) Human subject considerations.....	7
g) Adverse Events.....	7
h) Study records.....	7
i) References.....	9

a) Introduction

The purpose of this study is to gain a deeper understanding of oral precancer from the patient and professional perspective.

During the initial stages of the study we will work with patients who have been diagnosed with oral precancer. Using qualitative interview techniques we will explore the patient's experiences of diagnosis and will further investigate the patient's thoughts and feelings toward their illness and its management. Furthermore, we will investigate the impact of their experiences on lifestyle and specifically health related behaviour. Through this process we want to gain a deeper understanding of how these individuals experience their disease and treatment.

This study will go on to explore views of experience and management of oral precancer from the clinician's perspective. This phase of the study will target clinicians closely involved in the care of oral precancer patients. It will be informed by the earlier interviews undertaken with patients and, in particular, will investigate communication surrounding disease diagnosis and treatment.

We believe the study will provide important insights into patient experiences and understandings as well as clinical practice, which will help to manage this complex group of patients more effectively.

b) Background

What is oral precancer?

Oral precancer, also known as oral premalignancy or potential malignancy, is a term used to describe an oral lesion which *may* precede oral cancer. Potentially malignant disorders, such as leukoplakia, erythroplakia and speckled leukoplakia typically present in the mouth as predominantly white, red, or mixed white and red mucosal lesions. These precancers are labelled as such because it is recognised that they disorders in which dysplastic or frankly malignant changes occur with a higher degree of frequency as compared to normal oral mucosa (Brennan et al., 2007).

Dysplastic change represents one of the various prognostic indicators of malignant transformation (Brennan et al., 2007) and is generally regarded as heralding malignant change (Scully 1995). Dysplasia is graded by convention as mild, moderate or severe. With evidence suggesting that severe dysplasia has a higher potential for future development of malignancy (Rodrigues.V.C 1998).

Prevalence and transformation of oral premalignancy

Collective data on the prevalence and transformation of oral premalignant lesions is limited. Leukoplakia is the most common and best known oral precancerous lesion (van der Waal et al., 1997). The prevalence of leukoplakia documented varies and has been reported as ranging from 1.0% to 5.0% in the general population. (Lodi.G 2006) With malignant transformation into squamous cell carcinoma occurring in 4.4%-17.5% of leukoplakias (Rodrigues and Tuomainen 1998).The prevalence of erythroplakia is less than leukoplakia, however, most authors conclude that erythroplakia has a higher potential for malignant transformation.

Published data suggests the percentage of oral cancers in Europe and the USA which arise from precancerous lesions or conditions to be somewhere between 16.0 and 62.0%. However, work carried out in India has suggested that in this region 80.0% oral cancers were preceded by oral pre-cancerous lesions or conditions.(Gupta et al., 1989)

How is oral precancer currently treated ?

To date there are no widely accepted protocols for the management of potentially malignant oral lesions.(Lamey 1993) Survey based work targeting oral medicine and oral and maxillofacial surgeons highlighted significant differences in management options both within and between these two practitioner groups (Marley.J.J 1998). In general terms precancerous lesions exhibiting severe dysplasia tended to be managed in a more aggressive, often surgical manner. However, it was recognised that until a better understanding of the natural history of these lesions is achieved there will always be a degree of uncertainty as to the efficacy of any particular approach to treatment (Marley et al., 1996).

What is the significance of oral premalignancy ?

The significance of oral premalignancy is clearly its potential to undergo malignant transformation to oral squamous cell carcinoma. The concept of this two-step process of cancer development in the oral mucosa is well-established (Reibel 2003). Significant mortality and morbidity are associated with squamous cell carcinoma which continues to have poor survival rates at five years post diagnosis.

It is recognised, however, that not all premalignant lesions will progress to oral squamous cell carcinoma.

What are the associated risk factors and health related behaviour in oral premalignancy?

Risk factors for the development of oral squamous cell carcinoma are well documented. The two best known are tobacco smoking and alcohol consumption. These behaviours have long been implicated in oral squamous cell carcinoma development and research confirms that these too are highly important risk factors for oral premalignancy (Jaber M.A et al., 1999). It would appear that risk of disease development is dose dependant and that a combination of the two habits further increases disease risk. Importantly, however, it has been shown that regression of oral premalignant lesions may occur if such habits are discontinued (Gupta et al., 1995).

What do we know about oral precancer from the patient perspective?

At the present time, there is no information in the literature relating to oral precancer from the patient perspective. Patients' perceptions and their response to the diagnosis of oral precancer are critical, as the response of the patient in terms of how they change their risk behaviours is likely to be fundamentally important to outcome. It is for this reason that this study aims to explore this patient group in more detail. If we can establish how patients understand the message and respond, then we may be better able to manage this diverse group of patients. Work looking at a different type of precancer (cervical precancer) suggests this group of patients often have a poor understanding of what their diagnosis means, leading to distress, confusion and dissatisfaction with care (Karasz, McKee and Roybal 2003). Despite different demographic profiles, could parallel exist between this group and our oral precancer group?

What do we know about oral precancer from the clinician perspective?

Work in the literature relating to oral precancer primarily focuses on the possible management options for these lesions. Views of UK based practicing clinicians

involved in the care of oral precancer patients has been restricted to quantitative information relating to investigations and managements undertaken. Through clinician based interviews we wish to explore the professional experiences of working with patients who have oral precancer, information that it is not possible to gain through quantitative research.

c) **Aims and Objectives**

Aim

To investigate both patients and professionals experiences of oral precancer with a view to identifying opportunities to improve patient care

This will be achieved through two separate but related studies.

Study A objectives

This study will critically examine patients' experiences and understanding of oral precancer through a series of qualitative semi-structured interviews. The study's objectives are:

6. To gain an insight into the understanding patients have of their disease
7. To explore what patients recall of the information they receive in relation to their disease
8. To explore their views of the medium through which information was given
9. To explore their views of their ongoing clinical management
10. To explore the impact of the diagnosis on the individual's life and health related behaviours

Study B objectives

Study B will look at oral precancer from the clinician perspective using qualitative semi-structured interviews. The study's objectives are:

4. To determine how the diagnosis of oral precancer is explained to a patient and to ascertain how concerns are addressed.
5. To determine the how decisions are made relating to management options for patients with oral precancer.
6. To determine if behaviour change, specifically modification of risk factors, is considered an important factor in the management of oral precancer and if so what action is taken to assist patients with this

d) **Method**

Overall design

Study A will involve an oral precancer patient group and will use semi-structured qualitative interviews to identify important aspects of their experiences following the diagnosis of oral precancer

Study B will target clinicians involved in the care of patients with oral precancer. Again, using semi-structured qualitative interviews will explore the clinicians perspective of areas of importance highlighted by the patient group.

Study A

Purposive criterion based sampling will be used to identify a group of patients to participate in qualitative semi-structured interviews (Table 1)

Table 1. Patient interview criteria

Criteria	Details
Gender	Male Female
Age	18 - 40 years 40 + years
Management	No active treatment (KUO) Currently receiving treatment Previous treatment received - further disease diagnosed following treatment Previous treatment received - no further disease diagnosed since treated Multiple areas of disease
Location	Newcastle Sunderland
Risk factors	Smoker Drinker Smoker and drinker Never smoker and never drinker

Patients will be recruited using these criteria to ensure that patients with different experiences of disease diagnosis and management are recruited therefore allowing a broad range of views to be obtained

A semi-structured interview method will be used to allow for adequate insight into the patient experience as it provides an opportunity for detailed investigation of individual's personal perspectives. (Ritchie and Lewis 2003) Data collection and analysis will occur concurrently until data saturation, that is until no new ideas or themes arise from the data (Glaser 1965). From experience we expect saturation to occur at around 20 interviews (Durham et al., 2007).

20 patients will, therefore, be recruited from two geographical locations – Oral and Maxillofacial outpatient clinics in Newcastle and Sunderland. Patients will be provided with a full verbal explanation of the research and its purpose along with an information sheet, and an accompanying reply and consent form. If patients wish to participate they will be contacted by telephone or post to arrange a meeting. Once consented to participate, individual semi-structured interviews will be conducted by a trained researcher (RG) at a time and location convenient for the participant. A topic guide will be used to facilitate the interview process. The topic guide will be informed by the literature, clinicians with an experience of diagnosing and treating oral precancer as well as by colleagues with extensive experience of qualitative research data collection techniques. It is anticipated that the topic guide will evolve as the interview process progresses and new themes are identified. The interviews will be recorded digitally and transcribed verbatim, once the transcripts have been checked for accuracy the original

recordings will be destroyed. In line with Data Protection and Research Governance all information pertaining to individuals will be anonymised. All transcripts will be stored on a secure password protected computer network, and any hard copies will be stored in a secure locked private office.

Analysis

Data collection and analysis will occur concurrently to allow for issues which arise in earlier interviews, to be explored in more depth in subsequent interviews. In addressing the specified research objectives, the study seeks to examine the relative influence of: interpretation, communication, life impact. Thematic analysis, based on the ‘constant comparative method’ (Glaser 1965) will be employed. The validity of data interpretation will be ensured by independent coding and cross-checking by at least two members of the research team. Data analysis will take place at Newcastle University.

Study B

Purposive criterion based sampling will be used to identify a group of professionals to participate in qualitative semi-structured interviews (Table 2)

Table 2. Professional interview criteria

Criteria	Details
Gender	Male Female
Designation	Consultant
Specialty	Oral and Maxillofacial Surgery
Location	Variety of locations UK wide
Working environment	Teaching hospital Large regional unit District general hospital

Professionals will be recruited using these criteria, this will ensure, in a similar manner to the patient based study, that a broad range of views will be obtained.

Professionals will be provided with a explanation of the research and its purpose along with an information sheet and an accompanying reply and consent form. If professionals wish to participate they will sign and return the consent form provided. Once consented to participate, individual semi-structured interviews will be conducted by a trained researcher (RG) at a time and location convenient for the participant. Telephone interviews will also be offered to this group.

d) Enrolment Criteria

The following inclusion and exclusion criteria will be applied to recruit participants to the study.

Study A	Inclusion criteria	Exclusion criteria
	A diagnosis of oral precancer	Refusal to participate
	Willingness to take part in interview process	Under 18 years of age
	Able to provide informed consent	Unable to consent

Study B	Inclusion criteria	Exclusion criteria
	Professionals involved in the care of patients with oral precancer	Refusal to participate
	Willingness to take part in interview process	

e) Human Subject Considerations

Participant Confidentiality - Participants will be assured of confidentiality throughout the research process. Records will be assigned an identifier code, the solution to which will be known only to the principal investigator. In addition, a confidentiality agreement is in place with the transcription company.

