

The Experience of Taste Changes during Radiotherapy for Head and Neck Cancer: A Mixed Methods Study

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SUMMARY

Problems tasting food is a common side effect of radiotherapy and chemo-radiotherapy for head and neck cancer leading to malnutrition, increased use of tube feeding and reduced quality of life. Some patients carry on eating despite taste changes whereas others report everything tastes too awful and they stop eating becoming dependent upon a feeding tube for nutrition.

This study used a mixed methods approach supported by a critical realist framework to investigate the experience of taste changes during radiotherapy for head and neck cancer. The mixed methods approach enabled a full exploration of taste changes as well as measuring the extent of taste changes and when they arise. Sixty-one patients completed the MDASI-HN questionnaire, a patient reported outcome measure, in weeks 1 and 4 of treatment, with a purposive sample of twenty-one patients going on to take part in a semi-structured interview to discuss their experience of taste changes. The interview focussed on their experience as well as timing of and how patients managed their taste changes and what motivated them to continue eating.

Seventy-seven percent of participants having radiotherapy and 88% of participants having chemo-radiotherapy developed taste changes. Participants having chemo-radiotherapy for oro-pharyngeal cancer (88%) were the group most likely to experience taste changes. Females (92%) were more likely than males (75%) to experience taste changes. Taste changes were reported sooner than participants had been warned to expect them. Participants managed taste changes with a combination of determination, individual coping style, good symptom management and having someone to share the burden. A high score for problems tasting food on the MDASI-HN was not a good indicator of who would continue to eat and who would not. Strong survival instinct, fear of losing their swallow function and avoiding tube feeding were strong motivators for those who continued eating.

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THE EXPERIENCE OF TASTE CHANGES DURING RADIOTHERAPY FOR HEAD AND NECK CANCER – A MIXED METHODS STUDY

Chapter 1

1.1 Introduction

This thesis examines the experience of taste changes in patients undergoing radiotherapy (RT) or combined chemotherapy and radiotherapy (CRT) for head and neck cancer (HNC) using a mixed methods design. As a therapeutic radiographer I am trained to care for patients with cancer and this training encompasses both technical and caring aspects. Therapeutic radiographers are unique in that they are educated to care only for patients with cancer unlike any other profession. The role is very rewarding and is split between the technical aspects of delivering accurate and precise radiotherapy to effect a cure for cancer and the patient care aspect of caring for and supporting patients throughout a course of treatment. I was a Review Radiographer for almost 20 years, focussing on the holistic care and management of patients undergoing RT and CRT, providing practical, physical and emotional support. During this time I also qualified as an Independent Prescriber enabling me to provide timely pharmaceutical support for patients to manage their treatment side effects.

More recently I have been appointed to the role of Consultant Therapeutic Radiographer for Head and Neck Cancer. My area of clinical expertise is the management of treatment side effects and I have responsibility for the management of patients undergoing RT and CRT and also for the management and recording of late toxicities for patients with HNC who have undergone non-surgical treatment. I work as part of a multidisciplinary team (MDT) which includes dieticians, speech and language therapists, nurses and doctors.

1.2 Motivation for doing the research

Problems tasting food is a very common side effect experienced by patients undergoing RT for HNC. Studies report that up to 95% of patients undergoing RT for HNC report some degree of altered taste formally termed dysgeusia (Irvine et al,

2014; Ruo Redda and Allis, 2006). The experience of altered taste is poorly understood from the patient perspective, with some members of staff and carers alike wondering why the patient cannot “just eat anyway”, despite the patient reporting that everything tastes awful. Problems with tasting food lead to reduced appetite, weight loss and malnutrition making it difficult for the patient to tolerate treatment (Bressan et al, 2017; Shi et al, 2004; Semba et al, 1994). When considering how to design this research I was certain that I wanted to be better placed to advise patients on how to manage problems with altered taste. I often sit in clinic and hear members of the MDT telling patients that “there is nothing we can do” to help their taste changes, before moving on to deal with a symptom that is easier to manage such as nausea or pain. This has made me feel dissatisfied as I feel that problems with taste changes have been dismissed. I can only imagine how that might feel for the patient to have their concern ignored and swept aside.

Reflecting on my role as Therapeutic Radiographer, in particular the dual aspects of the role; I could see similarities with the phenomenon of taste changes. The physical manner of radiation causing damage to taste buds is the same for each patient; however, the way taste changes are experienced by each individual patient is very different. It is this individual perception that I was especially interested to uncover and learn from, as in clinical practice some patients appear to tolerate taste changes associated with RT better than others. In particular, I was interested to learn why some patients continue to eat despite these taste changes whereas others find the taste of food so repulsive they cannot imagine putting food in their mouth. The latter then become dependent upon tube feeding.

While working on an assignment for my Professional Doctorate I came across the following quote. McCarthy-Leventhal (1959), a doctor and accomplished cook, who also had head and neck cancer, writing from personal experience, described taste changes at the end of radiotherapy as “blindness of the mouth” and of staff failing to understand the difference between “food” and “diet”. She goes on to explain the impact of this on the patient: “Exhaustion and despair set in, and the already debilitated patient feels that it is all not worthwhile”. These comments reminded me of an interaction that I had with a patient in clinical practice at around the same time.

This interaction summed up the feelings of many patients who experience taste changes.

The patient who was coming towards the end of his treatment reported:

“I'm fed up of all this. I can't eat, I haven't been able to taste any food for over a month now. Everything I put in my mouth feels and tastes foul. Why would I want to eat anything that makes me feel like that? I just want to feel better and go back to work. If I had known, it was going to be this bad I wouldn't have agreed to have it.”

These comments are interesting for two reasons; firstly, the realisation that from the patient perspective at least, little seems to have changed in the intervening 56 years and secondly the vivid description of the impact of taste changes on the individual. It appears that from the patient perspective the side effects of treatment are perceived to be as bad as ever, despite the huge technical advances in the planning and delivery of RT for HNC.

There is a lack of research into patients with head and neck cancer experiences of taste changes due to radiotherapy. As previously stated, observations from clinical practice reveal that some patients carry on eating even though they cannot taste their food, whilst others refuse to eat anything, becoming malnourished and having to rely on enteral feeding. Understanding more about the impact of taste changes is important because patients who become malnourished have a poorer outlook than those who remain well nourished, for a number of reasons. Firstly, the malnourished patient struggles to cope with the demands of treatment and this may lead to gaps in treatment which are detrimental to the treatment outcome (Bressan et al, 2016; Larsson et al, 2007). Secondly, the patient who stops eating and becomes reliant upon tube feeding may never get back to eating again. This in turn leads to increased hospital admissions for enteral feeding and problems associated with this and reduced quality of life (QoL) for these patients (Corry et al, 2008; Semba 1994). If the patient stops swallowing anything their swallow muscles may atrophy and once this occurs it is extremely difficult to regain the function, so they may never be able to swallow even though they have potentially been cured of their HNC (Paleri et al, 2014). This obviously has a huge impact on their future QoL in addition to the physical effects. Finally, patients who stop eating have reduced QoL during treatment and are

slower to recover after treatment has been completed (Bressan et al, 2017; Baharvand et al, 2013). Patients can achieve adequate nutrition via a feeding tube but if they stop eating and do not do swallowing exercises they run the risk of never getting back to eating in the future when their other side effects have resolved and their cancer has been cured (Paleri et al, 2014; Corry et al, 2008).

I was interested to explore if we can learn from the patients who continue to eat, knowledge that would be helpful in supporting patients who might stop eating due to taste changes. By developing a deeper understanding of HNC patient's experiences of taste changes during radiotherapy, staff will be better placed to support patients in developing strategies to cope with this distressing side effect.

1.3 Background

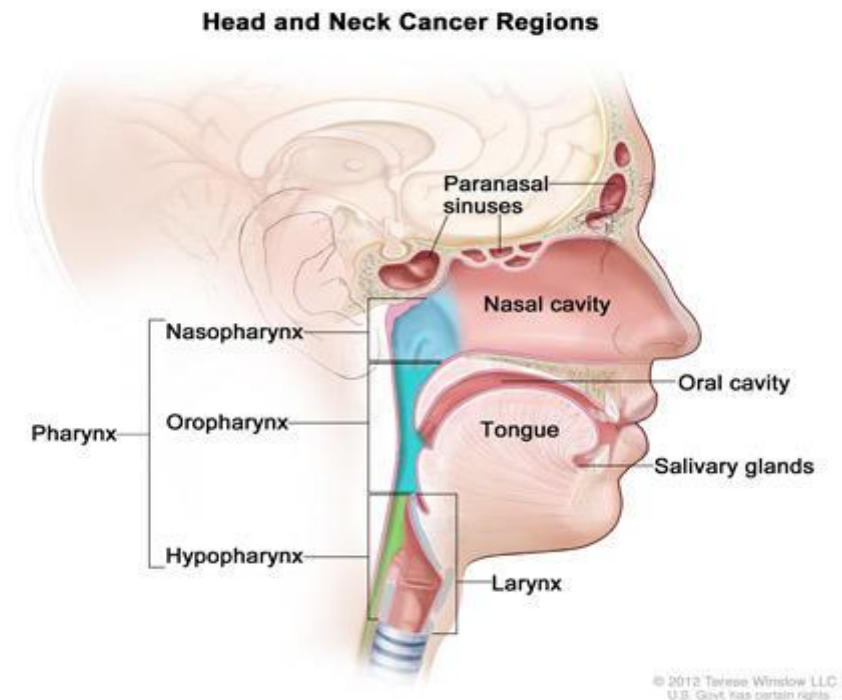
Previous research that has focussed specifically on taste changes has been very technical and laboratory based (Mossman, 1982; Yamashita et al, 2006; Baharvand et al, 2013) and while this is very important as it helps us to understand how, why and at what dose of radiotherapy that taste changes occur, it is less helpful when it comes to supporting the patient with taste changes. This body of research has relied upon measuring what the patient can taste using either chemical or electrogustometry (Mossman, 1982; Baharvand et al, 2013). These methods are very time consuming and rarely used clinically for this reason. It is argued that the same outcome might be achieved by asking the patient if their taste has been affected and what if any foods are they able to taste. In fact this would be more valuable as it takes into account the patient view of how they are managing, making better use of the restricted time that the healthcare professional spends with the patient.

I wanted to understand if individual patients or those with certain HNC diagnoses are more at risk of developing taste changes than others and I wanted the research to be patient focussed taking into account their own opinions as to how they manage taste changes as this would be valuable in advising future patients.

There have been a number of systematic reviews carried out that have looked at taste changes as a consequence of cancer treatment (Epstein et al, 2019; Hovan et al, 2010; Epstein and Barasch, 2010), however these are not specific to HNC although they do acknowledge that taste changes are a common consequence of treatment for HNC. There is limited qualitative research in to taste changes as a result of RT for HNC, with previous research focussing of side effects of RT for HNC in general rather than taste changes specifically.

1.4 Head and Neck Cancer

There are approximately 12000 cases of head and neck cancer recorded in the UK each year, making it the eighth most common cancer and making up 3% of all cancers (Cancer Research UK, 2020). In 2017 (the most recent year that figures are available for) it was the fourth most common cancer in males and 13th most common in females (Cancer Research UK, 2020). The male to female ratio is roughly 2:1 with 69% of HNC arising in males and 31% in females. HNC refers to cancers arising in the oral cavity, pharynx and larynx as well the rarer sites of the sinuses, salivary glands, nose and middle ear (see figure 1.1 below) and usually arise in the squamous cell epithelium lining the mucosal membranes of the head and neck regions. The incidence of HNC in the UK is rising and has increased by 33% between 1993-95 and 2015-17 (Cancer Research UK, 2020). The main reason for this increased incidence is HNC caused by human papilloma virus (HPV) and this rise has been greater in females than males. HPV related HNC typically is seen in the oropharynx and has led to a 50% increase in oropharyngeal cancer (OPC) over the last 20 years. HNC associated with smoking and drinking has reduced during the same time period (Mehanna et al, 2010).



(National Cancer Institute, 2012)

Figure 1.1 illustrating the sites that hand and neck cancers occur

1.5 Treatment of Head and Neck Cancer and Radiotherapy

Radiotherapy is a recommended treatment for HNC, with over 60% of those diagnosed with HNC undergoing RT as part of their treatment pathway (Donovan and Glackin, 2012; Cancer Research UK, 2020). It is a gruelling treatment given daily over 6-7 weeks, usually on an outpatient basis, although occasionally patients require inpatient treatment for supportive care if their symptoms or side effects are not able to be adequately managed as an out - patient. The common side effects associated with RT for HNC are mucositis, difficulty eating and swallowing, taste changes, xerostomia (dry mouth), pain, fatigue and sore skin (Baharvand et al, 2013 and Ruo Redda and Allis, 2006). All of these symptoms except fatigue are related to the position of the RT portals. Fatigue is a common symptom of all cancer treatments regardless of the site of the cancer (Rosenthal et al, 2007). These side effects usually resolve in time, once RT is completed, although some do not fully settle and become

long term or late side effects. A total dose of 60 -70 Gray (Gy) is delivered to the tumour and in cases of locally advanced HNC chemotherapy is recommended to be added to improve the effectiveness of the RT (NICE, 2017). Chemotherapy is either given on day 1 and day 21 of RT, or alternatively may be given once a week for 6- or 7-weeks dependent upon the RT regime being delivered and the patient's general condition. The chemotherapy drugs commonly used are either cisplatin or carboplatin. Where platinum based chemotherapy is contraindicated the monoclonal antibody Cetuximab may be recommended as an alternative (NICE, 2017). Both treatments are known to increase the acute toxicity associated with treatment, with cisplatin being known to lead to taste changes (Irvine et al, 2014).