Participant comfort - Participants will be invited to take part in the interview process at a place and time convenient to them. In study A, in order to allow patient participants to feel comfortable during their interview a choice of location, which is non-clinical, will be made available.

f) Adverse Events

It is not anticipated that there will be any adverse effect on the participants as a direct result of contributing to the study. However, if any clinical questions are raised during the course of the interview process by patient participants in study A, the participant will be referred back to the staff involved in their clinical care for appropriate advice.

g) Study Records

All records will be the responsibility of the principal investigator. The digital recordings will be wiped following transcription. Written records will be stored in a private locked office and computer records will be kept on a password protected, University owned computer. Following completion of the study records will be kept securely for a period of 10 years.

Appendix B. Ethical approval



National Patient Safety Agency

National Research Ethics Service

County Durham & Tees Valley 2 Research Ethics Committee

Professional Unit of Surgery
University Hospital of North Tees
Pipernickle Road
Stockton-on-Tees
TS19 8PE

Telephone: 01642 624164
Facsimile: 01642 624164

10 November 2008

Miss Rachel A Green
Clinical Fellow
Newcastle University
School of Dental Sciences
Framlington Place
Newcastle-Upon-Tyne
NE2 4BW

Dear Miss Green

Full title of study: Patient and professional views of experience and management of oral precancer
REC reference number: 08/H0908/77

Thank you for your recent letter, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). The favourable opinion for the study applies to all sites involved in the research. There is no requirement for other Local Research Ethics Committees to be informed or SSA to be carried out at each site.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Appendix C – Ethical approval for substantial amendment 1



National Patient Safety Agency

County Durham & Tees Valley 2 Research Ethics Committee

The Tatchell Centre
University Hospital of North Tees
Piperknowle Road
Stockton-on-Tees
TS19 8FE

Tel: 01642 624164
Fax: 01642 624164

09 October 2009

Miss Rachel A Green
Clinical Fellow
School of Dental Sciences
Newcastle University
Framlington Place
Newcastle-Upon-Tyne
NE2 4BW

Dear Miss Green

Study title: Patient and professional views of experience and management of oral precancer
REC reference: 08/H0908/77
Amendment number: 1
Amendment date: 25 September 2009

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The Committee noted that at the original review of this application, Members had recommended a separate submission for the professional group. However, in order not to lengthen the process unnecessarily, and in view of the fact that the amendment was detailed and questions posed to staff appeared harmless, this amendment was approved.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	Professional group - 1	31 August 2009
Participant Consent Form: Professional group	1	31 August 2009
Participant Information Sheet: Professional group	1	31 August 2009
Protocol	4	25 September 2009
Notice of Substantial Amendment (non-CTIMPs)	1	25 September 2009

Appendix D – Ethical approval for substantial amendment 2



National Research Ethics Service

County Durham & Tees Valley 2 Research Ethics Committee

The Tatchell Centre
University Hospital of North Tees
Piperknowle Road
Stockton-on-Tees
TS19 8PE

Tel: 01642 624164
Fax: 01642 624164

15 February 2010

Miss Rachel A Green
Clinical Fellow
School of Dental Sciences
Newcastle University
Framlington Place
Newcastle-Upon-Tyne
NE2 4BW

Dear Miss Green

Study title: Patient and professional views of experience and management of oral precancer
REC reference: 08/H0908/77
Amendment number: 2
Amendment date: 31 January 2010
Reason for substantial Amendment request: Addition of recruitment via post

The above amendment was reviewed on 12 February 2010 by the Sub-Committee in correspondence.

Ethical opinion

The Members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letter of invitation to participant	1	31 January 2010
Protocol	5	31 January 2010
Notice of Substantial Amendment (non-CTIMPs)	2	31 January 2010



**Attendance at an Oral and Maxillofacial outpatient clinic –
Patients' views and experience of care**

You are being invited to take part in a research study. Before you decide if you want to take part 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 study will ask people attending an out-patient oral and maxillofacial clinic about their experiences of care in this setting. It is designed to explore how people feel about their mouth condition and their treatment. We will do this by talking to a number of patients who attend this type of clinic. It is hoped that this information will be used to provide future patients helpful information and manage them more effectively.

Why have I been chosen for the study?

Over the last few months or years, you have been treated at Newcastle General Hospital. We would be interested in hearing about your experiences. Altogether 20 patients who attend this clinic will be invited to participate.

Do I have to take part?

It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time

What will happen to me if I take part?

If you decide to take part a researcher will contact you to arrange a convenient time for an interview. Think of this as an informal discussion. This discussion will take around 1 hour. This is all the time we ask of you to take part in the study.

There is a quiet room available for this discussion next to the clinic you normally attend, if you prefer the discussion may be carried out away from the hospital in your own home. The researcher will record the discussion on a small portable digital recorder. This is to make sure that we don't miss anything important that you have to say.

What do I have to do?

If you wish to take part please fill out and return the enclosed form. Once we have received this form from you a researcher will contact you to organise an interview.

What are the possible risks of taking part?

There are no perceived risks in taking part in the study. However, some people may not feel comfortable discussing their mouth problems in front of others.

What are the possible benefits of taking part?

It is hoped that the information that is gained from this study may give us a greater understanding of the issues people face when attending these clinics for diagnosis or management of oral conditions. We cannot guarantee that your participation in this study will be of direct benefit to you.

What will happen to the recordings and written copies of the interviews?

The information we collect from the interview will be transcribed (a written copy made) and analysed by the research team. This information is treated as confidential and the written copies of the interviews will be made anonymous so that it will not be possible to identify you as an individual from these written copies. These copies will be stored securely in a locked filing cabinet and no one outside the research team will have access to your information.

What will happen if I don't want to carry on with the study?

You are free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive in any way.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions (contact telephone number 0191 2228396). If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital.

Will my taking part in this study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential. The written copies of the interviews will have your name and address removed so that you cannot be recognised from it.

Who is organising and funding the research?

This study has been organised by the School of Dental Sciences - Newcastle University.

Who has reviewed the study?

The study has been reviewed by County Durham and Tees Valley 2 Research Ethics Committee.

Researcher Contact for Further Information

Miss Rachel Green
Newcastle University
Framlington Place
Newcastle upon Tyne
NE2 4BW

Tel: 0191 2228396

Appendix F. Professional information sheet



Professional views and experience of oral precancer

You are being invited to take part in the above study.

What is the purpose of the study?

This study builds on work being undertaken with patients who have been diagnosed with a potentially malignant oral lesion. That study looked at views and experience of oral potential malignancy from the patient's point of view.

We are now planning to conduct a study to find out professional views of the same condition. Specifically we are interested in information surrounding diagnosis, risk factors and treatment options and practices. We are interested in speaking to a variety of professionals involved in the care of these patients. It is hoped that the information gained from the study will be used to provide future patients helpful information, enabling them to be managed more effectively.

Why have I been chosen for the study?

As someone who is involved in the care of people with oral premalignancy, we would be interested in hearing your views. Altogether 20 clinical staff will be invited to participate.

Do I have to take part?

There is no obligation to take part. If you decide to take part you are still free to withdraw at any time

What will happen to me if I take part?

If you decide to take part a researcher will contact you to arrange a convenient time for an interview. This is usually done over the telephone. However, it may be possible to arrange an alternative location depending on your location. This discussion may take around 1 hour. The interviews will be audio recorded. This is all the time we ask of you to take part in the study.

What do I have to do?

If you wish to take part please fill out and return the enclosed form. Once we have received this form from you a researcher will contact you to organise an interview.

What will happen to the recordings and written copies of the interviews?

The audio recordings will be transcribed to aid data analysis. The transcripts will be anonymised, so that it is not possible to identify you. All information will be stored securely, with no one outside the research team having access to your information.

Who is organising and reviewed the research?

This study has been organised by the School of Dental Sciences - Newcastle University, it has reviewed by County Durham and Tees Valley 2 Research Ethics Committee.

Appendix G. Topic guide for patient interviews

Opening question

“Just to get things started, can you tell me a little bit about yourself, your age, family, job that sort of thing?”

SECTION 1. EXPERIENCE OF CARE

- **Understanding of disease**

What has your doctor told you about your condition?

What do you understand by your diagnosis?

Was there anything you didn't understand about what you were told?

Was there anyone else who gave you any information about your diagnosis?

How do you feel about the way you were given your diagnosis?

In your opinion, could this have been improved in any way?

Did you have any questions for your doctor at the time?

Did you feel satisfied with the answers you received?

Who do you think should give you this information?

Did you look for information outside of the clinic (for example, from friends and family or sources such as the internet)?

Was it helpful?

Did your doctor give you advice about looking for further information?

- **Treatment**

Have you received any treatment for your condition?

If yes –

How did you decide that this treatment that was best for you?

Looking back do you feel at the time you understood what these treatments would involve?

Who explained what would happen to you?

Can you tell me what you were told?

Is there anything that could have been improved about the explanation of the treatment?

Who do you feel is best to give this information?

Is there anything you would change about your treatment?

If no -

How did you decide that this type of management was best for you?

Can you tell me what you were told?

Looking back is there anything that could have been improved about the explanation of this type of management?

Who do you feel is best to give this information?

How do you feel about this choice of management now?

SECTION 2. IMPACT ON EVERYDAY LIFE

- **Affect on day to day living**

Do you find that having this disease makes any difference to your life?

Do you feel that you are prevented from doing normal things because of it?

Does having this disease mean that you don't do anything that you used to?

Have you told your friends and family about your mouth condition?

How did you explain it to them? What did you say?

How did they react?

- **Behaviour changes**

Did your doctor make you aware of anything you can do to improve your condition?
(particularly smoking and drinking?)

What did they say to you?

What did you feel about this advice?

Did you believe it?

Have you made any changes to your lifestyle since receiving this diagnosis?

If yes –

Did you find these changes easy?

Was there any support available to you to help with these changes? Did you use it, was it helpful?

Did someone tell you about support services? Who?

If no -

Why not?

Please note this is sheet is for guidance only

Appendix H. Topic guide for clinician interviews

Opening question

“Just to get things started, can you tell me a little bit about your involvement in the management of patients with oral precancer?”

SECTION 1. DIAGNOSIS OF ORAL PRECANCER

What terminology do you use to describe oral precancer or potential malignancy?

If I was a patient with oral precancer how would you explain the diagnosis of oral precancer to a me?

Do you think it is a difficult diagnosis to explain?

Do you think patients understand their diagnosis?

Other than yourself, are there any other sources of information you recommended to patients?

Do you think it makes any difference who delivers the information to the patients?

SECTION 2. EXPERIENCE OF BEHAVIOUR CHANGE

How do you broach the subject of risk factors with patients?

How do patients react to this?

What steps are taken to assist patients with changes in their behaviour?

What help is available at the clinic?

What sources of help do you employ?

What do you see as the main obstacles to patients changing their behaviour?

Do you think it is part of your role to provide this sort of information?

SECTION 3. MAKING TREATMENT DECISIONS

What management options do you offer to patients with oral precancer?

What influences your decision?

How do you support patients to make treatment decisions?

How do you feel patients cope with the management option of:

- Watchful waiting
- Medical management
- Surgical management

Please note this is just sheet is for guidance only

Appendix I. Presentations

This thesis contains research which has been presented at the following academic conferences:

Patient (mis)understanding of oral potentially malignant disorders

Association of British Academic Oral and Maxillofacial Surgeons

Cardiff 11/11/10

(Awarded second prize in the verbal presentation category)

Understanding patient views and experiences of oral precancer

International Association of Dental Research

Barcelona, Spain 16/07/10

R. Green, C. Exley, P.J. Thomson, J. Steele. Understanding patient views and experience of oral precancer, J Dent Res 89 (Spec Iss A): 2571, 2010

(www.dentalresearch.org)*

Understanding the transition from primary to secondary care: experiences of patients with oral precancer

British Association of Oral and Maxillofacial Surgeons

Nice, France 23 /06 /11

R. Green, P.J. Thomson, C. Exley, J.G. Steele. 2011. Understanding the transition from primary to secondary care: experiences of patients with oral precancer. British Journal of Oral and Maxillofacial Surgery 49, Supplement 1(0):S60

*Cited in Thomson, P.J. (Ed.). 2012. Oral Precancer: Diagnosis and Management of Potentially Malignant Disorders: Wiley-Blackwell

Appendix J. Tables detailing study sample groups

Patient participant variables (Study A)		
Gender	Male	Female
	14	14
Age	Over 40	Under 40
	27	1
Risk factors (tobacco use/alcohol consumption)	Present	Not present
	26	2
Management	Surgical	Conservative
	21	7
Location	Newcastle	Sunderland
	16	12

Clinician participant variables (Study B)		
Gender	Male	Female
	11	0
Designation	Consultant (for over 10 years)	Consultant (for under 10 years)
	6	5
Specialty	OMFS	Other
	11	0
Work environment	Teaching hospital	District general hospital
	5	6

*although part of the sampling criteria, the exact location of each participant is not documented to protect the anonymity of the participants.

References

- Aitken-Swan, J., and R. Paterson. 1955. "The Cancer Patient Delay in Seeking Advice." *British Medical Journal* (1):623.
- Alcaide-Raya, A., R. Hughes, and S. Warnakulasuriya. 2010. "How well informed are our Internet savvy patients on oral premalignant disorders?" 3(4):120-28.
- Anderson, R., and D. W. Thomas. 2003. "'Toothache stories': a qualitative investigation of why and how people seek emergency dental care." *Community Dent Health* 20(2):106-11.
- Andrus, M. R., and M. T. Roth. 2002. "Health literacy: A review." *Pharmacotherapy* 22(3):282-302.
- Armfield, Jason M., Judy F. Stewart, and A. John Spencer. 2007. "The vicious cycle of dental fear: exploring the interplay between oral health, service utilization and dental fear." *BMC Oral Health* 7:1.
- Armstrong, D. 1994. *Outline of sociology as applied to medicine*: Butterworth-Heinemann.
- Axell, T. 1987. "Occurrence of leukoplakia and some other oral white lesions among 20333 adult Swedish people." *Community Dentistry and Oral Epidemiology* 15:46-51.
- Axell, T., P. Holmstrup, I. R. H. Kramer, J. J. Pindborg, and M. Shear. 1984. "International Seminar on Oral Leukoplakia and associated lesions related to tobacco habits " *Community Dentistry and Oral Epidemiology* 12(3):145-54.
- Bailey, D., M. Mishel, M. Belyea, J.L. Stewart, and J. Mohler. 2004. "Uncertainty Intervention for Watchful Waiting in Prostate Cancer." *Cancer Nursing* 27(5):339-46.
- Bailey, D., and M. Wallace. 2007. "Critical Review: Is Watchful Waiting a Viable Management Option for Older Men With Prostate Cancer." *American Journal Of Men's Health*:18-28.
- Balshem, M. 1991. "Cancer, control and causality – talking about cancer in a working-class community." *American Ethnologist* 18(1):152-72.
- Baric, J. M., J. E. Alman, R. S. Feldman, and H. H. Chauncey. 1982. "Influence of cigarette, pipe and cigar smoking, removable partial dentures and age on oral leukoplakia." *Oral Surgery Oral Medicine Oral Pathology Oral Radiology and Endodontics* 54(4):424-29.

- Barnes, L., J.W. Eveson, P.A. Reichart, and D. Sidransky. 2005. *World Health Organization classification of tumours*. Lyon, France: IARC Press.
- Barry, C. A., C. P. Bradley, N. Britten, F. A. Stevenson, and N. Barber. 2000. "Patients' unvoiced agendas in general practice consultations: qualitative study." *British Medical Journal* 320(7244):1246-50.
- Becker, M. H., and L. A. Maiman. 1975. "Sociobehavioral determinants of compliance with health and medical care recommendations." *Medical Care* 13(1):10-24.
- Bell, S., M. Porter, C. Kitchener, P. Fraser, and E. Mann. 1995. "Psychological Response to Cervical Screening." *Preventive Medicine* 24(6):610-16.
- Bensing, Jozien M., Fred Tromp, Sandra van Dulmen, Atie van den Brink-Muinen, William Verheul, and Francois G. Schellevis. 2006. "Shifts in doctor-patient communication between 1986 and 2002: a study of videotaped general practice consultations with hypertension patients." *BMC family practice* 7:62.
- Berkman, N. D., S. L. Sheridan, K. E. Donahue, D. J. Halpern, and K. Crotty. 2011. "Low Health Literacy and Health Outcomes: An Updated Systematic Review." *Annals of Internal Medicine* 155(2):97-U89.
- Bhargava, K., L. W. Smith, N. J. Mani, S. Silverman, Jr., A. M. Malaowalla, and K. F. Bilimoria. 1975. "A follow up study of oral cancer and precancerous lesions in 57,518 industrial workers of Gujarat, India." *Indian journal of cancer* 12(2):124-9.
- Blot, W.J., D.M. Winn, and J.F. Fraumeni. 1983. "Oral Cancer and mouthwash." *Journal of the National Cancer Institute* (70):251-53.
- Bogardus, S. T., E. Holmboe, and J. F. Jekel. 1999. "Perils, pitfalls, and possibilities in talking about medical risk." *Jama-Journal of the American Medical Association* 281(11):1037-41.
- Bornstein, Michael M., Marc Frei, Pedram Sendi, Christoph A. Ramseier, and Peter A. Reichart. 2012. "Patients' awareness of the potential benefit of smoking cessation. A study evaluating self-reported and clinical data from patients referred to an oral medicine unit." *Clinical Oral Investigations* 16(1):55-62.
- Bottorff, J.L., P.A. Ratner, J.L. Johnson, C.Y. Lovato, and S.A. Joab. 1998. "Communicating cancer risk information: the challenges of uncertainty." *Patient Education & Counseling* 33:67-81.
- Bouquot, J.E, and S.B Whitaker. 1994. "Oral Leukoplakia - Rationale for diagnosis and prognosis of its clinical subtypes or "phases"." *Quintessence International* 25:133-40.

- Bouquot, Jerry E., Paul M. Speight, and Paula M. Farthing. 2006. "Epithelial dysplasia of the oral mucosa—Diagnostic problems and prognostic features." *Current Diagnostic Pathology* 12(1):11-21.
- Bourhis, R. Y., S. Roth, and G. Macqueen. 1989. "Communication in the hospital setting – A survey of medical and everyday language use amongst patients, nurses and doctors." *Social Science & Medicine* 28(4):339-46.
- Brashers, D.E. 2001. "Communication and Uncertainty Management." *Journal of Communication*:477-97.
- Braun, V., and V. Clarke. 2006. "Using thematic analysis in psychology." *Qualitative Research in Psychology* 3(2):77-101.
- Brennan, M., C.A. Migliorati, and P.B. Lockhart. 2007. "Management of oral dysplasia: a review." *Oral Surgery Oral Medicine Oral Pathology Oral Radiology and Endodontics* 103:S19.e1-S.e2.
- Brennan, M., C.A. Migliorati, P.B. Lockhart, D. Wray, I. Al-Hashimi, T. Axell, A.J. Bruce, W. Carpenter, E. Eisenberg, J.B. Epstein, P. Holmstrup, M. Jontell, R. Nair, H. Sasser, M. Schifter, B. Silverman, K. Thongprasom, M. Thornhill, S. Warnakulasuriya, and I. Van der Wall. 2007. "Management of oral dysplasia: a review." *Oral Surgery Oral Medicine Oral Pathology Oral Radiology & Endodontics* 103 (suppl 1):S19.e1-S19.e12.
- Britten, N. 1995. "Qualitative research 4. Qualitative interviews in medical research " *British Medical Journal* 311(6999):251-53.
- Brocklehurst, P. R., S. R. Baker, and P. M. Speight. 2009a. "A qualitative study examining the experience of primary care dentists in the detection and management of potentially malignant lesions. 1. Factors influencing detection and the decision to refer." *British Dental Journal* 208(2).
- Brocklehurst, Paul R., Sarah R. Baker, and Paul M. Speight. 2009b. "Factors affecting the referral of potentially malignant lesions from primary dental care: a pilot study in South Yorkshire." *Prim Dent Care* 16(1):13-8.
- Brown, Rhonda F., Phyllis N. Butow, Michael Henman, Stewart M. Dunn, Francis Boyle, and Martin H. N. Tattersall. 2002. "Responding to the active and passive patient: flexibility is the key." *Health expectations : an international journal of public participation in health care and health policy* 5(3).
- Bryant, Dianne, Elzbieta Bednarski, and Amiram Gafni. 2006. "Incorporating patient preferences into orthopaedic practice: Should the orthopaedic encounter change?" *Injury* 37(4):328-34.