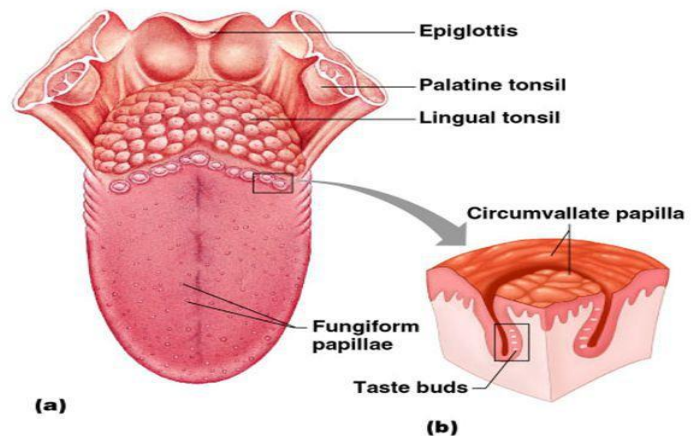
Historically radiotherapy to the head and neck region was planned to cover the known areas of cancer with a margin around this to ensure that all of the cancer was treated with RT. These fields would often include larger areas of normal tissues as the RT beams could not be shaped to avoid these structures. Treating these normal tissues led to higher levels of toxicity both during treatment and in the longer term. Modern RT techniques of Intensity Modulated RT (IMRT) and Volumetric Arc Therapy (VMAT) provide the opportunity to shape the RT beams so that the amount of normal tissue included in the RT field is reduced. This means that the RT dose to the cancer can be increased whilst minimising the dose to normal tissues leading to a higher chance of a cure for the patient as well as reducing toxicity and incidence of late side effects. However, it is not possible to avoid irradiating the taste buds as they are widely distributed throughout the mucosal membranes lining the mouth and throat, so it is inevitable some will be included in the RT treatment volume. The more modern techniques along with improved imaging capability on the treatment machines have helped to improve some of the late toxicity of RT for HNC but have done little to improve acute toxicity, including taste changes (Yamashita et al, 2006; Nutting et al, 2011 and Irvine et al, 2014).

1.6 The Effect of Radiotherapy on the Taste Buds

Taste buds are anatomical structures which contain receptor cells that mediate the sense of taste (Epstein and Barasch, 2009; Ruo Redda and Allis, 2006, Maes et al, 2002). The taste buds are located on the tongue, soft palate, pharynx, larynx, uvula, and upper third of oesophagus, lips and cheeks (Ruo Redda and Allis, 2006). The greatest concentration of taste buds is found on the dorsum of the tongue in the circumvallate, fungiform and foliate papillae (Maes et al, 20002). The diagram below shows the distribution and type of taste buds in the oral cavity and pharynx.

The Sense of Taste

- Taste buds house the receptor organs
- Location of taste buds
 - Most are on tongue
 - Soft palate
 - Cheeks



(eSchool, 2012)

Figure 1.2 illustrating the distribution and type of taste buds in the oral cavity

Irradiation of the taste buds leads to partial taste loss (hypogeusia), complete taste loss (ageusia) or abnormal taste (dysgeusia) (Ruo Redda and Allis, 2006; Maes et al, 2002). RT causes loss of taste through direct cytotoxic and anti-proliferative effects on the tissues of the oral cavity and pharynx, including the taste buds (Conger, 1973; Epstein et al, 2016). Radiation-induced damage to the nerves necessary to process taste had been considered to play a role in taste changes but has since been discounted primarily because of the relatively short recovery time for taste post RT, in most cases some improvement is seen between 3-8 weeks. If the nerves had been

damaged recovery would take much longer or would not occur. (Mossman, 1986 Nelson, 1998; Yamashita et al, 2006 and Mirza et al, 2008). The reduction in number of taste buds and the impact of RT on the quality and quantity of saliva may also have an effect upon taste but this has not been proven (Mirza et al, 2008). Most of the research addressing how RT affects the taste buds is historical having been carried out in the 1970s (Conger, 1973 and Mossman et al, 1979) and 1980s (Shatzman and Mossman, 1982 and Mossman, 1986).

It is necessary to treat the tissues that contain the taste buds to adequately treat HNC and therefore taste changes will continue to be a problem, because no matter how accurately we are able to define RT fields taste buds will continue to be included in the high dose volume.

There is little qualitative research into taste changes associated with RT for HNC, most concentrating on the impact of RT and the effect on nutritional intake (Donovan and Glackin, 2012; Larsson et al, 2007; Rose-Ped et al, 2002 and Gamble, 1998).

1.7 The Impact of Taste Changes upon the Patient

Patients undergoing RT or CRT for HNC are reviewed regularly during their treatment by the MDT, including myself. The aim of the review is to offer support to patients with any side effects they may be experiencing due to treatment and advise on how best to manage them. A holistic approach to care is taken with patients encouraged to discuss anything that may be impacting upon their ability to tolerate treatment whether it is physical, psychological, or social.

Taste is defined as the chemical stimulation of taste receptor cells in the oral cavity to perceive the primary tastes: sweet, sour, salty, bitter and umami. Flavour is a broader phenomenon encompassing the senses of taste, smell and touch which enables the perception of sensations with far greater complexity than the five basic tastes alone (Prescott, 1999 and Keast, 2004). Flavour perception is also influenced by food hedonics, which incorporates liking or wanting a food, which is in turn linked to increased appetite (Boltong and Campbell, 2013). It becomes apparent that taste is part of a more complex process.

Taste changes have a major effect on the QoL of the patient with HNC, being associated with weight loss, due to reduced appetite and altered eating habits, leading to malnutrition (Bressan et al, 2017; Epstein and Barasch, 2010 and Irune et al, 2014). Taste changes are also associated with reduced enjoyment of food, therefore leading to isolation, avoiding family meal times and social gatherings (Baharvand et al, 2013; Boltong and Campbell, 2013). This malnutrition leads to increased hospital admissions for feeding tubes to be placed and longer recovery times after treatment has been completed (Corry et al, 2008). Patients who stop eating and become dependent upon tube feeding risk longer term problems with dysphagia and will take longer to get back to eating than those patients who have continued to eat a modified normal diet throughout treatment (Paleri et al, 2014). In extreme cases, it may lead to patients being unable to complete their prescribed course of treatment and therefore reduced chances of cure. Semba et al (1994) and Shi et al (2004) noted that the patient with taste changes had a worse outcome than those who could continue eating and maintain good nutrition. They found that patients with taste changes were more likely to be malnourished, experience dysphagia and have reduced QoL. With IMRT and VMAT the clinician aims to avoid the pharyngeal constrictor muscles when planning RT to reduce the risk of this; however patients stop eating during RT for HNC for other reasons such as poor taste and pain and this also leads to these muscles becoming atrophied (Paleri et al, 2014). The current studies looking at the effect of taste changes on HNC patients have tended to focus on the impact of altered taste after treatment is completed whilst acknowledging that taste changes are observed as soon as 2 weeks into a course of RT (Baharvand et al, 2013; Maes et al, 2002). The researcher argues that early intervention would be a better approach to dealing with this problem as staff would be better placed to advise patients of the natural course of taste changes and support them during treatment. Therefore this study addresses taste changes as experienced by the patient during RT or CRT.

Although it is important to understand the process that causes taste changes, in clinical practice it is important that we are able to advise patients how to manage taste changes. Understanding what the patient is experiencing will help when devising care plans for them. Patients get distressed when they cannot enjoy food

and the resulting weight loss, loss of muscle and feelings of social isolation and problems with body image add to this distress (Larsson et al, 2007). There is a lack of experiential research looking specifically at taste changes as a result of RT or CRT for HNC and this study addresses that need.

It has been suggested that dietary counselling is the best way to deal with taste changes, although it is acknowledged that this seems to be more effective during follow up than during treatment (Ruo Redda and Allis, 2006; Epstein and Barasch, 2010). However, it is noted from clinical practice that although this will help some patients, others will not eat anything as all foods taste too bad to consider eating. Therefore advising them how to adjust their diet is not helpful or effective for all patients.

Hovan et al (2010) in their systematic review of taste changes induced by cancer therapies, concluded that management strategies are required to help patients cope and state that studies are required to clarify our understanding of this side effect. Epstein et al (2016) state that there is limited study in oncology patients despite the significant impact that taste has on oral intake and general physical and social well-being. There is clearly a gap in the literature looking at the experience of patients with HNC who develop taste changes during RT or CRT and this study aims to address this.

1.8 Study Questions

Taking all of this into account the following research questions were developed:

What is the experience of taste changes reported by patients undergoing RT or CRT for HNC?

This was then addressed by the following four sub-questions:

1. Which tumour sites and treatment regimens are most likely to experience taste changes?
2. When do these taste changes occur?
3. How are these taste changes managed by patients?
4. What motivates patients to continue eating when their food taste unpleasant?

1.9 Study Aims

The study aims were to determine the experience of taste changes for patients undergoing radiotherapy and concurrent chemo-radiotherapy (CRT) for HNC and better understand why some patients are able to continue eating and others are not. It is argued that by having a greater understanding of the experience of taste changes from the patient perspective staff will be better placed to support future patients through their treatment.

The first step was to conduct a scoping review of the literature to determine what is already known in relation to the extent and experience of taste changes due to RT or CRT for HNC

The findings of the scoping review and other relevant literature are presented in Chapter 2.

1.10 Guide to Thesis

Chapter 2 reports the scoping review carried out to determine what is already known regarding the experience of taste changes. It reports the findings of the review and highlights gaps in the published literature

Chapter 3 describes the mixed methods methodology and critical realist theoretical framework employed for this study.

Chapter 4 explains the methods used in the study including the tools employed and the justifications for choosing them.

Chapter 5 presents the results and analysis from the quantitative and qualitative strands from the study and then combines these results in keeping with mixed methods research.

Chapter 6 discusses the findings of the study in relation to how this answers the research questions, the relevant literature and implications for clinical practice.

Chapter 7 presents the conclusions and recommendations of the study.

Chapter 2

2.1 Literature Review

In this chapter I present the literature relating to taste changes associated with RT and CRT for HNC. There is limited literature that focusses only on taste changes related RT for HNC and even less that focusses on those taste changes from the perspective of the patient. I present the results from the scoping review that was carried out to discover the extent of knowledge and research in the area of taste changes as a consequence of RT or CRT for HNC followed by some of the wider literature that has included taste changes as part of their remit.

Teddlie and Tashakkori (2009) suggest that the literature review for mixed methods research should reflect the design used in the study. In this case the quantitative (questionnaire) strand came first followed by the qualitative interviews, so both aspects should be addressed in the literature presented.

It has already been determined that limited information exists in relation to taste changes during RT for HNC. Systematic reviews and systematic literature reviews in related areas have concentrated mainly on quantitative research, combined side effects of radiotherapy for HNC and taste changes in the general cancer population or taste changes caused by chemotherapy (Bressan et al, 2016; Epstein and Barash 2010 and Hovan et al, 2010). Irune et al (2014), in their review of treatment -related dysgeusia in head and neck cancer patients concluded that altered taste as a consequence of RT for HNC had not been sufficiently investigated and recommended better designed studies and with a primary objective of investigating altered taste.

No literature was found that addresses what motivates patients to continue eating when they have taste changes.

2.2 Scoping Review of Taste Changes

The aims of the scoping review were:

- To determine what is already known about taste changes as experienced by the patient during RT and CRT for HNC
- Determine which methods have been used to measure taste changes both subjectively and objectively
- Assess at which time points during RT taste changes have been measured and reported
- Determine whether patients with some tumour sites or treatment regimens are more likely to report taste changes

The objective of the scoping review was to examine the literature in a systematic way to determine the extent of and way in which taste changes as a result of RT for HNC are reported. This included quantitative reporting of taste changes as well as the subjective experience of taste changes. This information was used to inform the design of the study.

2.2.1 Scoping Review Question

Levac et al (2010), suggest that a good scoping review requires a clear question that assists with protocol development and the literature search and should be clearly linked to the purpose of the study.

The title for the scoping review was developed following the guidelines recommended by the Joanna Briggs Institute (JBI) methodology for JBI scoping reviews (2015). They recommend that the “PCC” mnemonic is used to construct a clear and meaningful title for the scoping review. PCC stands for Population (HNC patients); Concept (altered taste); Context (RT or CRT). This was used in preference to the PICO which is more commonly used in quantitative interventional research studies: P (patients or population); I (intervention); C (comparison); O (outcome)

Taking this into account the following scoping review question was developed:

How are taste changes experienced by the patient with HNC undergoing RT or CRT?

Sub questions were:

- How is altered taste measured in clinical trials and in clinical practice?
- What is the subjective experience of taste changes during RT or CRT for HNC?

It was important to understand more about the methods used to measure taste changes to decide upon the tools to use for this study.

2.3 Search Strategy

Prior to carrying out the scoping review a search was carried out of the following databases to discover if any systematic or scoping reviews had already been carried out on this topic:

- Campbell Collaborating Library of Systematic Reviews
- Centre for Reviews and Dissemination
- Joanna Briggs Institute
- PROSPERO

No reviews were identified that addressed taste changes as a result of RT for HNC from the patient perspective. In particular no studies were identified that addressed what motivates patients to continue eating when they have taste changes.

A scoping review was selected in this instance as it was necessary to define the boundaries of taste changes and how they affect the patient with HNC (JBI, 2015). An initial search of the literature suggested that there would be limited literature on this subject. Levac et al (2010), suggest that a scoping review should be carried out to examine the extent, range and nature of research activity or to identify gaps in existing literature. It is acknowledged that taste changes in relation to RT for HNC are a complex and poorly understood phenomena, particularly from the perspective of the patient. One of the main strengths of a scoping review is its ability to extract the essence of a diverse body of evidence, giving it meaning and significance that can be both developmental and creative (Davis et al, 2009). A scoping review is preferred to a systematic review when considering concepts such as patient experience or quality of care as it is essential that a wider range of literature is considered. A scoping review should be carried out with the same rigour as a systematic review and should be planned and have a protocol produced before beginning the review to reduce the

risk of bias and ensure that all relevant literature is included as well as defining inclusion and exclusion criteria (JBI, 2015).

Methodology for conducting a scoping review was first developed by Arksey and O'Malley (2005) and has been advanced by Levac et al (2010) and Colquhoun et al (2014) with JBI (2015) taking this a step further and recommending producing a protocol. A major difference between a scoping review and a systematic review is that a scoping review has no requirement to critically assess the quality of the papers included, ensuring that information from a wide range of sources is included. Scoping reviews will usually include a wider range of study designs and methodologies than systematic reviews (Pham et al, 2014). In this instance as the aim was to scope the available literature with a focus on patient perception, it was necessary to include a wide range of sources as patient opinion and perception may have been published in support groups and web sites. The lack of quality assessment has been criticised by some (Davis et al, 2009; Brien et al, 2010). However, Daudt et al (2013) argue that dependent upon the purpose of the scoping study this need not be a problem. In this instance it was decided that it was more important to capture patient experience than to make too strict an assessment of the quality. It was anticipated that there may be patient forums where taste changes had been discussed potentially providing greater insight into patient experience. I did not want to overlook this potential source of rich data.

2.3.1. Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were defined using the PCC mnemonic to determine the types of participants, concept and context of literature to be included for the scoping review.