- Bury, M. 1982. "Chronic illness as biographical disruption." *Sociology of Health & Illness* 4:167-82.
- Caelli, K., L. Ray, and J. Mill. 2003. "'Clear as Mud': Toward Greater Clarity in Generic Qualitative Research " *International Journal Of Qualitative Methods* 2(2).
- Cameron, L., E. A. Leventhal, and H. Leventhal. 1995. "Seeking medical care in response to symptoms and life stress." *Psychosomatic Medicine* 57(1):37-47.
- Caplan, L.S., and K.J. Helzlsouer. 1992. "Delay in breast cancer: a review of the literature." *Public Health Reviews* 20:187-214.
- Cawson, R.A. 1975. "Premalignant lesions in the mouth." *British Medical Bulletin* 31:164-68.
- Chadha, N. K., and C. Repanos. 2006. "Patients' understanding of words used to describe lumps: a cross-sectional study." *Journal of Laryngology and Otology* 120(2):125-28.
- Chalfant, H.P., and R.A. Kurtz. 1971. "Alcoholics and the sick role: assessments by social workers." *Journal of Health Society and Behaviour* 12:66-72.
- Chan, Y., J. C. Irish, S. J. Wood, L. E. Rotstein, D. H. Brown, P. J. Gullane, and G. A. Lockwood. 2002. "Patient education and informed consent in head and neck surgery." *Archives of Otolaryngology-Head & Neck Surgery* 128(11):1269-74.
- Chapman, K., C. Abraham, V. Jenkins, and L. Fallowfield. 2003. "Lay understanding of terms used in cancer consultations." *Psycho-Oncology* 12(6):557-66.
- Chapple, A., S. Ziebland, and A. McPherson. 2004. "Stigma, shame, and blame experienced by patients with lung cancer: qualitative study." *British Medical Journal* 328(7454):1470-73.
- Charles, C., A. Gafni, and T. Whelan. 1997. "Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)." *Social Science & Medicine* 44(5):681-92.
- Charmaz, K. 1983. "Loss of self: a fundamental form of suffering in the chronically ill." *Sociology of Health & Illness* 5:168-95.
- Chew-Graham, C. A., C. R. May, and M. S. Perry. 2002. "Qualitative research and the problem of judgement: lessons from interviewing fellow professionals." *Family Practice* 19(3):285-89.
- Chrostowska, M., and K. Narkiewicz. 2010. "Improving Patient Compliance with Hypertension Treatment: Mission Possible?" *Current Vascular Pharmacology* 8(6):804-07.

- Clarke, K.N., and M.M. Everest. 2006. "Cancer in the mass print media: Fear, uncertainty and the medical model." *Social Science and Medicine* 62(10):2591-600.
- Coar, L., and J. Sim. 2006. "Interviewing one's peers: methodological issues in a study of health professionals." *Scandinavian Journal of Primary Health Care* 24(4):251-56.
- Colbourne, L., and M. Sque. 2005. "The culture of cancer and the therapeutic impact of qualitative research interviews." *Journal of Research in Nursing* 10(5):551-67.
- Cornford, C.S., J. Harley, and N. Oswald. 2004. "The '2-week rule' for suspected breast carcinoma: a qualitative study of the views of patients and professionals." *British Journal of General Practice* 54:584-88.
- Counts, G. (Ed.). 2010. "Tobacco Effects" Sedgwickcounty. Retrieved June 21, 2010 (http://www.sedgwickcounty.org/healthdept/tobacco_effects.asp)
- Cowan, C. G., T. A. Gregg, S. S. Napier, S. M. McKenna, and F. Kee. 2001. "Potentially malignant oval lesions in Northern Ireland: a 20-year population-based perspective of malignant transformation." *Oral Diseases* 7(1):18-24.
- Crowley, MatthewJ, JanetM Grubber, MarenK Olsen, and HaydenB Bosworth. 2013. "Factors Associated with Non-Adherence to Three Hypertension Self-Management Behaviors: Preliminary Data for a New Instrument." *Journal of General Internal Medicine* 28(1):99-106.
- D'Alessandro, D. M., C. D. Kreiter, S. L. Kinzer, and M. W. Peterson. 2004. "A randomized controlled trial of an information prescription for pediatric patient education on the Internet." *Arch Pediatr Adolesc Med* 158(9):857-62.
- Davis, T. C., M. V. Williams, E. Marin, R. M. Parker, and J. Glass. 2002. "Health literacy and cancer communication." *Ca-a Cancer Journal for Clinicians* 52(3):134-49.
- Deber, R. B., N. Kraetschmer, S. Urowitz, and N. Sharpe. 2007. "Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations." *Health Expectations* 10(3):248-58.
- Dietrich, T., P. A. Reichart, and C. Scheifele. 2004. "Clinical risk factors of oral leukoplakia in a representative sample of the US population." *Oral Oncology* 40(2):158-63.
- Department of Health. 1988. "Smoking kills: A white paper on tobacco." London: HMSO

- Department of Health. 2006. "Our health, our care, our say: a new direction for community services." edited by Department of Health.
- Department of Health. 2010. "Equity and excellence: Liberating the NHS."
- Department of Health. 2012a. "The NHS's role in the public's health. A report from the NHS future forum."
- Department of Health. 2012b. "The NHS constitution for England." edited by Department of Health.
- Dolan, R.W., C.W. Vaughan, and N. Fuleihan. 1998. "Symptoms in early head and neck cancer: An inadequate indicator." *Otolaryngology - Head and Neck Surgery* 119(5):463-67.
- Donovan, J., N. Mills, M. Smith, L. Brindle, A. Jacoby, T. Peters, S. Frankel, D. Neal, and F. Hamdy. 2002. "Improving design and conduct of randomised trials by embedding them in qualitative research: ProtecT (prostate testing for cancer and treatment) study." *British Medical Journal* 325:766-69.
- Dubayova, Tatiana, Jitse P. van Dijk, Iveta Nagyova, Jaroslav Rosenberger, Eva Havlikova, Zuzana Gdovinova, Berrie Middel, and Johan W. Groothoff. 2010. "The impact of the intensity of fear on patient's delay regarding health care seeking behavior: a systematic review." *Int J Public Health* 55(5):459-68.
- Durham, J., C. Exley, R. Wassell, and J. G. Steele. 2007. "'Management is a black art'-- professional ideologies with respect to temporomandibular disorders." *British Dental Journal* 202(11):E29; discussion 682-3.
- Eaton, M. L., and R. L. Holloway. 1980. "Patient comprehension of written drug information." *American Journal of Hospital Pharmacy* 37(2):240-43.
- Edwards, Adrian, and Glyn Elwyn. 2009. *Shared Decision-Making in Health Care*. United States: Oxford University Press.
- Elwood, S. A., and D. G. Martin. 2000. "'Placing" interviews: Location and scales of power in qualitative research." *Professional Geographer* 52(4):649-57.
- Elwyn, Glyn, Dominick Frosch, Richard Thomson, Natalie Joseph-Williams, Amy Lloyd, Paul Kinnersley, Emma Cording, Dave Tomson, Carole Dodd, Stephen Rollnick, Adrian Edwards, and Michael Barry. 2012. "Shared Decision Making: A Model for Clinical Practice." *Journal of General Internal Medicine* 27(10):1361-67.
- Elwyn, Glyn, Steve Laitner, Angela Coulter, Emma Walker, Paul Watson, and Richard Thomson. 2010. "Implementing shared decision making in the NHS." *British Medical Journal* 341.

- Epstein, J. B., M. Gorsky, D. Fischer, A. Gupta, M. Epstein, and S. Elad. 2007. "A survey of the current approaches to diagnosis and management of oral premalignant lesions." *Journal of the American Dental Association* 138(12):1555-62.
- Field, P.A., and J.M. Morse. 1989. *Nursing research: the application of qualitative approaches*. London: Chapman and Hall.
- Flattery, M.P., J.M. Pinson, L. Savage, and J. Salyer. 2005. "Living with pulmonary artery hypertension: Patients' experiences." *Heart and Lung* 34(2):99-107.
- Fontana, A., and J.A. Frey. 1994. "'Interviewing: the art of science'." in *Handbook of Qualitative Research*, edited by N.K. Denzin and Y.S. Lincoln. Thousand Oaks, CA: Sage.
- Fox, C. 2010. "Evidence summary: what do we know from qualitative research about people's care-seeking about oral health?" *British Dental Journal* 209(5):225-31.
- Fraenkel, Liana, and Sarah McGraw. 2007. "What are the essential elements to enable patient participation in medical decision making?" *Journal of General Internal Medicine* 22(5):614-19.
- Freidson, E. 1970. *Profession of Medicine*. New York: Dodds Mead.
- Frohlich, K.L., B. Poland, E. Mykhalovskiy, S. Alexander, and C. Maule. 2010. "Tobacco control and the inequitable socio-economic distribution of smoking: smokers' discourses and implications for tobacco control." *Critical Public Health* 20(1):35-46.
- Furnham, A. 1994. "Explaining health and illness - lay perceptions on current and future health, the causes of illness, and the nature of recovery." *Social Science & Medicine* 39(5):715-25.
- Fylan, F. 1998. "Screening for cervical cancer: A review of women's attitudes, knowledge, and behaviour." *British Journal of General Practice* 48(433):1509-14.
- Gandini, S., E. Negri, P. Boffetta, C. La Vecchia, and P. Boyle. 2012. "Mouthwash and Oral Cancer Risk - Quantitative Meta-analysis of Epidemiologic Studies." *Annals of Agricultural and Environmental Medicine* 19(2):173-80.
- Garcia-Retamero, Rocio, and Mandeep K. Dhimi. 2011. "Pictures speak louder than numbers: on communicating medical risks to immigrants with limited non-native language proficiency." *Health Expectations* 14:46-57.
- Gerhardt, U. 1989. *Ideas about Illness: An Intellectual and Political History of Medical Sociology*. London: Macmillan.

- Gibson, B. J., J. Drennan, S. Hanna, and R. Freeman. 2000. "An exploratory qualitative study examining the social and psychological processes involved in regular dental attendance." *Journal of Public Health Dentistry* 60(1):5-11.
- Gilbert, N. 2008. *Researching Social Life*. London: SAGE.
- Glaser, B.G. 1965. "The constant comparative methods of qualitative analysis." *Social Problems* 12(436-445).
- Goffman, E. 1963. *Stigma. Notes on the Management of Spoiled Identity* Englewood Cliffs, New Jersey: Prentice-Hall.
- Goodson, M. L., K. Sugden, S. Kometa, and P. J. Thomson. 2012. "Complications following interventional laser surgery for oral cancer and precancerous lesions." *British Journal of Oral & Maxillofacial Surgery*: 50(7): 597-600.
- Government, HM. 2011. "Healthy lives, healthy people: a tobacco control plan for England." edited by Department of Health.
- Graham, H. 1987. "Women's smoking and family health." *Social Science & Medicine* 25(1):47-56.
- Gray, N. M., L. Sharp, S. C. Cotton, L. F. Masson, J. Little, L. G. Walker, M. Avis, Z. Philips, I. Russell, D. Whynes, M. Cruickshank, C. M. Woolley, and Tombola Grp. 2006. "Psychological effects of a low-grade abnormal cervical smear test result: anxiety and associated factors." *British Journal of Cancer* 94(9):1253-62.
- Great Britain, 2006. "NHS Act." London: HMSO.
- Green, J., and N. Thorogood. 2011. *Qualitative Methods for Health Research* London: SAGE Publications Ltd.
- Guest, G., A. Bunce, and L. Johnson. 2006. "How Many Interviews Are Enough?: An Experiment with Data Saturation and Variability." *Field Methods* 18:59-82.
- Guggenheimer, J., R.S. Verbin, J.T. Johnson, C.A. Horkowitz, and E.N. Myers. 1989. "Factors Delaying the Diagnosis of Oral and Oropharyngeal Carcinomas." *Cancer* 64:932-35.
- Gupta, P. C., R. B. Bhonsle, P. R. Murti, D. K. Daftary, F. S. Mehta, and J. J. Pindborg. 1989. "An epidemiologic assessment of cancer risk in oral precancerous lesions in India with special reference to nodular leukoplakia." *Cancer* 63(11):2247-52.
- Gupta, P. C., P. R. Murti, R. B. Bhonsle, F. S. Mehta, and J. J. Pindborg. 1995. "Effect of cessation of tobacco use on the incidence of oral mucosal lesions in a 10-yr follow-up study of 12,212 users." *Oral Dis* 1(1):54-8.

- Hack, T. F., L. F. Degner, and D. G. Dyck. 1994. "Relationship between references for decisional control and illness information among women with breast cancer – A quantitative and qualitative analysis." *Social Science & Medicine* 39(2):279-89.
- Hack, T. F., L. F. Degner, P. Watson, and L. Sinha. 2006. "Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer." *Psycho-Oncology* 15(1):9-19.
- Hallowell, N. 1998. "Providing letters to patients - Patients find summary letters useful." *British Medical Journal* 316(7147):1830-30.
- Hamadah, O., S. Hepburn, and P.J. Thomson. 2007. "Effects of active non-smoking programmes on smoking behaviour in oral precancer patients." *International Journal of Oral and Maxillofacial Surgery* (36):706-11.
- Hamadah, O., and P. J. Thomson. 2009. "Factors Affecting Carbon Dioxide Laser Treatment for Oral Precancer: A Patient Cohort Study." *Lasers in Surgery and Medicine* 41(1):17-25.
- Hannay, D.R. 1980. "The 'iceberg' of illness and 'trivial' consultations." *Journal of the Royal College of General Practitioners* 30(218):551-54.
- Hashibe, M., B. J. Jacob, G. Thomas, K. Ramadas, B. Mathew, R. Sankaranarayanan, and Z. F. Zhang. 2003. "Socioeconomic status, lifestyle factors and oral premalignant lesions." *Oral Oncology* 39(7):664-71.
- Hastings, G., and N. McLean. 2006. "Social marketing, smoking cessation and inequalities." *Addiction* 101(3):303-04.
- Hebert, J. R., P. C. Gupta, R. B. Bhonsle, H. Mehta, W. Zheng, M. Sanderson, and J. Teas. 2002. "Dietary exposures and oral precancerous lesions in Srikakulam District, Andhra Pradesh, India." *Public Health Nutrition* 5(2):303-12.
- Hedestig, O., P. Sandman, and A. Widmark. 2003. "Living with untreated localized prostate cancer: A qualitative analysis of patient narratives." *Cancer Nursing* 26(1):44-60.
- Helgason, A. R., and K. E. Lund. 2002. "General practitioners' perceived barriers to smoking cessation - results from four Nordic countries." *Scandinavian Journal of Public Health* 30(2):141-47.
- Holmstrup, P., P. Vedtofte, J. Reibel, and K. Stoltze. 2006. "Long-term treatment outcome of oral premalignant lesions." *Oral Oncology* 42:461-74.
- Holmstrup, P., P. Vedtofte, J. Reibel, and K. Stoltze. 2007. "Oral premalignant lesions: is a biopsy reliable?" *Journal of Oral Pathology & Medicine* 36(5):262-66.

- Hounsgaard, Lise, Lone Kjeld Petersen, and Birthe D. Pedersen. 2007. "Facing possible illness detected through screening--experiences of healthy women with pathological cervical smears." *European Journal of Oncology Nursing* 11(5):417-23.
- Jaber M.A, Porter S.R, Gilthorpe M.S, Bedi R, and Scully C. 1999. "Risk factors for oral epithelial dysplasia - the role of smoking and alcohol." *Oral oncology* 35:151-56.
- Jackson, C.J., P. Bosio, M. Habiba, J. Waugh, P. Kamal, and M. Dixon-Woods. 2006. "Referral and attendance at a specialist antenatal clinic: qualitative study of women's views." *British journal of Obstetrics and Gynaecology* 113(8):909-13.
- Jansen, J., P. N. Butow, J. C. M. van Weert, S. van Dulmen, R. J. Devine, T. J. Heeren, J. M. Bensing, and M. H. N. Tattersall. 2008. "Does Age Really Matter? Recall of Information Presented to Newly Referred Patients With Cancer." *Journal of Clinical Oncology* 26(33):5450-57.
- Johnson, N. W., S. Warnakulasuriya, and M. Tavassoli. 1996. "Hereditary and environmental risk factors; clinical and laboratory risk markers for head and neck, especially oral cancer and precancer." *European Journal of Cancer Prevention* 6:5-17.
- Jones, R. B., J. Pearson, A. J. Cawsey, D. Bental, A. Barrett, J. White, C. A. White, and W. H. Gilmour. 2006. "Effect of different forms of information produced for cancer patients on their use of the information, social support, and anxiety: randomised trial." *British Medical Journal* 332(7547):942-46A.
- Juraskova, I., P. Burtow, L. Sharpe, and M. Campion. 2007. "'What does it mean?' Uncertainty, trust and communication following treatment for pre-cancerous cervical abnormalities." *Psycho-Oncology* 16:525-33.
- Kahn, R.L., and C.F. Cannell. 1957. *The dynamics of interviewing; theory, technique and cases*. Oxford, England: John Wiley and Sons.
- Kalliala, Ilkka, Tadeusz Dyba, Pekka Nieminen, Timo Hakulinen, and Ahti Anttila. 2010. "Mortality in a long-term follow-up after treatment of CIN." *International Journal of Cancer* 126(1):224-31.
- Kanatas, A. N., S. E. Fisher, D. Lowe, T. K. Ong, D. A. Mitchell, and S. N. Rogers. 2011. "The configuration of clinics and the use of biopsy and photography in oral premalignancy: a survey of consultants of the British Association of Oral and Maxillofacial Surgeons." *British Journal of Oral & Maxillofacial Surgery* 49(2):99-105.

- Karabulut, A., J. Reibel, M. H. Therkildsen, F. Praetorius, H. W. Nielsen, and E. Dabelsteen. 1995. "Observer variability in the histologic assessment of oral premalignant lesions." *Journal of Oral Pathology & Medicine* 24(5):198-200.
- Karasz, Alison, M. Diane McKee, and Krista Roybal. 2003. "Women's experiences of abnormal cervical cytology: illness representations, care processes, and outcomes." *Annals of Family Medicine* 1(4):196-202.
- Kavanagh, A. M., and D. H. Broom. 1997. "Women's Understanding of Abnormal Cervical Smear Test Results: A Qualitative Interview Study." *British Medical Journal* 314:1388-91.
- Kavanagh, A. M., and D. H. Broom. 1997 1998. "Embodied Risk: My Body, Myself? ." *Social Science & Medicine* 43(3):437-44.
- Kelly, M.P., and D Field. 1996. "Medical sociology, chronic illness and the body." *Sociology of Health & Illness* 18(2):241-57.
- Kessels, R. P. C. 2003. "Patients' memory for medical information." *Journal of the Royal Society of Medicine* 96(5):219-22.
- Khan, Z., F. Appleton, and J. Turner. 2008. "Is cervical intra-epithelial neoplasia symptomatic?" *Journal of Obstetrics & Gynaecology* 28(3):336-37.
- Kramer, I. R. H., R. B. Lucas, J. J. Pindborg, L. H. Sobin, J. Banoczy, W. Hahn, J. E. Hamner, F. S. Mehta, W. G. Shafer, and et al., 1978. "Definition of leukoplakia and related lesions an aid to studies on oral precancer." *Oral Surgery Oral Medicine Oral Pathology* 46(4):518-39.
- Kugaya, A., T. Akechi, T. Okuyama, T. Nakano, I. Mikami, H. Okamura, and Y. Uchitomi. 2000. "Prevalence, predictive factors, and screening for psychologic distress in patients with newly diagnosed head and neck cancer." *Cancer* 88(12):2817-23.
- Kulasegaram, M.C., M.C. Downer, J.A. Jullien, J.M. Zakrzewska, and P. M. Speight. 1995. "Case-control study of oral dysplasia and risk habits among patients of a dental hospital." *Oral Oncology* 31B:227-31.
- Kumar, Anand, Luke Cascarini, James A. McCaul, Cyrus J. Kerawala, Darryl Coombes, Daryl Godden, and Peter A. Brennan. 2013. "How should we manage oral leukoplakia?" *British Journal of Oral and Maxillofacial Surgery* 51(5):377-83.
- Lamey, P. J. 1993. "Management options in potentially malignant and malignant oral epithelial lesions." *Community dental health* 10 Suppl 1:53-62.
- Last, JM 1963. "The iceberg: "completing the clinical picture" in general practice. ." *Lancet*:28-31