All adult patients with a diagnosis of primary head and neck cancer were included in the review. The term head and neck cancer is an umbrella term which encompasses a range of sub sites and all of these were included in the literature review. Taste buds are located widely throughout the oral cavity, tongue, pharynx, larynx and hypopharynx (Epstein and Barasch, 2010) so all of these sites were included. Patients

undergoing chemotherapy as well as RT were included as CRT regimes are commonly used to treat HNC. It is acknowledged that chemotherapy can also have an effect on taste but the effect upon the patient is the same whether they are having RT alone or CRT. Only participants having curative treatment were included.

Participants having palliative RT were excluded as were participants who did not have a primary diagnosis of HNC.

The concept of taste changes in relation to RT for HNC is very complex and this needed to be well defined for the purpose of the review. Many terms are used to describe these changes both in clinical practice and toxicity reporting. All of the following were included: taste changes, altered taste, taste perception, dysguesia, hypoguesia, aguesia as well as any additional terms identified from the initial search of the literature. The main focus for this study was the patient experience of taste changes, however, to ensure that all aspects of taste changes were included the review included quantitative as well as qualitative reporting of this phenomenon.

Studies where the primary outcome was not altered taste were excluded from the review.

The context for this study was curative external beam radiotherapy including IMRT and VMAT as well as conformal and older RT techniques. Any treatment regime with radiation doses of 55Gy or greater were included. Only curative radiotherapy treatment regimens were included as palliative regimes deliver lower radiation doses and taste changes would necessarily be expected at these lower doses. In the UK most RT for HNC is now administered using IMRT or VMAT techniques but this has only become common practice in the last 5-10 years. Older studies would have used conventional RT, and this was included to ensure an in-depth coverage of the concept. Only studies that have been reported in the English language were included as the author had no access to translation services. Whilst it is acknowledged that this had the potential to introduce bias, many papers from outside the UK are written in English so it was anticipated that a wide range of countries would be included. Literature from the earliest start date of each database searched was included and up until the end of October 2017.

2.3.2 Identifying Relevant Studies

In keeping with a scoping review a wide range of sources were included, such as letters, patient forums and guidelines as well as the more traditional databases, search engines, conference proceedings and reference lists.

Although breadth and comprehensiveness are essential components of a scoping review it is acknowledged that feasibility must also be taken into account (Arksey and O'Malley, 2005; Brien et al, 2010). In common with a systematic review it is essential that a rigorous and transparent method is used to comprehensively identify and analyse all the relevant literature (Pham et al, 2014; DiCenso et al, 2010).

A well-documented search strategy demonstrates that a review has been carried out in a rigorous and logical manner providing reassurance of quality (Pham et al, 2014). When developing the search strategy, I enlisted the help of a librarian to ensure I had included as much literature as possible and understood the search mechanisms and utilised effective search techniques.

The JBI (2015) recommends a three-step search strategy, with each step being clearly stated.

An initial search was made of Medline and CINAHL with limits of English language papers and studies on human subjects only included. No limit was made on methodology or dates. As this was a scoping review the intention is to include all methodologies initially to assess what research has been carried out. No date limit was made as it is already known that a personal correspondence regarding taste changes was published in The Lancet in 1959 which has provided a rich insight into the patient experience of taste changes.

This initial search was followed by an analysis of the text words contained in the title and abstract of the retrieved papers. These keywords (see table 2.1 below) including those listed above were used to search the following databases:

- MEDLINE
- CINAHL
- EMBASE

- AMED
- Scopus
- Web of Science
- Sigle
- Google and Google Scholar
- Macmillan Cancer Care

Searching the grey literature and websites was particularly important in this case as there may have been patient reports of taste changes in group forums and support group websites.

When selecting keywords, care was taken to consider terms that are used in different countries, for example radiotherapy is referred to as radiation therapy in many countries, so both terms were used. The term “head and neck cancer” can cause problems when searching as it contains the word, AND which is used to combine searches. Related terms were included, and truncation and wildcards were used to ensure that all variations in spellings were accounted for. Abstracts were reviewed to determine any new keywords for inclusion and finally references from relevant papers were reviewed to identify any papers that had not been identified previously. Daudt et al (2013) and Davis et al (2009) suggest that this is an iterative rather than a linear process and it may be necessary to repeat steps to ensure that the literature is covered in a comprehensive manner. In fact, this process proved to be easier than expected due to the limited literature available, with papers commonly appearing on more than one search and in the reference list of other papers. Arksey and O’Malley (2005) talk about researchers “fine tuning their search of the literature” and it was anticipated that new terms would become apparent once the initial search has been carried out. The only terms added after the initial search were taste acuity and parageusia, which turned out to have only been used in one study each.

Table 2.1 below shows the keywords included in the scoping review.

Participants	Concept	Context
“head and neck cancer”	Taste changes	Radiotherapy
Head and neck neoplasm*	Altered taste	Radiation therapy
Head and neck tumour\$	Dysgeusia	IMRT
Oral cancer	Hypogeusia	VMAT
Throat cancer	Ageusia	Chemo – radiotherapy
Tonsil cancer	Taste perception	Chemo - irradiation
Oropharyngeal cancer	Gustatory changes	
Laryngeal cancer	Parageusia	
Tongue cancer	Taste acuity	

Table 2.1 keywords used for the scoping review

An initial search of MEDLINE identified 58 papers which on reviewing the abstracts were reduced to 18 papers for inclusion in the review. See Appendix 1 for search schedule. The rejected papers were:

12 - did not address taste changes

9 – RT or CRT not the only treatment modality

9 – no patient reported measure of taste changes

A search of CINAHL identified a further 5 papers of which one was rejected as it was a duplicate from the previous search.

This gave a total of 22 papers to be reviewed in-depth to provide further keywords and search information before the full search was carried out.

The same search strategy (see appendix 5) was then applied to each of the databases and websites listed above with appropriate adjustments made as required by individual databases. No additional papers or sources of information were uncovered and no websites or patient forums were identified where taste changes had been reported or discussed. This is summarised in the PRISMA diagram below (PRISMA group, 2009).

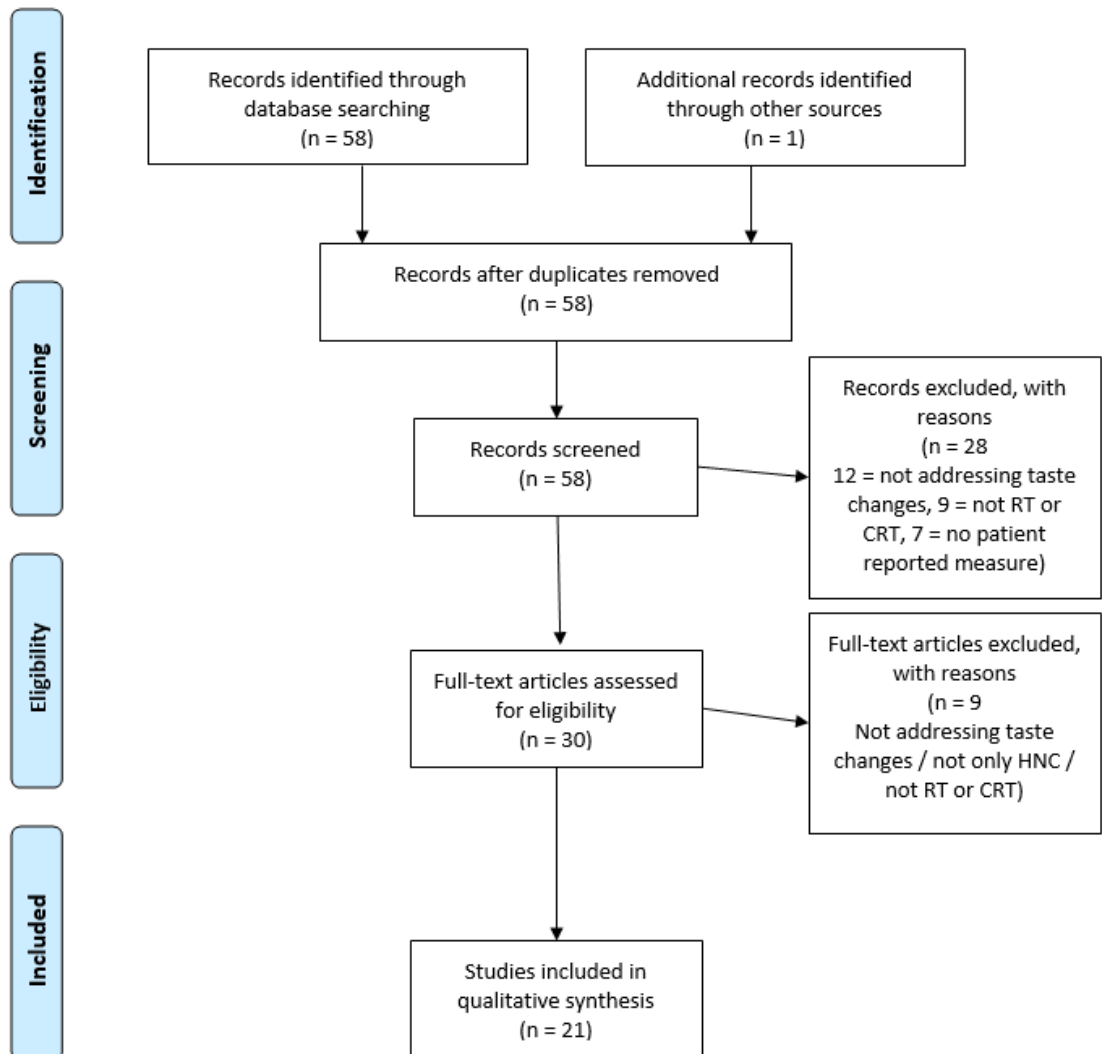


Figure 2.1 PRISMA Flow Diagram

2.3.3 Study Selection

The studies and papers identified then had the inclusion and exclusion criteria applied to them by the researcher. This would ideally have been carried out by two researchers, but the nature of this study made this inappropriate. The papers identified were the final ones included in the study. As previously stated Arksey and

O'Malley's framework (2005) does not include any assessment of quality of the literature included, so all identified papers and sources of relevant information were included. As the focus of this scoping study was to understand taste changes from the patient perspective and inform future research, the quality of the research included was not assessed. However, this was addressed in the literature review itself. The process was iterative, being driven by what was discovered once the literature has been studied. It was anticipated that on line forums and support groups may have provided some information regarding taste changes and how patients manage taste changes but this did not prove to be the case.

Some researchers have suggested that the lack of quality assessment of literature included in scoping studies may lead to difficulties in interpreting their results (Brien et al, 2010; Grant and Booth, 2009), however, this did not prove to be problematic with this review. The inclusion of some sort of quality assessment is in conflict with one of the main premises of a scoping review, that it should map a wide range of literature; examining its extent, range and nature (Ehrich, 2002; Arksey and O'Malley, 2005). The risk of missing this potentially rich data was felt to be more important than the quality of the research and data included in the scoping review. One of the aims of the scoping review was to find out what has been reported to inform further research and adding too rigid quality guidelines may have excluded important information. Using this process ensured that personal reflections of taste changes were included in the review providing valuable insight into patient experience. These would have been excluded using other methods.

2.3.4 Charting the Data

Charting the data is the term used to describe data extraction in a scoping review (JBI, 2015). It is intended to provide the reader with a description of the literature included in the review. When deciding upon which data should be charted the PRISMA-P checklist was consulted. This gave guidance as to which items should be included in a review protocol (Shamseer et al, 2015).

General information was gathered in a tabular form (see table 2.2 below). Qualitative data was reported thematically as per the original study, with no attempt being made by the researcher to carry out thematic analysis between different studies.

The following table was used to extract data from the relevant papers.

Table 2.2 Papers included in Scoping Review

Author Year country	Aims	Study sample size	Methodology	Treatment Regime	Taste changes primary outcome	Key findings	Limitations
Epstein J. et al 2016 USA	Understanding the impact of taste changes in oncology care, including the physiology of taste and how it is impacted by cancer and its treatment	N/A	Review article	RT and systemic treatments	Yes	Limited study of taste in oncology patients despite its significant impact Discusses problems with lack of taste including dysgeusia or phantogeusia associated with taste aversions, nausea and reduced dietary intake. Highlights the need for well-validated PROM's for taste	Not specific to HNC
Sapir E. et al 2016 Michigan USA	Predictors of dysgeusia in OPC patients treated with CRT at 1,3,6 and 12 months after RT utilising PROM, UWQoL and HNQoL	73	Patient reported symptoms compared with RT dose Taste changes and dry mouth	CRT	yes	Taste impairment significantly correlated to mean radiation dose to oral cavity Dysgeusia associated with reduced QoL and worsening dysphagia in patients having CRT for OPC Salivary flow not related to dysgeusia HNC patients report potential taste reduction least important symptom before RT by end of RT and 21/2 months later rated similar to pain, dry mouth and dysphagia for affecting QoL	

Alvarez-Camacho M. et al 2015 Switzerland	Taste and Smell disturbance in H&N RT impact on QoL at baseline, end of trt and 21/2 month FU using UWQoL	116	Longitudinal study	RT & CRT	No	Taste and smell important predictors or reduced QoL	Assesses taste and smell together, rather than taste alone
Irvine E. et al 2014 UK	Treatment related dysgeusia in HNC, assessed at various time points systematic review		Literature review	RT & CRT	yes	Taste changes peaks 3-4 weeks into RT Can persist beyond 1 year after RT Severity not linked to dose of RT Appropriate terminology should be used e.g dysgeusia, ageusia, not always clear what has been measured with some studies	
Baharvand M. et al. 2013 Iran	Taste alteration & impact on QoL after RT for HNC measured before RT and 3 weeks after completion, utilises whole of mouth technique and interviews	22	Cohort study	RT	yes	HN RT causes taste changes and negatively affects QoL All patients had dysgeusia after RT and 72% had total taste loss. Slat and bitter tastes most affected.	No measures taken during RT
McLaughlin L. 2013 USA	Taste dysfunction in cancer	92	Exploratory cross-sectional	Mixed	Yes	Statistically significant weight loss was associated with dysgeusia	No subjective measures used Taste not measured during treatment

	survivors measured using chemical taste concentration measures					Participants were not able to distinguish between bitter and sour tastes in particular but had difficulty with all tastes.	
Porter S. et al 2011 UK	Review current knowledge of taste dysfunction associated with HNC during and post RT using both objective and subjective measures	N/A	Review of evidence	RT	Yes	The loss of umami may especially lessen dietary intake and reduce QoL as this taste cue influences the pleasure of foods. Evaluation of taste rarely forms part of management protocols yet affects nutrition greatly Poor taste – reduced dietary intake, weight loss, potentially poorer treatment outcomes and reduced QoL.	
Epstein J. & Barasch A. 2010 USA	Taste dysfunction in cancer patients		Literature review	RT and chemo	Yes	Taste dysfunction in cancer patients impacts QoL and impairs oral intake Patient evaluation should include full history and examination with PROM's recommended. Understanding, prevention and management of taste disorders in cancer patients requires continuing study	Not specific to HNC or RT but included because of patient assessment and management of taste changes.
Hovan A. et al 2010 Canada, Sweden and USA	Systematic review of dysgeusia induced by cancer therapies	N/A	Systematic review	RT and CRT	Yes	No effective treatment strategy to treat dysgeusia Dysgeusia has negative impact on QoL Considering the high prevalence of dysgeusia in published studies and QoL deficits associated with dysgeusia,	May have excluded some studies/information sources due to strict inclusion criteria of systematic review. Search strategy not published.