- Lee, R.M., and C.M. Renzetti. 1993. *Researching sensitive topics*: SAGE Publications.
- Legare, F., S. Ratte, K. Gravel, and I. D. Graham. 2008. "Barriers and facilitators to implementing shared decision-making in clinical practice: Update of a systematic review of health professionals' perceptions." *Patient Education and Counseling* 73(3):526-35.
- Lerman, C., S. M. Miller, R. Scarborough, P. Hanjani, S. Nolte, and D. Smith. 1991. "Adverse psychologic consequences of positive cytologic cervical screening." *American Journal of Obstetrics and Gynecology* 165(3):658-62.
- Lerner, E. B., D. V. K. Jehle, D. M. Janicke, and R. M. Moscati. 2000. "Medical communication: Do our patients understand?" *American Journal of Emergency Medicine* 18(7):764-66.
- Lewis, J, and J Ritchie. 2003. *Qualitative research practice: A guide for social science researchers*. London: SAGE.
- Lewis, P.A., M. Charny, D. Lambert, and J. Coombes. 1989. "A fatalistic attitude to health amongst smokers in Cardiff." *Health Education Research* 4(3):361-65.
- Ley, P. 1979. "Memory for medical information " *British Journal of Social and Clinical Psychology* 18(JUN):245-55.
- Lind, P.O. 1987. "Malignant transformation in oral leukoplakia." *Scandinavian Journal of Dental Research* (95):449-55.
- Lipkus, I. M. 2007. "Numeric, verbal, and visual formats of conveying health risk: Suggested best practices and future recommendations." *Medical Decision Making* 27(5):696-713.
- Lipkus, I. M., G. Samsa, and B. K. Rimer. 2001. "General performance on a numeracy scale among highly educated samples." *Med Decis Making* 21(1):37-44.
- Lippman, S.M., J.G. Batsakis, B.B. Toth, R.S. Weber, Lee J.J., J.W. Martin, G.L. Hays, H. Goepfert, and W.K. Hong. 1993. "Comparison of low-dose isotretinoin with beta carotene to prevent oral carcinogenesis." *New England Journal of Medicine* (328):15-20.
- Lodi, G., A. Sardella, C. Bez, F. Demarosi, and A. Carrassi. 2008. "Interventions for treating oral leukoplakia." *Cochrane Database of Systematic Reviews* (4).
- Lodi, G., C. Scully, M. Carrozzo, M. Griffiths, P. B. Sugerman, and K. Thongprasom. 2005. "Current controversies in oral lichen planus: Report of an international consensus meeting. Part 2. Clinical management and malignant transformation." *Oral Surgery Oral Medicine Oral Pathology Oral Radiology and Endodontology* 100(2):164-78.

- Lodi, Giovanni, and Stephen Porter. 2008. "Management of potentially malignant disorders: evidence and critique." *Journal of Oral Pathology & Medicine* 37(2):63-69.
- Lodi, G., Sardella, A., Bez, C., Demarosi, F., Carrassi, A. 2006. "Interventions for treating oral leukoplakia." *Cochrane Database of Systematic Reviews* 4.
- Lowes, L., and P. Gill. 2006. "Participants' experiences of being interviewed about an emotive topic." *Journal of Advanced Nursing* 55(5):587-95.
- Lowry, R. J., and M. A. Craven. 1999. "Smokers and drinkers awareness of oral cancer: a qualitative study using focus groups." *British Dental Journal* 187(12):668-70.
- Lowry, R. J., S. Hardy, C. Jordan, and G. Wayman. 2004. "Using social marketing to increase recruitment of pregnant smokers to smoking cessation service: a success story." *Public Health* 118(4):239-43.
- Lumerman, H., P. Freedman, and S. Kerpel. 1995. "Oral epithelial dysplasia and the development of invasive squamous cell carcinoma." *Oral Surgery Oral Medicine Oral Pathology Oral Radiology and Endodontics* 79(3):321-29.
- MacLeod, C., and I.L. Cohen. 1993. "Anxiety and the interpretation of ambiguity: A text comprehension study." *Journal of Abnormal Psychology* 102(2):238-47.
- Marley, J. J., C. G. Cowan, P. J. Lamey, G. J. Linden, N. W. Johnson, and Kaas Warnakulasuriya. 1996. "Management of potentially malignant oral mucosal lesions by consultant UK oral and maxillofacial surgeons." *British Journal of Oral & Maxillofacial Surgery* 34(1):28-36.
- Marley, J.J., G.J. Linden, C.G. Cowan, P-J. Lamey, N.W. Johnson, K.A.A.S. Warnakulasuriya, and C. Scully. 1998. "A comparison of the management of potentially malignant oral mucosal lesions by oral medicine practitioners and oral and maxillofacial surgeons in the UK." *Journal of Oral Pathology and Medicine* 27(10):489-95.
- Marshall, C., and G.B. Rossman. 2006. *Designing qualitative research* London: SAGE.
- Marshall, J. R., and P. Boyle. 1996. "Nutrition and oral cancer." *Cancer Causes & Control* 7(1):101-11.
- Martinez, R. G. 2005. "'What's wrong with me?': cervical cancer in Venezuela - living in the borderlands of health, disease, and illness." *Social Science & Medicine* 61(4):797-808.
- Maserejian, N. N., K. J. Joshipura, B. A. Rosner, E. Giovannucci, and A. I. Zavras. 2006. "Prospective study of alcohol consumption and risk of oral premalignant lesions in men." *Cancer Epidemiology Biomarkers & Prevention* 15(4):774-81.

- Mashberg, A., and A. M. Samit. 1989. "Early detection, diagnosis and management of oral and oropharyngeal cancer." *Cancer Journal for Clinicians* 39(2):67-88.
- Mays, N., and C. Pope. 1995. "Qualitative Research: Rigour and qualitative research." *British Medical Journal* 311:109-12.
- Mays, N., and C. Pope. 1995. 2000. "Qualitative research in health care Assessing quality in qualitative research " *British Medical Journal* 320:50-2.
- McDowell, L. 1998. "Elites in the City of London: some methodological considerations." *Environment and Planning A* 30(12):2133-46.
- McNair, R., A. Taft, and K. Hegarty. 2008. "Using reflexivity to enhance in-depth interviewing skills for the clinician researcher." *Bmc Medical Research Methodology* 8:6.
- Malterud, K. 2001. "Qualitative research: standards, challenges, and guidelines." *The lancet* 358(9280):483-488
- Meana, M., D. E. Stewart, G. M. Lickrish, J. Murphy, and B. Rosen. 1999. "Patient preference for the management of mildly abnormal Papanicolaou smears." *Journal of Womens Health & Gender-Based Medicine* 8(7):941-47.
- Mechanic, D. 1962. "The concept of illness behaviour." *Journal of Chronic Disease* 15:189-94.
- Mechanic, D. 1978a. *Medical Sociology*. New York: Free Press.
- Mechanic, D. 1978b. "Sex, illness, illness behaviour, and the use of health services." *Social Science & Medicine* 12B:207-14.
- Mechanic, D, and E.H Volkart. 1960. "Illness behaviour and medical diagnosis." *Journal of Health and Human Behaviour* 1:86-94.
- Mehanna, Hisham M., Tim Rattay, Joel Smith, and Christopher C. McConkey. 2009. "Treatment and follow-up of oral dysplasia – a systematic review and meta-analysis." *Head and Neck-Journal for the Sciences and Specialties of the Head and Neck* 31(12):1600-09.
- Mehta, F. S., J. J. Pindborg, P. C. Gupta, and D.K. Daftary. 1969. "Epidemiologic and histologic study of oral cancer and leukoplakia among 50,915 villagers in India." *Cancer* 24:832-49.
- Mehta, F.S., B.C. Shroff, P.C. Gupta, and D.K. Daftary. 1972. "Oral Leukoplakia in relation to tobacco habits. A ten-year follow-up study of Bombay policemen." *Oral Surgery Oral Medicine Oral Pathology* 34:426-33.

- Melnikow, J., M. Kuppermann, S. Brich, B. Chan, and J. Nuovo. 2002. "Management of the low-grade abnormal Pap smear: What are women's preferences?" *The Journal of Family Practice* 51(10):849-55.
- Metz, James M., Pamela Devine, Albert DeNittis, Heather Jones, Margaret Hampshire, Joel Goldwein, and Richard Whittington. 2003. "A multi-institutional study of Internet utilization by radiation oncology patients." *International Journal of Radiation Oncology*Biological*Physics* 56(4):1201-05.
- Miles, Anne, Sanne Voorwinden, Sarah Chapman, and Jane Wardle. 2008. "Psychologic predictors of cancer information avoidance among older adults: The role of cancer fear and fatalism." *Cancer Epidemiology Biomarkers & Prevention* 17(8):1872-79.
- Mirbod, S. M., and S.I Ahing. 2000. "Tobacco-Associated Lesions of the Oral Cavity: Part 1. Nonmalignant Lesions." *Journal of The Canadian Dental Association* 66(5):252-56.
- Mishel, M. H. 1999. "Uncertainty in chronic illness." *Annu Rev Nurs Res* 17:269-94.
- Moorecroft, C., J. Cantrill, and M.P. Tully. 2004. "Can in-depth research interviews have a 'therapeutic' effect for participants?." *International Journal of Pharmacy Practice* 12(4):247-54.
- Morse, D.E., R.V. Katz, D.G. Pendrys, T.R. Holford, D.J. Krutchkoff, E. Eisenberg, D. Kosis, and Mayne. S.T. 1996. "Smoking and drinking in relation to oral epithelial dysplasia." *Cancer, Epidemiology, Biomarkers and Prevention* 10:769-77.
- Morse, D.E., W.J. Psoter, D. Cleveland, D. Cohen, M. Mohit-Tabatabai, D.L. Kosis, and E. Eisenberg. 2007. "Smoking and drinking in relation to oral cancer and oral epithelial dysplasia." *Cancer Causes Control* 18:919-29.
- Moscicki, Anna-Barbara, Yifei Ma, Charles Wibbelsman, Teresa M. Darragh, Adaleen Powers, Sepideh Farhat, and Stephen Shiboski. 2010. "Rate of and Risks for Regression of Cervical Intraepithelial Neoplasia 2 in Adolescents and Young Women." *Obstetrics and Gynecology* 116(6):1373-80.
- Murti, P. R., R. B. Bhonsle, J. J. Pindborg, D. K. Daftary, P. C. Gupta, and F. S. Mehta. 1985. "Malignant transformation rate in oral submucous fibrosis over a 17-year period." *Community Dentistry and Oral Epidemiology* 13(6):340-41.
- Muzzin, L. J., N. J. Anderson, A. T. Figueredo, and S. O. Gudelis. 1994. "The Experience of Cancer." *Social Science & Medicine* 38(9):1201-08.

- Nankivell, P., and H. Mehanna. 2011. "Oral Dysplasia: Biomarkers, Treatment, and Follow-up." *Current Oncology Reports* 13(2):145-52.
- Napier, S.S., and P.M. Speight. 2008. "Natural history of potentially malignant oral lesions and conditions: an overview of the literature." *Journal of Oral Pathology and Medicine* 37(1):1-10.
- Nason, R. W., A. Binahmed, K. A. Pathak, A. A. Abdoh, and G. K. B. Sandor. 2009. "What is the adequate margin of surgical resection in oral cancer?" *Oral Surgery Oral Medicine Oral Pathology Oral Radiology and Endodontology* 107(5):625-29.
- Navon, L., and A. Morag. 2004. "Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer." *Social Science & Medicine* 58(11):2337-47.
- Neal, R. D., and V. L. Allgar. 2005. "Sociodemographic factors and delays in the diagnosis of six cancers: analysis of data from the 'National Survey of NHS Patients: Cancer'." *British Journal of Cancer* 92(11):1971-75.
- Nettleton, S., I. Watt, L. O'Malley, and P. Duffey. 2005. "Understanding the narratives of people who live with medically unexplained illness." *Patient Education & Counseling* 56:205-10.
- Neville, B.W., and T.A. Day. 2002. "Oral Cancer and Precancerous Lesions." *CA Cancer Journal for Clinicians* 52:195-215.
- NICE. 2011. "Hypertension: Clinical management of hypertension in adults." NICE.
- NICE. 2008. "NICE public health intervention guidance - Brief interventions and referral for smoking cessation in primary care and other settings."
- Nicholls, D. 2009. "Qualitative Research Part One - Philosophies." *International Journal of Therapy and Rehabilitation* 16(10):526-33.
- Niederdeppe, J., and A.G. Levy. 2007. "Fatalistic Beliefs about Cancer Prevention and Three Prevention Behaviours." *Cancer Epidemiology Biomarkers & Prevention* 16(5):998-1003.
- Norum, J., A. Grev, M. A. Moen, L. Balteskard, and K. Holthe. 2003. "Information and communication technology (ICT) in oncology. Patients' and relatives' experiences and suggestions." *Supportive Care in Cancer* 11(5):286-93.
- NRES.
- Nuttall, N. M., J. G. Steele, C. M. Pine, D. White, and N. B. Pitts. 2001. "The impact of oral health on people in the UK in 1998." *British Dental Journal* 190(3):121-26.

- Ong, L. M. L., Jcjm Dehaes, A. M. Hoos, and F. B. Lammes. 1995. "Doctor-patient communication – A review of the literature " *Social Science & Medicine* 40(7):903-18.
- Pampel, F. C. 2002. "Inequality, diffusion, and the status gradient in smoking." *Social Problems* 49(1):35-57.
- Parker, R., and P. Aggleton. 2003. "HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action." *Social Science & Medicine* 57(1):13-24.
- Parsons, T. 1951. *The Social System*. New York: Free Press.
- Pau, A.K.H., R. Croucher, and W. Marcenes. 2000. "Perceived inability to cope and care-seeking in patients with toothache: a qualitative study." *British Dental Journal* 189(9):503-06.
- Pavia, M., C. Pileggi, C. G. A. Nobile, and I. F. Angelillo. 2006. "Association between fruit and vegetable consumption and oral cancer: a meta-analysis of observational studies." *American Journal of Clinical Nutrition* 83(5):1126-34.
- Pill, R., and N. C. H. Stott. 1982. "Concepts of illness causation and responsibility – some preliminary data from a sample of working-class mothers." *Social Science & Medicine* 16(1):43-52.
- Pindborg, J. J., J. Reibel, and P. Holmstrup. 1985. "Subjectivity in evaluating oral epithelial dysplasia, carcinoma in situ and initial carcinoma." *Journal of Oral Pathology & Medicine* 14:698-708.
- Pindborg, J. J., P. A. Reichart, C.J. Smith, and I. Van der Waal. 1997. "Histological Typing of Cancer and Precancer of the Oral Mucosa."
- Pitiyage, Gayani, W. M. Tilakaratne, Mahvash Tavassoli, and Saman Warnakulasuriya. 2009. "Molecular markers in oral epithelial dysplasia: review." *Journal of Oral Pathology & Medicine* 38(10):737-52.
- Poate, T.W.J, and K.A.A.S. Warnakulasuriya. 2006. "Effective management of smoking in an oral dysplasia clinic in London." *Oral Diseases* 12:22-26.
- Poh, Catherine F., Samson Ng, Kenneth W. Berean, P. Michele Williams, Miriam P. Rosin, and Lewei Zhang. 2008. "Biopsy and histopathologic diagnosis of oral premalignant and malignant lesions." *Journal of The Canadian Dental Association* 74(3):283-88.
- Poole, K., K. Hood, B. D. Davis, I. J. Monypenny, H. Sweetland, D. J. T. Webster, K. Lyons, and R. E. Mansel. 1999. "Psychological distress associated with waiting for results of diagnostic investigations for breast disease." *Breast* 8(6):334-38.

- Popay, J., and G Williams. 1996. "Public health research and lay knowledge." *Social Science & Medicine* 42(5):759-68.
- Popay, J., G. Williams, C. Thomas, and T. Gatrell. 1998. "Theorising inequalities in health: the place of lay knowledge." *Sociology of Health & Illness* 20(5):619-44.
- Pope, C., and N. Mays. 1995. "Reaching the Parts Other Methods Cannot Reach - an Introduction to Qualitative Methods in Health and Health-Services Research." *British Medical Journal* 311(6996):42-45.
- Pope, C., and N. Mays. 1995 2006. *Qualitative research in health care*. Oxford: Blackwell.
- Posner, T., and M. Vessey. 1988. *Prevention and Cervical Cancer: The Patients View*: King Edwards Hospital Fund for London.
- Powe, B. D., and S. Weinrich. 1999. "An intervention to decrease cancer fatalism among rural elders." *Oncology Nursing Forum* 26(3):583-8.
- Preston, C., F. Cheater, R. Baker, and H. Hearnshaw. 1999. "Left in limbo: patients' views on care across the primary/secondary interface." *Quality in Health Care* 8(1):16-21.
- Ptacek, J. T., and T. L. Eberhardt. 1996. "Breaking bad news - A review of the literature." *Jama-Journal of the American Medical Association* 276(6):496-502.
- Rajaram, S. S., J. Hill, C. Rave, and B. F. Crabtree. 1997. "A biographical disruption: the case of an abnormal pap smear." *Health Care Women Int* 18(6):521-31.
- Ramseier, C.A., S. Warnakulasuriya, I.G. Needleman, J.E. Gallagher, and A. Lahtinen. 2010. "Consensus Report: 2nd European Workshop on Tobacco Use Prevention and Cessation for Oral Health Professionals." *International Dental Journal* 60:3-6.
- Rapley, T. 2010. "Some pragmatics of Data Analysis." in *Qualitative Research: Theory, Method and Practice*, edited by D. Silverman. London: Sage.
- Reibel, J. 2003. "Prognosis of oral pre-malignant lesions: significance of clinical, histopathological and molecular biological characteristics." *Critical Reviews in Oral & Medicine* 14:47-62.
- Reichart, P.A. 2001. "Identification of risk groups for oral precancer and preventive measures." *Clinical Oral Investigations* 5(4):207-13.
- Richards, H., and C. Emslie. 2000. "The 'doctor' or the 'girl from the University'?" Considering the influence of professional roles on qualitative interviewing." *Family Practice* 17(1):71-75.

- Richardson, J.C., B.N. Ong, and J. Sim. 2006. "Is chronic widespread pain biographically disruptive?" *Social Science & Medicine* 63:1573-85.
- Risberg, T., S. W. Sorbye, J. Norum, and E. A. Wist. 1996. "Diagnostic delay causes more psychological distress in female than in male cancer patients." *Anticancer Research* 16(2):995-99.
- Ritchie, J., and J. Lewis. 2003. *Qualitative research practice*. London: SAGE publications.
- Rodrigues, V.C., and H. Tuomainen. 1998. "Oral cancer in the UK: to screen or not to screen." *Oral Oncology* 34:454-65.
- Roed-Petersen, B. 1982. "Effect on oral leukoplakia of reducing or ceasing tobacco smoking." *Acta Dermato Venereologica* 62(2):164-67.
- Röing, Marta, Jan-Michael Hirsch, and Inger Holmstrom. 2007. "The uncanny mouth - a phenomenological approach to oral cancer." *Patient Education & Counseling* 67(3):301-6.
- Rozniatowski, O., M. Reich, Y. Mallet, N. Penel, C. Fournier, and J. L. Lefebvre. 2005. "Psychosocial factors involved in delayed consultation by patients with head and neck cancer." *Head and Neck-Journal for the Sciences and Specialties of the Head and Neck* 27(4):274-80.
- Rutten, Lila J. Finney, Neeraj K. Arora, Alexis D. Bakos, Noreen Aziz, and Julia Rowland. 2005. "Information needs and sources of information among cancer patients: a systemic review of research (1980-2003)." *Patient Education & Counseling* 57:250-61.
- Ryan, G.W., and H.R. Bernard. 2000. "Data management and analysis methods." in *Handbook of qualitative research*, edited by N.K. Denzin and Y.S. Lincoln: Sage.
- Saito, T., C. Sugiura, A. Hirai, K. Notani, Y. Totsuka, M. Shindoh, T. Kohgo, and H. Fukuda. 1999. "High malignant transformation rate of widespread multiple oral leukoplakias." *Oral Diseases* 5(1):15-19.
- Scambler, A., G. Scambler, and D. Craig. 1981. "Kinship and friendship networks and women's demands for primary care." *Journal of the Royal College of General Practitioners* 31(233):746-50.
- Scambler, G. 2003. *Sociology as applied to medicine*. Edinburgh: Saunders.
- Schuller, A. A., T. Willumsen, and D. Holst. 2003. "Are there differences in oral health and oral health behavior between individuals with high and low dental fear?" *Community Dentistry and Oral Epidemiology* 31(2):116-21.