						increased efforts for patient education, prevention and treatment warranted	
Yamashita H. et al 2009 Japan	Assess the impact of umami taste change during RT from baseline and weekly to week 10-12 using whole of mouth and subjective measures	52	Followed patients on RT	RT no surgery	yes	Umami taste significantly altered by week 3 and begins to improve by week 8 Presence of mucositis does not appear to impact taste changes? effect of xerostomia	
Ruo Redda M. & Allis S. 2006 Italy	RT induced taste impairment discusses how they are measured		Review	RT	Yes	Negative effect of taste impairment on QoL, weight loss, reduced appetite and altered pattern of food intake Taste impairment begins a few weeks after the beginning of RT. Damage to the major salivary glands during RT for HNC leads to disturbance in taste acuity Almost all patients report changes to taste acuity at doses of 60Gy.	
Yamashita H. et al 2006 Japan	Acute and late taste changes on the irradiated tongue during weeks 3 and 5	118	experimental 2 groups Grp A most of tongue treated	RT	Yes	Taste changes not observed if tip of tongue not treated with or without chemo Taste changes temporal for both groups	This information is contradicted by other studies e.g. Mirza et al 2008

	of RT and 8 weeks later using objective measures		Grp B tip of tongue avoided				
Ravasco P. 2005 Portugal	Taste and compliance in patients with cancer	N/A	Review alterations in taste and taste aversions	RT	Yes	Alterations in taste - food aversions - malnutrition- poor outcomes Umami – provides enhancement of savoury flavours and is responsive to Amino Acids Substantial impairment of umami taste is associated with pt distress and negative impact on QoL Taste returns 2-4 months after RT Poor nutrition associated with limited activity, poor mobility and poor mental state post RT (Ravasco, 2003) Regular contact with HCP, vital for compliance and team approach recommended	
Shi H-B. et al 2004 Japan	Investigate the recognition of umami taste & 4 basic tastes in H&N RT at baseline, 15Gy, 30Gy, 45 and 60 Gy using taste threshold measures and	30	RT patients	CRT	yes	Umami impairment different to other 4 tastes Strongly correlated to reduced QoL	

	taste questionnaire						
Maes A. et al 2002 Belgium	Quantify prevalence of & distress caused by taste loss at 2,6,12 and 24 months after RT using both objective and subjective measures	73	Descriptive Cross-sectional comparative design across 4 groups	RT	Yes	Loss of taste most pronounced at 2 months. Bitter and salt tastes most impaired. Partial taste loss persisted at 1-2 years and caused moderate discomfort	Taste changes during RT not measured
Rose-Ped A. et al 2002 USA	Personal experience of RT for H&N carried out after RT using interviews	33	interviews	RT	No	90% reported taste changes 53% complete loss 33% distorted taste 13% reduced taste	Interviews were carried out after RT, therefore relying upon patient's memory
Zheng W-B. et al 2002 Japan	Prospective study of taste disorders caused by RT for HNC using threshold testing weekly and 6 months after for 11 cases only	40	Prospective study - experimental	CRT	Yes	The main cause of taste dysfunction during RT for HNC is damage to the taste buds in the RT field Bitter taste most affected	No subjective measures used

Fernando I. et al 1995 UK	Prospectively assess the impact of RT on taste dysfunction in HNC using questionnaire and objective taste testing in relation to position of RT fields	26	Prospective longitudinal study	RT	Yes	Irradiation of the tongue rather than parotid gland responsible for objective and subjective taste changes Taste loss leads to anorexia and weight loss Volume of tongue in RT field should be kept to a minimum	Older RT techniques used. Participants divided into 4 groups depending upon tumour volume, therefore only small numbers in each group
Mossman K. 1994 Arizona USA	Oral complications & review of what is already known	N/A	Review article	RT	No	Impact of taste changes on QoL	
Conger A. & Wells M. 1969 USA	Assess the effect of radiation on number and structure of taste buds using laboratory based tests		Experimental Human and mice	RT	Yes	75-99% decrease in taste acuity to sugar, acid and quinine at end of RT recovers to pre-treatment level within 60-100 days	No subjective measures used
McCarthy-Leventhal E. 1959 UK	Personal correspondence during and after RT	1	Report of taste changes	RT	yes	Failure of HCP to understand impact of taste changes	Personal opinion, so unclear how representative this is of other patient experiences.

A total of 21 papers were included in the review and these were published between the dates 1959 and 2016. Papers from USA (6), UK (4), Japan (3), Belgium, Switzerland, Portugal and Iran were included.

12 papers reported participants who had RT only and 6 included participants who had CRT.

7 papers recorded both objective and subjective measures of taste; 4 papers reported objective measures; 4 subjective measures and 3 did not use a measure of taste changes.

10 papers recorded taste changes during and after RT with only 3 recording baselines measures.

Taste changes were the primary outcome for 12 of the papers, others were included because taste was one of the secondary outcomes and taste changes were covered in detail or taste and smell were considered (Alvarez-Camacho et al, 2015).

None of the papers focussing solely on taste changes reported any qualitative data.

2.4 Findings

The main findings of the scoping review are now presented.

2.4.1. The Effect of Radiation on the Taste Buds

Conger and Wells (1969) looked at the effect of radiation on the number and structure of taste buds and reported that both the number of taste buds and number of cells per taste bud rapidly declined 9 days after treatment began and that the average life span of a taste cell is 10 days. They reported a 75 – 99% decrease in taste acuity to sugar, acid, and quinine at the end of RT with recovery to pre-treatment level within 60 – 100 days. Their research pre-dates the discovery of umami sense of taste and therefore is not discussed. This research was fundamental to the

understanding of the effect of RT on taste buds at a cellular level. It does not provide any insight into how these changes were perceived by the patient.

Yamashita et al (2009); Rose-Ped et al (2002) and Irune et al (2014) report that taste changes peak 3-4 weeks into RT, with umami sense of taste being significantly altered at this point. The umami sense of taste is of interest because it is associated with enjoyment of food and appetite and Yamashita et al (2009) suggest it has a role to play in assessing the nutritional value of food. This suggests that a reduced sense of umami taste could lead to patients considering that food has no nutritional value and therefore be less likely to eat it. Due to the impact of umami sense of taste on appetite and enjoyment of food it is closely linked to how much patients eat and taking full meals rather than snacks.

There is lack of consensus as to whether dose of RT delivered affects the severity of taste changes experienced. For curative RT doses of at least 50Gy are delivered and for this review doses of 55Gy and above were included and whilst no agreement was seen at what dose levels taste changes might be expected, all agreed that they would be expected with doses of 50Gy and above (Baharvand et al, 2013; Ruo Redda and Allis, 2006; Rose-Ped et al, 2002). The dose range of 55Gy and above was selected because this is the dose range employed for curative RT in the researcher's department and participants in the study would have received a RT dose within this range. Hovan et al (2010) suggest that a dose of 60Gy will cause taste changes in 90% of patients. All of these studies measured taste changes at differing points during treatment and using a combination of subjective and objective measures, so it is difficult to compare their outcomes. Yamashita et al (2006) reported that taste changes were not observed if the tip of the tongue was not included in the radiation field but this has not been observed in other studies (Irune et al, 2014). It is known that taste buds are widely distributed over the tongue, pharynx and oral cavity, so it seems unlikely that avoiding the tip of the tongue would prevent taste changes. Certainly, in clinical practice patients who do not have the tip of their tongue included in their treatment field still report taste changes. It is acknowledged that the anterior tongue contains the taste buds that are crucial to detection of taste stimuli, so there is potential benefit in avoiding this portion of the tongue with the radiation field if

this is possible without compromising the treatment volume (Irvine et al, 2014). Fernando et al (1995) in their prospective study looking at the effects of RT for HNC on taste dysfunction found that the volume of tongue treated rather than the region of the tongue treated was significantly associated with the development of taste changes. Their study was carried out before IMRT and VMAT techniques were in use so larger and less well defined treatment volumes would have been in use then compared to more recent research.

Sapir et al (2016) in their study of 73 patients undergoing IMRT for HNC assessed the effect of the dose of radiation to the oral cavity on patient reported dysgeusia and explored the effect of salivary flow on taste as saliva is required to dissolve food particles. They also assessed xerostomia (dry mouth) using a patient reported questionnaire. They found that radiation dose of 53Gy or greater to the oral cavity was associated with severe taste changes during treatment and at 3 months afterwards. Salivary flow did not appear to have an impact on taste changes at any of their measurement points (1,3,6 and 12 months after treatment), however patient reported xerostomia appears to be related to long term problems with taste changes. Other studies (Irvine et al, 2014; Fernando et al, 1995 and Mossman 1986) have suggested that lack of saliva might also have some effect on taste but have concluded that it cannot be the only factor effecting taste changes during RT for HNC.

Research has looked at substances that may help to protect taste buds and taste during RT, but none has been found effective in clinical practice (Halyard et al, 2007; Antonadou et al, 2002 and Ripamonti et al, 1998). Halyard et al, (2007) in their randomised controlled study found no statistical difference between the group treated with zinc sulphate 45mg three times a day and the placebo group in terms of dysgeusia, with 73% reporting dysgeusia in the zinc group and 84% in the placebo group. Studies have aimed to determine if any sense of taste is more affected by RT, but there has been lack of consensus about this (Maes et al, 2002; Mossman and Henkin, 1978 and Mossman et al, 1982). Staff often tell patients that the sweet sense of taste is less affected so they may prefer sweeter foods but there is little evidence to support this. Clinical practice suggests that patients are more concerned about lack of taste in general, rather than noticing which part of their taste has been

affected, although, some patients report that everything tastes salty or bitter even when they have added sugar to it. It may be helpful to advise patients on foods they might find more acceptable if it were known which of the senses of taste are most affected however research (Maes et al, 2002; Mossman and Henkin, 1978 and Mossman et al, 1982) and clinical practice suggests that this differs between patients.

2.4.2 Relationship between Tumour Site and Taste Changes

McLaughlin and Mahon (2014) in their meta-analysis of the relationship between impaired taste, treatment type and tumour site in HNC patients found no significant relationship between tumour site and occurrence of taste changes. They suggest that this illustrates the pervasive nature of taste changes in patients undergoing RT or CRT for HNC and recommended that healthcare professionals consider all patients having RT for HNC at risk of taste changes. Their meta-analysis included participants with cancers of all head and neck sites, such as oral cavity, pharynx, oro-pharynx and larynx. This is interesting as some clinicians suggest that patients having RT for laryngeal cancer do not experience taste changes. Experience from clinical practice suggests that patients having RT for laryngeal cancers do indeed report problems tasting food and for this reason patients with laryngeal cancers were included in the study. Maes et al (2002) study looking at time scale of loss and recovery of taste caused by RT included oral cavity, oro-, hypo- and nasopharynx and salivary gland cancers. However their study sample size for each tumour site was too small to draw any conclusions as to whether some sites were at greater risk of taste changes. None of the other studies included have described the tumour sites included, instead using the umbrella term HNC.

2.4.3 Measurement of Taste Changes

A variety of measures were used with some studies using more than one tool to assess taste changes. Eight studies recorded both objective and subjective measures, three studies used objective measures only and four subjective measures only. Of

these studies nine measured the impact of taste changes on QoL and all found that altered taste negatively impacted QoL.

The most commonly used QoL measure was the University of Washington Quality of Life Measure (UWQoL) used in 6 studies with the Head and Neck Quality of Life (HNQoL) measure used in two.

Whole of mouth taste threshold measures were used in seven studies to measure acuity of sweet, salty, bitter and sour senses of taste. Only two of these studies measured umami taste (Shi et al, 2004 and Yamashita et al, 2009).

Taste is made up of five basic qualities, sweet, sour, bitter, salty and umami (Chaudhari et al, 2000). Earlier studies concentrated on the 4 previously more recognised senses of taste sweet, sour, salty and bitter (Shi et al, 2004). More recently umami also known as the “fifth sense” of taste has been recognised and included in studies on taste changes during treatment for HNC. Umami is a Japanese word meaning delicious and the umami taste is found in many foods such as meat, fish, milk, tomato and vegetables (Shi et al, 2004). Epstein et al (2016) suggest that loss of umami taste may have more effect than loss of other tastes as it is associated with interest in eating and enjoyment of food.

It has been suggested (Boltong and Campbell, 2013) that taste should be distinguished from flavour as taste refers to the process whereby only specialised taste receptors are stimulated. Flavour refers to the stimulation of other receptors in addition to taste receptors, such as tactile, thermal, pain and smell receptors (Ruo Redda and Allis, 2006). Clinical experience suggests that patients and healthcare professionals have the same understanding of and are describing the same phenomena when they talk about taste. For the purposes of this study taste and taste changes have been considered to mean what the patient describes when they report that they cannot taste anything, as this is the terminology that is in general use clinically.

The validated tools currently in use to assess taste changes during RT or CRT ask about the severity of taste change, without any focus on the individual qualities of taste (Epstein and Barasch, 2010). The most commonly used scoring tools are the

common toxicity criteria – adverse events (CTC-AE v4) and the scale of subjective total taste acuity (STTA). These tools have been criticised as not being specific enough, having a limited range of responses to choose from. The CTC–AE v4 is currently used in the researcher’s clinical practice and experience suggests that any patient who experiences taste changes is invariably scored as a 2, therefore giving little if any definition between the experiences of different patients and suggesting that taste changes are only ever moderate. Personal experience from clinical practice has shown that altered perception of taste is often one of the first changes reported by patients after they start RT, leading to decreased nutritional intake before the soreness and pain associated with oral mucositis begins. This has also been observed in the literature (Bressan et al, 2016; Ruo Redda and Allis, 2006).

There are a number of tests that are utilised to objectively measure taste changes, although none are used routinely in clinical practice. The tests that have been commonly used in research studies are outlined below.

Chemical gustometry consists of measurement of detection and recognition thresholds and taste intensity responsiveness (Baharvand et al, 2013; Ruo Redda and Allis, 2006; Maes et al, 2002). The detection threshold corresponds to the lowest concentration of the stimulus distinguished by the patient as different from water by the phrase “I can detect a taste”, or “this taste is sugar” for example (Mossman et al, 1982). Commonly used taste solutions are (Ruo Redda and Allis, 2006):

- Sodium chloride – salt
- Sucrose or glucose – sweet
- Citric acid – sour
- Quinine sulphate – bitter
- Monosodium glutamate – umami

Electrogustometry is a physical method based on the determination of the recognition threshold of an electrical stimulus such as a continuous wave from a cathode to an anode placed on the tongue while another electrode closes the circuit (Ruo Redda and Allis, 2006). This method is rarely used clinically and is criticised as the electrical stimuli rarely produce a classic taste sensation of sweet, sour, bitter

and salty (Epstein et al, 2016). This technique is most efficient when checking the function of the sensory pathway. This method is flawed as it has been tested in populations who are known to have been experiencing problems tasting their food.

Both chemical and electrogustometry are time consuming and of limited value in the clinical setting and therefore are rarely used with subjective scoring tools being preferred.

2.4.4 Recovery of Taste

There is lack of agreement as to when taste changes begin to recover following treatment. Conger and Wells (1969) report that taste acuity for sugar, acid and quinine have recovered to pre-treatment level within 60-100 days. However it is not clear if patients were reporting that they could taste food normally at this stage, or were simply reporting that they could detect these different tastes.

Maes et al (2002) in their study aimed to quantify the prevalence and distress caused by taste loss at 2, 6, 12 and 24 months after RT for HNC. They used taste acuity tests and taste questionnaires. They found that taste loss was most pronounced at 2 months after treatment with a gradual recovery over the year following RT with partial taste loss still present at 24 months in a small number of patients. Distress caused by taste loss was as high as 82% for one of the groups in their study. Maes et al (2002) do not report taste changes during RT so it may be that taste changes were greater at some point prior to the point where their measurements begin.

Yamashita et al (2009) looked specifically at umami taste dysfunction in 52 patients undergoing RT for HNC. They used whole of mouth testing to determine taste recognition threshold for umami taste at baseline and weekly for 10-12 weeks. They report that umami sense of taste is significantly affected by week 3 of treatment and begins to improve by week 8 which in most cases is 2-3 weeks after treatment has been completed.

These studies are not measuring the same thing, but it may be argued that measuring umami taste is more relevant as this has a greater impact on enjoyment of food and

eating nourishing meals. McLaughlin (2013) found that patients could not accurately predict which sense of taste was most severely impaired only that it did not taste right. She did not include a measure of umami taste in her study. This suggests that it is not important to patients which part of their taste has been affected, it is the fact that it has been affected that has the greatest impact. McLaughlin (2013) suggests that assessment of taste changes should be included in nursing practice due to the associated impact on QoL and decreased appetite.

2.4.5 The Experience of Taste Changes

McCarthy-Leventhal (1959) and Epstein et al (2016) discussed the failure of healthcare professionals to recognise and understand the impact of taste changes in patients with HNC undergoing RT. The impact of taste changes on quality of life (QoL) was reported by Porter et al (2011); Ravasco (2005); Sapir et al (2016); Shi et al (2004) and Baharvand et al (2013). It is interesting to note that despite this impact being reported in a number of papers between 1994 and 2016 healthcare professionals have been slow to recognise this impact. It may be the perceived lack of being able to do anything to help taste changes leads healthcare professionals to avoid dealing with taste changes, preferring to focus on symptoms that they feel they can help with such as pain or nausea. It has also been suggested that patients do not die of taste changes and therefore it is not considered to be a serious side effect (Hovan et al, 2010).

Ravasco (2005) and Porter et al (2011) discuss the effect that loss on umami sense of taste has on nutritional intake and enjoyment of food. Both go on to discuss that evaluation of taste rarely forms part of the patient assessment despite the effect poor taste has on dietary intake, weight loss, reduced QoL and potentially poorer treatment outcomes.

Sapir et al (2016) report that taste changes are associated with worsening dysphagia in patients undergoing CRT for oropharyngeal cancer. They also make the interesting observation that HNC patients report potential taste reduction the least important

symptom before RT, however, at the end of RT and 21/2 months post RT it is rated as being as big a problem as pain, dry mouth and dysphagia for impact on QoL. This suggests that patients need to be better educated prior to starting treatment about the impact taste changes might have for them. Hovan et al (2010) in their systematic review of dysgeusia induced by cancer therapies suggest that considering the high prevalence of dysgeusia in patients undergoing RT for HNC greater effort needs to be made in the prevention and treatment of taste changes.

2.4.6 Methodologies used to Study Taste Changes

A range of methodologies were utilised in the papers included in the literature review as would be expected given the range of studies included.

The most commonly used method was the review article with three of these being systematic reviews. These were included because their primary focus was taste changes in HNC (Hovan et al, 2010, Irune et al 2014 and Ruo Redda and Allis, 2006). Other reviews focussed on reviewing evidence of which senses of taste are affected by RT and what is currently known about taste changes in HNC (Ravasco, 2005 and Porter et al, 2011).

Cross-sectional comparative methodology was used by Maes et al (2002) and McLaughlin (2013) to measure taste changes at various time points after RT.

Conger and Well (1969) and Yamashita et al (2006) used experimental methods to measure the effect of different doses of RT to taste buds and regions of the oral cavity.

Other methodologies used included longitudinal design, cohort study, interviews and a combination of subjective and objective measures.

Only Rose-Ped et al (2002) used patient experience as the focus for the study, interviewing 33 patients after they had completed treatment to evaluate their experiences. This study discussed other side effects in addition to taste changes but was included as there was extensive discussion of taste changes from the personal

perspective. Rose-Ped et al (2002) reported that 90% of participants recorded either complete or distorted sense of taste. Although this paper did not focus exclusively on taste changes it was included because of the depth of information provided regarding taste changes.

All other studies utilised a form of subjective measures for taste changes, although some used an objective measure or QoL instrument also.

Using multiple methods has the advantage of taking into account patient experience as well as objective measures. It is argued that whilst quantitative data is helpful for understanding the extent of taste changes the objective and qualitative data are more useful in understanding patient experience and therefore assisting our understanding of how best the patient with taste changes might be supported.

The sample sizes of the studies included in the literature review ranged from 1 – 118, with the majority having being between 20 -50 participants (Bahravand et al 2013; Yamashita et al, 2009; Shi et al, 2004; Rose-Ped et al, 2002). The single report was a personal correspondence from a HNC sufferer (McCarthy-Leventhal, 1959. Yamashita et al (2006) carried out an experimental study with 118 participants using chemical gustometry to determine the extent of acute and late taste changes on the irradiated tongue.

2.4.7 Other Papers Discussing Taste Changes

Papers that focussed on eating problems in patients with HNC often comment on the impact of taste changes (Rose and Yates, 2013; Donovan and Glackin, 2012; Larsson et al, 2007). These papers discussed the need for accurate information for patients and provision of support before during and after treatment. Donovan and Glackin (2012) identified the following themes as being important for patients undergoing RT for HNC: waiting and uncertainty; disruption to daily life; side effects from RT and psychological wellbeing.

Larsson et al (2007) also identified disruption to daily life, waiting as key themes for patients undergoing RT for HNC. In addition they described patients feeling “left to

their own devices” and “needing a hand to hold”. All three of these papers highlighted the strong link between taste changes and reduced QoL.

2.5 Conclusions and Recommendations

It appears that all HNC tumour sites are at risk of developing taste changes and therefore all were included in this study.

How RT effects the taste buds is relatively well understood with historical research having focussed on this aspect of taste changes (Conger and Wells, 1969; Mossman, 1994). Less is known about the timing of taste changes during RT and this has been investigated in this study.

Previous research has focussed on which qualities of taste are affected by radiation to the taste buds but have tended to focus on the 4 main qualities with umami sense of taste having limited research as it was only defined in 2000 (Yamashita et al, 2006; Shi et al. 2004).

There has been little research on the impact of taste changes from the patient perspective with research on impact generally focussing on side effects of RT for HNC in general.

Studies have recognised the need for well-designed research looking at the impact of taste changes from the patient perspective and management of this troublesome side effect (Irvine et al, 2014; Porter et al, 2010; Hovan et al, 2010)

There is a gap in the research looking at the experience of taste changes during RT for HNC from the patient perspective, including when taste changes occur and what enables some patients to continue eating when others stop.

There is also a need for accurate information for patients experiencing taste changes so that they may be appropriately supported before and during their treatment.

No studies were identified that looked at what motivates and enables patients to continue eating when they have taste changes.

Taking all of the above in to account the following research questions and aims and objectives were developed:

What is the experience of taste changes reported by patients undergoing RT or CRT for HNC?

This was then addressed by the following four sub-questions:

1. Which tumour sites and treatment regimens are most likely to experience taste changes?
2. When do these taste changes occur?
3. How are these taste changes managed by patients?
4. What motivates patients to continue eating when their food taste unpleasant?

2.5.1 Aims and Objectives

This study aimed to address these gaps by utilising a mixed methods methodology with critical realist theoretical framework, accepting that participants are having the same treatment for their HNC but will be experiencing their treatment and associated side effects in different ways because of their individual differences. The MDASI-HN questionnaire was used to highlight participants with the worst self-reported taste changes. These participants were then invited to take part in a semi-structured interview to discuss their experience of taste changes, how they have managed and if they are still managing to eat what has motivated and helped them to continue eating.

1. To quantify the extent and impact of altered taste during treatment. This was achieved by comparing the scores from the MDASI-HN questionnaire in week 1 to those from week 4 of treatment, when taste changes are reported to reach their peak.
2. The impact and how participants manage taste changes will be

determined by the supplementary questions added in week 4 for those scoring 5 or greater for problems tasting food item on MDASI-HN.

3. Analyse demographic, baseline and week 4 data to determine if the group of participants who developed taste changes were clinically or demographically different from those participants who did not develop taste changes.
4. To explore the experience of taste changes in patients undergoing RT for HNC through interviews carried out with participants who developed problems tasting food as defined by a score of 5 or greater on MDASI-HN.
5. Analyse interviews thematically to explain the results of the MDASI-HN and describe and understand the participant's experiences of taste changes.

In the next chapter I discuss the methodology and theoretical framework used to frame the study.

Chapter 3

3. Methodology and Theoretical Framework

In this chapter I discuss the methodology selected for this research study, the theoretical framework underpinning the research, and justify the reasons for these choices. Good mixed methods research should combine the strengths of both qualitative and quantitative research while avoiding the limitations of both (Creswell and Plano Clark, 2011). This has been achieved by applying a critical realist theoretical framework which has allowed for the individual experiences of participants including both their similarities and differences to be taken into account enabling a fuller account of taste changes to be described.

3.1 Mixed Methods Methodology

Methodology can be understood as a theory of how research needs to proceed to produce valid knowledge and guides the design and process of the research, including decisions about data collection tools, sampling, data analysis and how inferences are made (Braun and Clarke, 2013; Andrew and Halcomb, 2009 and Teddlie and Tashakkori, 2009).

A mixed methods approach has been selected for this study, specifically an explanatory sequential mixed methods approach. Mixed methods research is a systematic approach to addressing research questions that involve collecting, analysing and synthesising both quantitative and qualitative data in a single research project (Creswell and Plano Clark, 2011; Davidson, 2009). A mixed methods design must have at least one quantitative and one qualitative method associated with it (Creswell and Plano Clark, 2011). Mixed methods studies should combine both methods whilst observing theoretical and methodological congruence (Andrew and Halcomb, 2009). It is essential that the synthesis of quantitative and qualitative data is planned to take place at a predetermined stage of the research process, either during the study planning, data collection, analysis or reporting (Halcomb et al, 2009). Mixed methods research has gained impetus in recent years, particularly in

healthcare research as it can be utilised to explore and describe as well as assess and evaluate (Andrew and Halcomb, 2009). This is particularly pertinent for this study where the aim was to explore the experience of taste changes, including the extent of and how patients manage their taste changes, rather than merely measure them. The research questions for this study clearly have both quantitative and qualitative elements, asking about the experience (qualitative) and also the extent and timing (quantitative) of the occurrence of taste changes as experienced by patients undergoing RT for HNC. Therefore a mixed methods design was the only way to answer these questions effectively providing the data required to understand the phenomena in more detail.

3.2 Theoretical Framework

A critical realist framework underpins this research, fitting both the values and beliefs of the researcher in clinical practice and the requirements of mixed methods research. The design of this study fits the ontological assumptions associated with the critical realism theoretical framework. Critical realism is best understood across three domains (McEvoy and Richards, 2006):

- The empirical – that which exists and can be observed directly
- The actual – refers to reality that exists but may not be observed or experienced in some way
- The real – structures and mechanisms that causes or influences what is seen or experienced

This in turn fits very well with the scientific knowledge of how radiation damages taste buds, which is the same process for each patient. However the way this phenomenon is experienced is very individual being filtered through personal experiences, values and beliefs.

A critical realist ontology suggests that both quantitative and qualitative approaches are important to use in a single research project in order to fully explore and understand the structures and mechanisms of what can be observed and

experienced. This approach also underpins the work of therapeutic radiographers acknowledging the technical and patient care aspects of their role.

Critical realism is an appropriate philosophical approach to underpin this research as it has an inclusive perspective which can accommodate the strengths of both positivist and constructivist positions while avoiding their weaknesses (Maxwell and Mitapalli, 2011). Critical realism integrates the realist ontology, that there is a real world that exists independently of our perceptions, theories and constructions, in this case taste changes as caused by radiotherapy, with a constructivist epistemology, that our understanding of the world is inevitably a construction from our own perspectives and stand point (Creswell and Plano Clark, 2011). Taste changes are caused in the same way for each patient undergoing RT for HNC, leading to loss of function and therefore loss of ability to taste food normally. Each patient with HNC will experience taste changes in a different way dependent upon their own perspectives, beliefs and previous experiences. Their experience of taste changes will be constructed and filtered through their own personal lens. The constructivist approach is associated with the understanding or meaning of a phenomena being formed from the individuals personal history and their social interactions (Creswell and Plano Clark, 2011). Adopting this approach to the research permits the understanding and acceptance of individual experiences. The axiology behind this research is a personal belief that patients are individuals and should be treated as such and should be valued for the unique way that they experience and respond to treatment for their HNC. This is a belief that I carry through to my clinical work. Patients with HNC are all having very similar treatment but the ways in which they experience treatment is very different and they have differing needs depending upon previous experiences, and the level of practical and emotional support available to them. This should be borne in mind when developing care plans for patients, as individual needs vary so should the care provided. This ensures that individual patients receive the care that they need rather than adopting a “one size fits all” approach, running the risk of not “fitting” some patients.