- Scott, S. E., E. A. Grunfeld, J. Main, and M. McGurk. 2006. "Patient delay in oral cancer: A qualitative study of patients' experiences." *Psycho-Oncology* 15(6):474-85.
- Scott, S. E., E. A. Grunfeld, and M. McGurk. 2006. "Patient's delay in oral cancer: A systematic review." *Community Dentistry and Oral Epidemiology* 34(5):337-43.
- Scott, S., M. McGurk, and E. Grunfeld. 2008. "Patient delay for potentially malignant oral symptoms." *European Journal of Oral Sciences* 116(2):141-47.
- Scott, S.E., E. Grunfeld, V. Auyeung, and M. McGurk. 2009. "Barriers and Triggers to Seeking Help for Potentially Malignant Oral Symptoms: Implications for Intervention." *Journal of Public Health Dentistry* 69(1):34-40.
- Scully, C. 1995. "Oral Precancer: Preventive and Medical Approaches to Management" *Oral Oncology* 31B:16-26.
- Shaw, I. 2002. "How lay are lay beliefs?" *Health* 6(3):287-99.
- Shinn, E., K. Basen-Engquist, L. Tao, A. Hansis-Diarte, D. Bostic, J. Martinez-Cross, A. Santos, and M. Follen. 2004. "Distress after an abnormal Pap smear result: scale development and psychometric validation." *Preventive Medicine* 39:404-12.
- Shugars, D.C., and L.L. Patton. 1997. "Detecting, diagnosing, and preventing oral cancer." *Nurse Practitioner* 22(6):109-10.
- Sieber, J. E., and B. Stanley. 1988. "Ethical and professional dimensions of socially sensitive research " *American Psychologist* 43(1):49-55.
- Sihota, S, and L Lennard. 2004. "Health Literacy: being able to make the most of health." London: National Consumer Council.
- Silverman, D. 2000. *Doing Qualitative Research*. London: SAGE.
- Silverman, Jr S. 1988. "Early diagnosis of oral cancer." *Cancer* 1988(62(8Suppl)):1119-24.
- Silverman, S., M. Gorsky, and F. Lozada. 1984. "Oral Leukoplakis and malignant transformation - A follow-up study of 257 patients" *Cancer* 53(3):563-68.
- Slaughter, D.P., H.W. Southwick, and W. Smejkal. 1953. "'Field cancerization" in oral stratified squamous epithelium. Clinical implications of multicentric origin." *Cancer* 6(5):963-68.
- Smith, L. K., C. Pope, and J. L. Botha. 2005. "Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis." *Lancet* 366(9488):825-31.
- Speight, P. M., P.M. Farthing, and J.E. Bouquot. 1996. "The pathology of oral cancer and precancer." *Current Diagnostic Pathology* 3:165-77.

- Speight, Paul M. 2007. "Update on oral epithelial dysplasia and progression to cancer." *Head and neck pathology* 1(1):61-6.
- Stacey, D., C. L. Bennett, M. J. Barry, N. F. Col, K. B. Eden, M. Holmes-Rovner, H. Llewellyn-Thomas, A. Lyddiatt, F. Legare, and R. Thomson. 2011. "Decision aids for people facing health treatment or screening decisions." *Cochrane Database of Systematic Reviews* (10).
- Sturges, J.E., and K.J. Hanrahan. 2004. "Comparing Telephone and Face-to-Face Qualitative Interviewing: a Research Note." *Qualitative Research* 4(1):107-18.
- Suls, J., P. Green, G. Rose, P. Lounsbury, and E. Gordon. 1997. "Hiding worries from one's spouse: Associations between coping via protective buffering and distress in male post-myocardial infarction patients and their wives." *Journal of Behavioral Medicine* 20(4):333-49.
- Syrjanen, S., G. Lodi, I. von Bultzingslowen, A. Aliko, P. Arduino, G. Campisi, S. Challacombe, G. Ficarra, C. Flaitz, H. M. Zhou, H. Maeda, C. Miller, and M. Jontell. 2011. "Human papillomaviruses in oral carcinoma and oral potentially malignant disorders: a systematic review." *Oral Diseases* 17:58-72.
- Thomson, A. M., S. J. Cunningham, and N. P. Hunt. 2001. "A comparison of information retention at an initial orthodontic consultation." *European Journal of Orthodontics* 23(2):169-78.
- Thomson, P. J. (Ed.). 2012. *Oral Precancer: Diagnosis and Management of Potentially Malignant Disorders*: Wiley-Blackwell.
- Thomson, P. J., and J. Wylie. 2002. "Interventional laser surgery: an effective surgical and diagnostic tool in oral precancer management." *International Journal of Oral and Maxillofacial Surgery* 31(2):145-53.
- van der Meij, E. H., H. Mast, and I. van der Waal. 2007. "The possible premalignant character of oral lichen planus and oral lichenoid lesions: A prospective five-year follow-up study of 192 patients." *Oral Oncology* 43(8):742-48.
- van der Waal, I. 2009. "Potentially malignant disorders of the oral and oropharyngeal mucosa; terminology, classification and present concepts of management." *Oral Oncology* 45(4-5):317-23.
- van der Waal, I. 2009. 2010. "Potentially malignant disorders of the oral and oropharyngeal mucosa; present concepts of management." *Oral Oncology* 46(6):423-25.
- van der Waal, I., K.P. Schepman, E.H. Van der Meij, and L.E. Smeele. 1997. "Oral leukoplakia: a clinicopathological review." *Oral Oncology* 33:291-301.

- van Oijen, M.G.C.T., and P.J. Slootweg. 2000. "Oral Field Cancerization: Carcinogen-induced Independent Events or Micrometastatic Deposits." *Cancer Epidemiology, Biomarkers & Prevention* 9:249-56.
- Walker, F.M., J. Emery, D. Braithwaite, and T.M. Marteau. 2004. "Lay Understanding of Familial Risk of Common Chronic Diseases: A Systematic Review and Synthesis of Qualitative Research." *Ann Fam Med* 2(583-594).
- Wardle, Jane, Amanda Pernet, and David Stephens. 1995. "Psychological consequences of positive results in cervical cancer screening." *Psychology & Health* 10(3):185-94.
- Warnakulasuriya, K. A. 2011. "Squamous cell carcinoma and precursor lesions: prevention." *Periodontology 2000* 57:38-50.
- Warnakulasuriya, Kaas, C. K. Harris, D. M. Scarrott, R. Watt, S. Gelbier, T. J. Peters, and N. W. Johnson. 1999. "An alarming lack of public awareness towards oral cancer." *British Dental Journal* 187(6):319-22.
- Warnakulasuriya, S. 2001. "Histological grading of oral epithelial dysplasia: revisited." *Journal of Pathology* 194:294-97.
- Warnakulasuriya, S., T. Dietrich, M.M. Bornstein, E.C. Peidro, P.M. Preshaw, C. Walter, J.L. Wennstrom, and J. Bergstrom. 2010. "Oral health risks of tobacco use and effects of cessation." *International Dental Journal* 60:7-30.
- Warnakulasuriya, S., N.W. Johnson, and I. Van der Waal. 2007. "Nomenclature and classification of potentially malignant disorders of the oral mucosa." *Journal of Oral Pathology & Medicine* 36:575-80.
- Warnakulasuriya, S., J. Reibel, J. Bouquot, and E. Dabelsteen. 2008. "Oral epithelial dysplasia classification systems: predictive value, utility, weaknesses and scope for improvement." *Journal of Oral Pathology & Medicine* 37(3):127-33.
- Warnakulasuriya, Saman. 2009. "Global epidemiology of oral and oropharyngeal cancer." *Oral Oncology* 45(4-5):309-16.
- Wei, L., S. Zheng-Yu, L. Wang, Y. Hu, S. Xue-Ming, Z. Zeng-Tong, and L. Jiang. 2011. "Malignant potential of oral and labial chronic discoid lupus erythematosus: a clinicopathological study of 87 cases." *Histopathology* (59):292-98.
- West, R., A. McNeill, and M. Raw. 2000. "Smoking cessation guidelines for health professionals: an update." *Thorax* 55(12):987-99.
- WHO. 1973. "Report of a meeting of investigators on the histological definition of precancerous lesions." Geneva.

- Williams, G. 1984. "The genesis of chronic illness: narrative re-construction." *Sociology of Health & Illness* 6(2):175-200.
- Williams, J. K., D. L. Schutte, C. A. Evers, and C. Forcucci. 1999. "Adults seeking presymptomatic gene testing for Huntington disease." *Image J Nurs Sch* 31(2):109-14.
- Williams, S.J. 2000. "Chronic illness as a biographical disruption or biographical disruption as a chronic illness? Reflections on a core concept." *Sociology of Health & Illness* 22(1):40-67.
- Winn, D.M. 2001. "Tobacco use and oral disease." *Journal of Dental Education* 65(4):306-12.
- Ybarra, Michele L., and Michael Suman. 2006. "Help seeking behavior and the Internet: A national survey." *International Journal of Medical Informatics* 75(1):29-41.
- Zain, R. B. 2001. "Cultural and dietary risk factors of oral cancer and precancer - a brief overview." *Oral Oncology* 37(3):205-10.
- Zhang, L. W., M. Williams, C. F. Poh, D. Laronde, J. B. Epstein, S. Durham, H. Nakamura, K. Berean, A. Hovan, N. D. Le, G. Hislop, R. Priddy, J. Hay, W. L. Lam, and M. P. Rosin. 2005. "Toluidine blue staining identifies high-risk primary oral premalignant lesions with poor outcome." *Cancer Research* 65(17):8017-21.
- Zide, Michael F. 2008. "Actinic Keratosis: From the Skin to the Lip." *Journal of Oral and Maxillofacial Surgery* 66(6):1162-76.
- Ziebland, S., and A. McPherson. 2006. "Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness)." *Medical Education* 40(5):405-14.
- Zola, I. K. 1973. "Pathways to the doctor-from person to patient." *Social Science & Medicine* 7(9):677-89.