For this study an explanatory sequential mixed methods design was selected, acknowledging that the research questions had both quantitative and qualitative

aspects. The first part of the study involved the administration of a validated participant self-completed questionnaire (MDASI-HN) at two time points, weeks 1 and 4 of treatment, generating quantitative data. At the second time point those participants who had developed problems with tasting food were asked to complete some supplementary questions, generating qualitative data. This was followed up with the semi-structured interviews devised to explain and understand some of the data from the MDASI-HN questionnaire and supplementary questions, as well as learning more about patient experience, again producing qualitative data. Creswell and Plano Clark (2011) suggest that this methodology is suitable for studies where a qualitative follow up strand, such as interviews is used to explain initial quantitative results, in this case a questionnaire. They go on to say that the design is particularly appropriate when the researcher can return to participants to collect a second round of qualitative data. Radiotherapy is typically delivered daily Monday to Friday over six weeks and therefore provides an excellent opportunity to approach participants at more than one time point to collect data, without adding to their burden. Data was collected at 2 time points for the questionnaire participants and for those participants who took part in interviews this was the third point for data collection.

Creswell and Plano Clark (2011) talk about the philosophical challenges of starting with a quantitative positivist stance and moving to a qualitative constructivist approach as the research moves from first to second phase, however the critical realist philosophy facilitates this collaboration (Maxwell and Mittapalli, 2011). Maxwell and Mittapalli (2011) expand on this by suggesting that a realist ontology which supports the existence of a world that exists independently of our perceptions, is combined with a constructivist epistemology which is inevitably understood through a construction of our own perceptions and stand point.

Using a critical realist philosophy facilitates an explanatory approach which goes beyond simple triangulation of quantitative and qualitative results where the results from one strand are used to confirm the findings of the other. McEvoy and Richards (2006) describe using methodological triangulation for completeness in order to obtain complementary perspectives and a greater level of detail than could have been achieved by using either data source alone. For this research project neither

the MDASI-HN questionnaire, the supplementary questions nor the semi-structured interviews would have answered the research questions in enough detail to have been useful clinically or to add to the current body of scientific knowledge. The aim being to use each strand of the research to expand and explain the findings of the other, rather than merely confirming the findings. Applying a critical realist philosophy has facilitated a greater depth of understanding of the experience of taste changes and enabled a better understanding of how to support patients. For example the MDASI-HN identified participants who scored themselves as having the greatest problems with tasting food; these participants were then invited to take part in an interview where it was possible to uncover what this meant for individual participants and uncover similarities and differences in the experience. Maxwell and Mittapalli (2011) argue that ontological, epistemological and axiological assumptions are real properties of researchers and their evaluations and are part of what Mark et al (2000) call values. These assumptions inevitably influence the researcher's purposes and actions to some degree and are often implicit and not easily abandoned or changed, particularly in the case of personal values. Acknowledging, valuing and accepting these differences allows the researcher to gain diverse perspectives on the phenomena being studied so to deepen the understanding. The critical realist perspective also allows for and supports the fact that although participants are having the same treatment their experiences will be shaped by their own personal views and values but based upon real events.

The critical realist perspective on research design is to view the relationship that the researcher establishes with the participants as a real component of the "design in use" of the study (Maxwell and Mittapalli, 2011). This is rarely addressed in discussions of research design and one that is often critical to the actual functioning of the study (Maxwell, 2002 and 2005). This aspect has been particularly important in this study as the researcher works closely in clinical practice with the patient group recruited for the study. This had implications for the study in many ways. Firstly patients may have felt pressured into taking part in the study, as it was being led by someone heavily involved in their care. This was addressed by another member of staff approaching the patient to introduce the study and to ask if they were

interested in taking part in the study. At the recruitment stage the patient would only have met the researcher on one occasion so the relationship had not been formed at that point. Secondly participants who developed taste changes may have felt pressured into taking part in the interview stage of the study, as by that point they had built a relationship with the researcher. However just under half of participants with taste changes declined to take part in the interview, so this probably was not the case. It is also possible that participants might have been more likely to take part in the interview because by that stage they had developed a relationship with the researcher. The effect of the researcher during the interview cannot be ignored and it may be that the participant was more open because they had already established a relationship and felt comfortable with the researcher. A possible counter argument to this is that the participant may not have felt comfortable criticising the care provided by a team that the researcher is part of. Overall it was felt that the fact that the researcher had a close working relationship with the participants was helpful for the functioning of the study and allowed for open dialogue, with participants being very keen to provide information that might help future patients. It was necessary to remain mindful of these facts when analysing the data to reduce the potential for bias and distortion of facts. Prior to starting the interview stage of the research it was planned that the researcher would not answer any questions from the participants regarding their care during the interview. However it quickly became clear that for the interview to proceed smoothly a different solution to this would need to be found. Each interview participant asked the interviewer if their taste would improve after treatment was completed and it was decided that the interviewer needed to answer this question for the interview to proceed. This was managed by the interviewer asking the participant what they had been told regarding this already and then providing the standard answer "research suggests that taste begins to improve somewhere between 3-8 weeks after RT and will take a number of months to resolve". This is discussed in more detail in the results chapter. The critical realist philosophy allowed for this to happen, so long as the impact of the interviewer was acknowledged. It is argued that other philosophical approaches would not have permitted the interviewer to respond to questions in this way and the interviews may have been more stilted and the quality of the data would have

been negatively affected. This is supported by McEvoy and Richards (2006) who state that for critical realists the ultimate goal of research is to develop deeper levels of explanation and understanding. It was also important for the researcher that the values she holds in clinical practice could be present in her research.

Maxwell and Mittapalli (2011) identified four areas that realism can contribute to mixed methods research:

- Causal explanation
- Mind and reality
- Validity
- Diversity

Causal explanation focusses on the context of the research and demands that the context of the research is considered alongside the process of the research.

Mind and reality permits the acceptance that emotions, beliefs and values are part of reality and not simply extractions from behaviours or constructions of the observer. This supports the view that patients are individuals and need to be considered as such.

Validity and quality are a vital part of any good research study and are often the area where quantitative and qualitative researchers have the biggest disagreements. Addressing these points in mixed methods research can be even more problematic. A realist approach to validity entails that a valid description, explanation or interpretation must not only be supported by evidence but should address plausible alternative descriptions, explanations and interpretations of the phenomenon about which the claim is made (Barad, 2007; Maxwell and Mittapalli, 2011). This is important for the study because it permits more than one valid explanation of how participants manage their taste changes for example, providing several options for advising future patients.

Wiggins (2011) in his thesis examining the dilemma of mixed methods examined the ontological beliefs underpinning mixed methods research and reported that most researchers fail to satisfy the ontological beliefs of both the quantitative and qualitative paradigms of mixed methods research. Most research has a stronger

focus on either the qualitative or quantitative aspects of the research ignoring the other. Although this research has more focus on the qualitative aspects of the experience of taste changes the quantitative data has also provided important information that would not have been observed from the qualitative data alone.

The ontological beliefs associated with mixed methods research are “reality is what is useful, practical and works”. The epistemological beliefs focus on reality as known through using many tools of research that reflect objective and subjective evidence (Chenail, 2011).

This makes a mixed methods approach suitable for this study, where the aim is to understand the experience of taste changes, including the extent and timing of those taste changes during RT for HNC.

3.3 Pragmatism

Pragmatism is a world view typically associated with multiple methods of data collection to best answer the research question (Creswell, 2014) and has traditionally been associated with mixed methods research. The pragmatic approach focuses on the practical implications of the research and emphasises the importance of conducting research in a way that best addresses the research question (Chenail, 2011). Tashakkori and Teddlie (2003a) suggest that pragmatism is the best philosophical foundation for mixed methods research, but to honour both quantitative and qualitative methods and be explicit about when each is being used (Creswell and Plano Clark, 2011).

Although pragmatism was considered as the theoretical framework for this research it was not felt to be the best way to approach the research questions. The main criticism is that pragmatism is ontology free and therefore has no basis for an epistemological stance. Pragmatism draws upon many ideas, including employing “what works”, with the focus on the consequences of the research and the importance of the research question rather than the methods used (Creswell and Plano Clark, 2011). Mixed methods research is associated with using diverse

approaches and valuing both objective and subjective knowledge and in doing so mirrors the approach adopted in clinical practice when supporting patients through their treatment for HNC. However, pragmatism can be criticised for delivering what works now without developing a greater understanding of what has led to this. Taking a critical realist approach ensures that the interpretation of each new piece of data is made in the light of earlier data and this cyclical and iterative nature leads to better data integration and deeper understanding (Allmark and Machaczek, 2018). One of the first ideas that led to this research was the fact that some patients with taste changes carry on eating, whereas, others cannot bear to put food in their mouth. Clearly there is more to understand in this circumstance as what works for one person does not appear to apply to another. Patients are individual and need supporting in different ways to get them through their treatment and by being restricted in how we respond to patient needs runs the risk of providing substandard care. Improved clinical outcomes can be achieved by focussing on what works for individuals and supporting them to help them discover what works for them. Pragmatism begins with a practical problem and ends with a resolution of the problem for now, at least (Allmark and Machaczek, 2018). Using this approach would have run the risk of only discovering one version of what works for patients with taste changes whereas it appears that a single approach will not resolve this complex problem.

3.4 Justification of the Critical Realist Framework

Critical realism was selected as the most appropriate theoretical framework for this study as the ultimate goal was to develop deeper levels of explanation and understanding of the experience of taste changes (McEvoy and Richards, 2006). This also supports the researchers preferred way of working with patients, helping them to find the best way for them to manage their side effects of RT, appreciating that patients are individuals and have preferred ways of approaching problems. Forcing them to take an approach that goes against their preferences runs the risk of alienating them leading to poorer outcomes.

It was felt that the critical realist approach provided greater validity for the results as

it acknowledged different interpretations of the phenomena of taste changes. Critical realism is compatible with both qualitative and quantitative research questions and treats both perspectives as equally valid and useful (Maxwell and Mirtapalli (2011)).

3.5 Other Methodologies Considered

A qualitative study was considered initially, with the focus on the experience of taste changes using Interpretative Phenomenological Analysis (IPA). Although this could have successfully answered some of the questions regarding the experience of taste changes it would have been much less effective at assessing the extent of taste changes. The MDASI-HN questionnaire helped to identify participants who were self-reporting the worst problems with taste changes for interviews. Without this there is a risk that participants who appeared to be coping well with taste changes would have been approached for interview, ignoring those who appeared to be coping less well and this could have introduced bias to the study, as well as missing out important relevant data. As previously stated, in clinical practice it appears that some patients tolerate taste changes better than others, however, this is purely the perception of the researcher and the participant account might be quite different. In approaching only patients who appeared to be managing well the stories of those participants who appear to be coping less well might have been overlooked, missing out on their experiences and the learning associated with it, as well as introducing potential bias.

3.6 Justification of Mixed Methods

Overall mixed methods has proven to be the best way to research the experience of taste changes during RT for HNC. The combination of quantitative and qualitative methods has ensured that the research questions have been explored in depth and have aligned with the critical realist framework that has guided the study. It has

allowed the very real experience of taste changes to be constructed through the stories of the individual participants who have experienced taste changes.

The use of a questionnaire and semi-structured interviews has been effective in producing the raw data that has been analysed and interpreted to answer the research questions.

In the next chapter I discuss the methods used to carry out the study.

Chapter 4

4. Methods

In this chapter I describe the methods used in the study and the justifications for their selection. The primary research question was “what is the experience of taste changes during RT for HNC?”, with follow up questions looking at the extent of taste changes, how patients manage these taste changes and what motivates them to continue eating. These questions have both quantitative and qualitative aspects to them so a mixed methods approach was selected. There was more of a focus on the qualitative data as this described the experience and how participants managed the symptom. See appendix 1 for study protocol.

The following table 4.1 summarises the other methods considered for the study and why they were rejected before deciding upon a mixed methods design to best answer the research questions.

Method	Reason for rejection
Quantitative approach - questionnaire	This would not have uncovered the personal experience of taste changes and the reasons underlying the behaviours observed.
Qualitative approach - interviews	This would have provided qualitative data relating to the experience of taste changes. However identifying participants would have been problematic with the researcher approaching patients she subjectively felt were managing taste changes well. This had the potential to introduce bias and exclude the opinions of those apparently doing less well.
Interpretative Phenomenological	This approach could not have addressed

Analysis	the questions regarding the diagnoses and treatment regimens most at risk of taste changes.
Mixed Methods Study with a Pragmatic Approach	This approach would not have allowed for more than one version of reality as perceived by the individual point of view in the way that the critical realist approach has and does not have an ontological and epistemological basis unlike critical realism. This would have led to a narrower description of taste changes.

Table 4.1 Methods considered for the study

4.1 Setting

The study took place in the radiotherapy department at Velindre Cancer Centre in Cardiff. Velindre is a specialist hospital for the non-surgical treatment of cancer which includes radiotherapy, chemotherapy and other systemic anticancer treatments. Patients with HNC attend the department daily for 6-7 weeks for their radiotherapy treatment. They are seen weekly in the radiotherapy review clinic by me and other members of the MDT, including review radiographers, dietician, speech and language therapist and clinical nurse specialist. At this appointment the team assess how the patient is tolerating treatment and offer advice on managing any side effects. The patient is also given the opportunity to discuss any issues that are affecting them at that time. A holistic approach is taken to patient care to ensure that the patient is as well supported as possible throughout their treatment.

4.2 Study Design and Recruitment

4.2.1 Inclusion/Exclusion Criteria

Inclusion Criteria

- Any patient over 18 years of age undergoing radical RT or CRT over 6 or 7 weeks with a diagnosis of primary HNC, with taste changes a possible side effect of this treatment.
- Able to understand written/spoken English

Exclusion Criteria

- Patients who have pre-existing taste changes or loss of taste.
- Patients who are unable to understand or speak English
- Patient does not have a diagnosis of primary HNC
- RT being given with palliative intent i.e. less than 6 weeks duration
- Has had RT to head and neck region previously.

4.2.2. Recruitment

Every patient who met the eligibility criteria during the time period from November 2017 until June 2018 was approached to take part in the study. Only five patients did not accept the information sheet and all who accepted the information sheet gave their consent to take part in the study.

Potential participants were approached to take part in the study when they attended their review clinic appointment on day 2 of radiotherapy. This is a planned clinic that runs alongside radiotherapy treatment. I run this clinic in my clinical role assisted by a team of review radiographers. The review radiographers were asked to explain the study to the patient and offer them a patient information leaflet (see appendix 2) if they were interested in taking part. I was not involved in this part of the study to avoid putting pressure upon patients to take part in the study. If the patient accepted an information sheet their details were passed to me and I arranged to meet the patient the following day when they attended for RT. I checked that the patient if they had been given the information sheet, if they had a chance to look at the information and if so did they want to take part. They were also given the opportunity to ask any questions about the study. If the participant was agreeable, they were asked to sign a consent form (see appendix 3) and given the first MDASI-HN questionnaire to

complete either then or if they preferred they could take it away and return it the next day.

Participants were given the second questionnaire at the beginning of week 4 of treatment and again asked either to complete it then or return it the next day. The week 4 MDASI-HN questionnaire had a sheet of supplementary questions attached and participants were asked to complete these questions if they had scored 5 or greater for problems with tasting food. In addition they were asked to provide their contact details if they were willing to take part in a semi-structured interview to discuss how their taste had been affected and how they had managed this symptom. I contacted participants who had provided their contact details to arrange a convenient time for the interview to take place. The interview was generally undertaken at a time co-ordinated with their RT appointment.

The information from the MDASI-HN and supplementary questions was used to guide the questions in the semi-structured interviews. The explanatory design is recommended when the researcher wants to look at the extent of a problem and how it is experienced by participants (Creswell and Plano Clark, 2011). Schneerson and Gale (2015) suggest that quantitative methods can enhance qualitative research by adding scope, depth and description to the research question. Morgan (1998) states that preliminary quantitative methods can be utilised to inform qualitative studies by guiding data collection such as interviews. During the interview I had the patient's questionnaire and answers to supplementary questions available so that answers could be clarified and investigated in more detail.

Data from the MDASI-HN was analysed using the scoring guidelines provided by the MD Anderson Institute (Rosenthal et al, 2007). The supplementary questions were analysed using thematic analysis as was the interview data. The quantitative and qualitative data were analysed separately initially and then combined so that the qualitative results provide explanation, interpretation and understanding of the quantitative results.

4.3 Study Procedures

I identified potential participants at the planning meeting which takes place on the Friday before the patient is due to start their treatment the following Monday. The patient is not present at this meeting, but it is attended by oncologists, medical physicists and therapeutic radiographers including myself with the intention of sharing information about any technical, procedural or social issues that may cause problems during the course of RT. I routinely attend this meeting as part of my clinical role and was able to identify any patients who may develop taste changes and were appropriate to be approached to take part. A pragmatic approach to recruitment was adopted with the study being offered to any patient who might develop taste changes as a result of their treatment. The Review Radiographer was asked to approach the patient in their first routine review clinic appointment and if they met the entry criteria, in particular they should not have any problems with tasting food at that stage; explain the study to them and give them a patient information sheet if they were interested in taking part. The review radiographer then gave the researcher the names of any patients who had accepted a patient information sheet and she then approached the patient the next day to answer any questions about the study and ask them if they would participate. If the patient agreed to take part, written consent was taken and the first MDASI-HN questionnaire was given to the patient. They were asked to either complete it then or if they preferred they could take it away and return it the next day. It is acknowledged that allowing the participant to take the questionnaire away may reduce the return rate but as patients attend daily for RT if the participant did not return the questionnaire the next day they could be reminded to do so. Any participant who did not return the questionnaire by the end of the first week of RT was excluded from the study as it would not be possible to determine when the questionnaire was completed. Only one participant failed to return their questionnaire in week 1 of RT. Giving the participant the opportunity to take the questionnaire away with them may have increased the return rate as it reduced the pressure upon the participant to complete it immediately. Those participants who returned the first questionnaire were then given the same questionnaire plus the supplementary questions at the beginning of week 4 of RT. It

was explained to each participant that they should complete the questionnaire as they had done previously and if they scored 5 or more for altered taste they were asked to complete the supplementary questions. If they were willing to be interviewed they were asked to add their contact details at the end of the questionnaire. Those participants who consented to an interview were interviewed in either week 5, 6 or 7 of RT. The interviews took place in the quiet room in the radiotherapy department and were audio digitally recorded. Before the interview, consent was taken again to ensure that the participant was still agreeable to the interview and understood the procedure. It was explained that the interview would be recorded but only me and possibly my supervisors would listen to the recording. I transcribed the interview as soon as possible after the interview and then anonymised the transcript so that the participant could not be identified. Refreshments and tissues were available for the participant during the interview and it was explained to them that they could take a rest whenever they required, and the interview could be stopped if they were finding it too difficult to continue. It was explained to them that there were no right or wrong answers and the interview was aimed at finding out about their experiences of altered taste and how they had coped with this. I had the participant's week 4 questionnaire and answers to the supplementary questions available during the interview and used the information from these to probe some of the answers where appropriate.

The majority of interviews lasted 30-40 minutes. After the interview I ensured that the participant was feeling well and answered any questions that may have arisen. If necessary, the participant was referred to other members of the MDT for appropriate support.

Although the interviews were transcribed as soon as possible following the interview no formal analysis took place until all the interviews had been transcribed.

4.3.1 Sample Size and Justification

Approximately 250 patients a year are treated with RT for HNC in the department. It was planned that 60-70 patients would need to be recruited to the quantitative part

of the study to ensure that sufficient patients would be recruited to the qualitative interview part of the study. No formal sample size calculation was done as this is an exploratory and descriptive study. It is accepted that up to 95% of patients undergoing RT or CRT for HNC will develop taste changes (Irvine et al. 2014), so the majority of patients would be potentially at risk of developing problems tasting their food. It was anticipated that more than 50% of patients would be eligible and agree to complete the MDASI-HN in weeks 1 and 4. It was also anticipated that fewer participants would agree to be interviewed due to the impact of side effects and the more time-consuming nature of the semi-structured interview.

Sampling for sequentially organised mixed methods studies is frequently purposive (Brannen and Halcomb, 2009). A purposive sample was used in this study, with the intention of selecting participants who would potentially experience the phenomenon being studied, (Creswell and Plano Clark, 2011) in this case taste changes as a result of RT for HNC.

For this study it was important that sufficient patients were recruited for the semi-structured interviews as the information from these would provide rich data about how the participants experience taste changes. Once the sample size for the qualitative interviews was determined, an estimate of the numbers to be recruited for the quantitative phase was made. When deciding upon the sample size for the semi-structured interviews the following criteria were considered (Morse, 2000):

- Quality of the data
- The scope of the study
- Nature of the topic
- The amount of useful information obtained from each participant
- The number of interviews with each participant
- The use of shadowed data
- The qualitative method and study design used

Malterud et al (2016) propose the concept of “information power” to guide sample size for qualitative studies. They suggest that the size of a sample with sufficient information power depends upon:

- The aim of the study

- Sample specificity
- Use of established theory
- Quality of dialogue
- Analysis strategy

There are clear overlaps between the two strategies and a combination of both was used to determine the number of interviews that needed to be conducted. This outlined below.

4.3.2 The Scope of the Study

There are particular problems with deciding on the sample size for interviews at the planning stage of a qualitative study (Hammersley, 2015). The broader the scope of the research question the longer it will take to reach saturation. This runs the risk of having only a superficial and shallow explanation of the topic (Morse, 2000, Malterud et al, 2016). For this study the topic is well defined and specific and will focus on taste changes suggesting a smaller number of interviews is required to reach saturation.

Hennink et al (2016) suggest that there is difficulty in defining saturation and even more difficulty in proving that it has been achieved. The literature does a poor job of operationalising the concept of saturation and providing little description on how it might be determined (Guest et al, 2006; Hennink et al, 2016).

4.3.3. The Nature of the Topic

If the topic being studied is clear and the information easily obtained in the interview, then fewer participants are needed than if the topic is below the surface with information difficult to uncover (Morse, 2000). It was not anticipated that participants would feel awkward discussing taste changes as it is not felt to be an embarrassing or difficult subject, again suggesting that fewer participants would be required. The questionnaire will have identified patients experiencing taste changes,

so only those experiencing problems with tasting food will be included in the interviews.

4.3.4 Quality of the Data

Some participants will express themselves better than others, they may be more articulate or more willing to share their experiences (Morse, 2000). It is known that patients with HNC may experience difficulties in communicating as a result of their disease and its treatment (Donovan and Glackin, 2012). The researcher is used to communicating with these patients daily in clinical practice and would not want to exclude patients because of communication difficulties as this may lead to missing important data. Clinical experience suggests that participants may experience difficulty putting into words how their taste has been affected. In this study participants were only be interviewed on one occasion. It is acknowledged that it is difficult to determine the quality of the data before the study takes place, however the fact that the researcher is used to working with this patient group should help improve quality (Malterud et al, 2016).

4.3.5 Shadowed Data

Shadowed data refers to patients talking about the experiences of others as well as their own (Morse, 2000). In the radiotherapy department patients often share experiences and support each other during their treatment, comparing what worked for them. It is possible during the interview that patients may talk about advice given to them by other patients on managing taste changes, if this happens the data would be included in the study as it is relevant to the research question. Morse (2000) suggests that use of shadowed data can enhance and enrich the analysis.

4.3.6 Analytic Strategies and Qualitative Sample Size

The two main methods for analysing data from interviews involve developing categories or developing themes (Morse, 2015). Developing categories involves extracting data using content analysis and the categorical grouping of items.

Developing themes is an interpretive process identifying themes that may run throughout the interview and be inferred or signalled, rather than being directly present (Morse, 2015). Thematic analysis was selected to analyse the interviews and supplementary questions in this study.

Hennink et al. (2016) and Guest et al. (2016) have retrospectively looked at qualitative interview studies to determine when saturation of ideas had been achieved. In a study of interviews of 24 patients with HIV it was found that code saturation had been reached by the time 9 interviews had been analysed but for meaning saturation to be achieved between 16 and 24 interviews were required (Hennink et al, 2016). Further analysis demonstrated that 50% of the codes identified were present in interview one with a further 25% being identified in interviews two and three. 90% of the codes identified were present by interview nine and interesting these figures remained the same no matter what order the interviews were analysed (Hennink et al, 2016). Hennink et al (2016) conclude that code saturation may be achieved with few interviews as it provides an outline of the main domains of inquiry, but further data are needed to provide depth, richness and complexities that hold important meaning for understanding the phenomena of interest.

Malterud et al (2016) with their concept of “information power” suggest that the more information the sample holds, relevant for the study, the lower the number of participants needed. They go on to suggest that although an initial approximation of sample size is required for planning, the final sample size must be continuously evaluated during the research process.

With all of this in mind it was proposed that between 20 and 25 interviews would be carried out with HNC patients who were experiencing altered taste as a consequence of RT for HNC. Given that it is anticipated that around half of participants would agree

to be interviewed a target number of between 60 to 70 participants was required for the questionnaire stage of the study. This number was decided upon taking into account the fact that 80-90% of participants were likely to develop taste changes. Recruitment continued until enough participants had agreed to take part in a semi-structured interview, with a total of 64 participants being recruited and 22 taking part in interviews.

4.4 Data Collection Tools and Materials

4.4.1 Questionnaire

As previously stated measuring taste changes in the clinical setting either objectively or subjectively is not easy and not commonly carried in a structured way. Electro and chemical gustometry are inefficient and difficult for the patient. The CTCAE is commonly used to grade the side effects of radiotherapy both in clinical practice and clinical trials, however this has very limited grading for taste changes compared to other toxicities, only utilising 0-2 scale. Clinically patients invariably score 2 giving very little differentiation between what individual patients are experiencing. The CTCAE grades most other toxicities between 0-4 which equates in simple terms to 0 if symptom is not present, 1 – mild, 2 – moderate, 3 – severe and 4 as bad as is imaginable.

It was clear that none of these tools were suitable for use in this study. It was important to the researcher that the patient's own experience was captured, rather than a clinician recording what they thought the patient was experiencing. Patient reported outcome instruments have the advantage of avoiding inter-rater variability as well as directly capturing patient perceptions (Rosenthal et al, 2008). For this reason a patient reported instrument was preferred over a QoL instrument or clinician completed instrument. Patient reported symptoms tend to be more severe than clinician reported and therefore may be a more accurate representation of symptom burden (Cleland et al, 2010; Rosenthal et al, 2014).

With this in mind a review of validated questionnaires that measure taste changes was undertaken to see if there was a tool available that would allow for participants

to self-report how their taste had been affected by RT or CRT. In addition to measuring taste changes the questionnaire was used to identify participants with the worst taste changes to take part in the interview section of the study.

McLaughlin and Mahon (2014), in their meta-analysis of the relationship among impaired taste and treatment, treatment type and tumour site in HNC identified four validated questionnaires that included taste as one of the domains. They identified these instruments by searching the Health and Psychosocial Instruments (HAPI) database. A repeat search of the database did not identify any additional instruments for consideration. The instruments identified were the MD Anderson Symptom Inventory Index-Head and Neck (MDASI-HN); the European Organisation for Research and Treatment of Cancer (EORTC) Head and Neck Cancer Module (QLQ_H&N35), University of Washington quality of life questionnaire (UW-QoL), and the Radiation Therapy Oncology Group Common Terminology Criteria for Adverse Events (CTCAE). These questionnaires were examined to assess their suitability for use in this study.

Irune et al (2014) in their review of treatment-related dysgeusia in head and neck cancer patients reported that there is no single validated tool that addresses taste alone. In addition to the CTCAE scoring system they identified the Scale of Subjective Total Taste Acuity (SSTA) which has been modified from the Late Effects of Normal Tissue/ Somatic Objective Management Analytic (LENT/SOMA) scoring system. The SSTA was considered in addition to those identified by McLaughlin and Mahon (2014).

The CTCAEv4 is commonly used in clinical practice and in research studies to grade any adverse event related to cancer treatment. It is used in clinical practice by the researcher and colleagues when reviewing HNC patients during RT but was rejected for use in this study as it uses a very limited grading system for altered taste:

- Grade 0: symptom not present
- Grade 1: altered taste but no change in diet
- Grade 2: altered taste with change in diet: noxious or unpleasant taste or loss of taste.

It is not known why for taste changes a scale of 0-2 is used when other symptoms are graded 0-4, however, it suggests that taste changes are not considered to be a serious event. It may be argued that although it is unlikely that a patient will die from having problems tasting food directly the resultant malnutrition from not eating can be very damaging. The CTCAE is completed by the clinician after discussion with the patient and this study focusses on patient experience, therefore a self-complete questionnaire is preferred. This tool was rejected as it does not provide sufficient sensitivity for this study as one of the aims was to understand more about how taste is affected during RT.

STTA was rejected as although it uses a wider scale (0-4) than CTCAE, experience from clinical practice suggested that most participants would score themselves as 3 or 4 therefore still providing little information about the severity of their taste changes. The STTA is reported as follows:

- Grade 0: Same acuity as before treatment
- Grade 1: Mild loss of taste acuity, but not inconvenient to daily life
- Grade 2: Moderate loss of taste and sometimes inconvenient to daily life
- Grade 3: Severe loss of taste acuity and frequently inconvenient to daily life
- Grade 4: Almost complete or complete loss of taste.

It was also felt that as this study is concerned with patient experience it would be helpful to understand any other symptoms that might change at the same time as taste.

The EORTC QLQ-HN35 comprises a total of 35 questions but only three of these relate to taste. It uses an ordinal 4-point scale, so provides more information about the prevalence of a symptom than the CTCAE but was rejected as it would gather information that would not be required for the study. It would be unethical to gather more information than is required for the study. The questions relating to taste could not be utilised alone as this would invalidate the tool.

The UW-QOL questionnaire asks specifically about taste with the patient asked to tick the most appropriate response from the following:

- I can taste food normally

- I can taste most foods normally
- I can taste some foods
- I cannot taste any foods

It also asks about 11 other symptoms specific to head and neck cancer patients and the patient is then asked to select up to three of these symptoms that have been particularly important to them over the last 7 days. This is followed by three more general questions about their QoL. This is then scored in an ordinal way with a lower number indicating a higher QoL. This questionnaire is patient reported and would give specific information about altered taste but would also collect information not necessary for this study. Whilst the UWQoL undoubtedly addresses taste and other issues related to RT and CRT for HNC it was not felt to be suitable for the needs of this study.

The MDASI-HN was designed to measure the symptom burden of HNC treatment symptoms and the impact of those symptoms on daily life (Rosenthal et al, 2007). The instrument consists of 13 general cancer symptom burden questions and nine items specific to HNC. Multi-dimensional measures have been criticised for mixing up these to create a single measure, however, the MDASI-HN also gives the opportunity for symptoms to be scored individually or in clusters of symptoms while maintaining validity (Rosenthal et al, 2007). One of the advantages of the MDASI-HN is that it includes problems tasting food as one of the symptoms associated with treatment of HNC whereas other tools do not include it. The team responsible for the development of the MDASI-HN consulted widely as to which items should be included. As well as reviewing relevant literature they spoke to HNC patients who had or were having a variety of treatments including surgery, radiotherapy and chemotherapy or a combination of these. They also sought opinion from representatives all healthcare professionals involved an HNC treatment and care including surgeons, oncologists, nurses, dental hygienists, speech and language therapists and dieticians. The fact that the team who developed the MDASI-HN consulted widely with patients and the MDT made the questionnaire attractive as it matched the study philosophy of being inclusive and patient centred. The reliability coefficient for the HNC specific items was 0.83 and tasting food was among the most

prevalent severe symptoms in the initial psychometric testing of the instrument (Rosenthal et al, 2007). The MDASI-HN uses a 0- 10 scale, where 0 indicates that the symptom is not present and 10 being as bad as you can imagine, giving the participant the opportunity to score on a wider scale than some of the other validated tools. The questionnaire can be completed in under seven minutes so would not be too much of a burden for participants to complete. Rosenthal et al (2007) argue that their tool is superior to others, particularly QoL measures as these frequently do not relate to symptom severity. It has been shown (Vokes et al, 2000) that some symptoms do not impact on QoL whereas QoL may be impacted by items that have not been included in the questionnaire. Rosenthal et al (2007) have attempted to overcome this by including the symptom interference items. This theory was interesting because as already stated some patients stop eating completely due to taste changes whereas others continue to eat, giving the impression that some patients are bothered more than others by their symptoms.

The MDASI-HN questionnaire was selected for use in the study as this collects the most information regarding symptoms relating to altered taste and has been proven to be reliable in indicating problems with tasting food. MDASI-HN uses an 11-point scale so will give patients the opportunity to report a greater level of differentiation of the altered taste they are experiencing. It was anticipated that this would give greater detail of the magnitude of distress being experienced by participants, with a score of 5-6 indicating that the symptom is causing moderate distress and a score of 7 or greater indicating severe distress (Rosenthal et al, 2007). MDASI-HN is particularly useful for longitudinal assessment of patients as it is essential to provide long term care for these patients. Although participants were only requested to complete the questionnaire on 2 occasions in this study it made it more important that the selected tool was easy to complete so that participants were not reluctant to complete it on the second occasion. It is acknowledged that some patients appear to be upset by their side effects more than others and it was hoped that the symptom interference scores in addition to symptom burden would shed some light upon this. In addition to the MDASI-HN questionnaire participants who scored 5 or greater for problems tasting food in week 4 of treatment were asked to complete some

supplementary questions to uncover more about their experience.

4.4.2 Supplementary Questions

It was anticipated that not every participant who scored 5 or greater for problems tasting food would agree to take part in an interview. In an attempt to understand more about the experience of taste changes from a wider selection of participants, supplementary questions were developed to be given to those participants who scored themselves as 5 or greater for problems with tasting food on the MDASI-HN in week 4 of treatment. It was hoped that those participants who did not want to take part in an interview would take the time to answer these questions and therefore provide some insight to their experiences and their views could still be included in the final analysis.

In clinical practice patients report that they can taste some flavours better than others, or that everything tastes bland or everything tastes foul. Some patients report that they find the texture of certain foods off-putting. It was hoped that the supplementary questions would provide some insight to this. As previously stated, all patients having RT for HNC are seen weekly in the review clinic by the MDT made up of review radiographers including myself, dieticians, speech and language therapists, specialist nurses and oncologists. One of the most difficult symptoms for the MDT to treat or advise about is altered taste. With all of this in mind the researcher approached a representative of each of the professions present at the MDT to find out what questions would be helpful for them to have answers to, so that they would be better placed to advise patients. They were also asked to consider patient interactions they have had were they wished they were better placed to advise the patient when developing these questions. Each member of the MDT approaches the problem of altered taste in a subtly different way depending upon their professional background. It was important that these questions focussed on the practical implications of taste changes and reflected discussions commonly had with patients during the review session with an aim of better understanding the problems associated with taste changes. They were then given sight of the proposed questions

and asked to comment on them before they were finalised. The researcher finalised the list of questions but aimed to ensure that the perspective of each profession was captured. The following questions were developed:

1. Are you able to taste any foods? YES/NO

If yes, please list some foods that you are able to taste.

2. Do you find the texture of some foods puts you off eating them? YES/NO

If yes, please list some textures of food you find off putting

3. Do you find the smell of some foods puts you off eating them? YES/NO

4. What advice, if any have you been given to help you cope with taste changes?

5. What advice would you give to someone else going through the same treatment who has taste changes?

6. Would you be willing to be interviewed about how taste changes have affected you during your treatment? YES/NO

Please provide your contact details if you are willing to take part in an interview to discuss taste changes:

Name:

Telephone number:

E-mail address:

Participants who gave consent were then invited to take part in a semi-structured interview, to discuss their experiences in more depth.

4.4.3 Semi-structured Interviews

Semi-structured interviews were the only qualitative data collection method considered for this study. They are the most commonly used qualitative data collection tool in mixed methods research and are associated with multiple philosophical assumptions meaning they are a flexible data collection tool (Bryman 2006; Povee and Roberts, 2015) and suitable to use with a critical realist framework. The semi-structured interview is designed to ascertain subjective responses from the participant with regard to a particular situation or phenomena that they have experienced (McIntosh and Morse, 2015). Semi-structured interviews are commonly used when the researcher has objective knowledge of the subject and wishes to uncover subjective knowledge of the situation or phenomena (McIntosh and Morse, 2015; Morse and Field, 1995). The researcher has knowledge of taste changes from her clinical work and also had the information from the patient MDASI-HN and answers to supplementary questions available during the interview.

The interviews had an explanatory purpose to find out more about the experience of taste changes with the participant as the informer, having the epistemological privilege as the knower in this situation (McIntosh and Morse, 2015).

Semi-structured interviews were carried out with participants during weeks 5-7 of RT either before or after their RT appointment, or at another time if that were more convenient for the participant. It was hoped that linking the interview to the RT appointment rather than inviting the patient to a separate appointment would increase the chance of the participant agreeing to take part. The interviews took place in the quiet room in the RT department and were audio digitally recorded. It was important for the interview to be conducted at a time when the patient was still experiencing taste changes so that they were talking about how they were affected at that time, rather than speaking from memory, even though it was acknowledged that this would be a time when participants were at the peak of their treatment reaction and for some patients their voice quality would be affected and the presence of copious thick secretions could make communication difficult. In order to address these issues, the participant was made as comfortable as possible with water

and tissues available for their comfort. Participants were encouraged to take a rest during the interview as necessary. As participants were attending the radiotherapy department daily, face to face interviews was the only method considered. The advantages of face-to-face semi structured interviews are that both verbal and non-verbal communication can be optimised and more complex issues explored as the interviewer can more easily clarify any misunderstandings (McIntosh and Marsh, 2015; Irvine et al, 2013). Communication difficulties are common in patients with HNC and meeting face to face minimises their concerns that they will not be understood due to surgical and radiation changes to the mouth.

One of the disadvantages of face-to-face interviews is that the participant may feel inhibited discussing sensitive issues. There is also the possibility of the unwanted interviewer effect. This was a particular consideration of this study as the interviewer was also responsible for clinical care for this patient group. This will be discussed in more detail later in the thesis.

The questions for the interview focussed on the impact of taste changes for the participant and were developed using their replies to the supplementary questions, giving the opportunity to probe the answers given. The main areas of questioning were:

- How has your taste been affected?
- What has that been like for you?
- Is there anything you can taste?
- How have you managed?
- What motivates you to carry on eating?

The interview questions were developed taking into account what is known and what was needed to be discovered. In this instance it is known how taste changes are caused by RT but less is understood about how patients experience taste changes and how they manage this difficult side effect and what motivates them to carry on eating when food tastes so bad. In addition to this information obtained from the literature review was also utilised when developing the subject areas for the semi-structured interviews.

Once the interview schedule had been developed it was reviewed by the researchers' supervisors and adjusted in light of the feedback received. The feedback related to asking open ended questions and not leading the participants in a particular direction, to avoid potentially introducing bias. The importance of using prompts to encourage participants to provide more detail was also discussed. Before being used in the study a pilot interview was carried out with a patient undergoing RT for HNC who was experiencing taste changes. The data from the pilot interview was not included in the final analysis.

The semi-structured interview was well suited to this study, as the interviewer was able to remain on topic but was still able to respond to the participant, therefore giving the interview structure whilst still allowing for further investigation of the participants comments (Bartholomew et al, 2000). In addition to questions outlined in the interview schedule any responses to the supplementary questions were explored further with the participant. During semi-structured interviews participants respond as they wish and the interviewer keeps the interview on subject while remaining responsive to the participant (McIntosh and Marsh, 2015). A descriptive/interpretive approach privileges the participant as the knower, they are the expert as they are experiencing the phenomenon and it is this experience that the interviewer aims to uncover (Bartholomew, 2000; McIntosh and Morse, 2015). It is essential that questions are open ended and formulated to generate discussion. For example:

"Can you tell me how your taste has been affected during your treatment please?"

The interviewer may diverge from the script and use probes to elaborate responses (Irvine et al, 2013). The probes may be scheduled or unscheduled, for example, they may be used to encourage the participant to expand their answer or as a sub question (McIntosh and Morse, 2015). The following are examples of prompts that were used during the interviews: "In what way....." or "Tell me more about....."

The questions should follow a logical order and move from easier to more complex or sensitive questions for example the emotional impact of taste changes was explored later in the interview.

Although the semi-structured interviews should be delivered following the interview schedule as far as possible, some participants spoke very freely and covered some of the additional questions without being prompted. In this circumstance the participant was not interrupted but allowed to continue their story. The interviewer ensured that all topics had been covered by reviewing the interview schedule and asking the participant if they wished to add anything else. At the end of the interview the participant was asked if there was anything else they would like to add that had not already been covered. This question frequently encouraged the participant to speak again and it wasn't unusual for the participant to talk for a further 5-10 minutes often disclosing things they had not covered previously.

McIntosh and Morse, (2015) state that semi-structured interviews are an ideal data collection tool in addition to a questionnaire for an explanatory mixed methods research study. The semi-structured interviews proved to be a very effective data collection tool for this study complementing and expanding upon the data collected using the questionnaire.

4.4.4 Pilot Interview

The pilot interview was important as it gave the interviewer the opportunity to practice asking the questions and responding to the participant replies. It helped to get a feel for the flow of the interview and if the questions were appropriate at eliciting relevant responses. The pilot interview was audio digitally recorded which also gave the researcher the opportunity to get used to using this equipment. The interview was then listened to by the researcher and supervisors and advice given on improvements that could be made, such as increased use of prompts and giving the participant time to consider their responses before interrupting.

The researcher is experienced in clinical interviews and less so in research interviews, so it was important that the correct technique was used. Clinical interviewing can be good preparation for research interviews but the purpose and context is different and it must be remembered that the focus of data collection is broad in the research

interview, whereas, clinical interviewing is focussed on identifying a problem and managing it (Tod, 2015). The interviewer needed to give the participant the opportunity to answer the questions without interrupting too soon and spoiling their flow, whilst still giving prompts when they were interested to know more about the idea the participant was talking about.

4.5 Data Analysis

4.5.1 MDASI-HN Analysis

A list of participants and their allocated study number was entered into an Excel spreadsheet along with their diagnosis, age, treatment regime and whether they had a gastrostomy tube placed prior to RT or an NG tube placed during treatment. On the paper questionnaire participants were identified only by their study number. Descriptive statistics were used to analyse demographic data such as age and diagnosis of participants. The mean age of participants was calculated along with the standard deviation and compared to population level data where this was available. Questionnaire data for each participant was collected on a paper version of the MDASI-HN and then entered into an Excel spreadsheet for analysis. The data entry was then double checked for correctness and any corrections made as needed. The participants had completed the questionnaire themselves and the questionnaire proved to be very straightforward to complete with very few cases where the participant had not understood what was expected of them. Some participants sought clarification at the time they were completed or when they returned them so any problems were resolved ensuring good quality data was collected. The questionnaire consists of 22 symptoms (13 core cancer symptoms common to most cancer sites and 9 HNC specific items) and 6 symptom interference items. Participants are asked to rate how severe their symptoms have been over the last 24 hours on a scale of 0 – 10, where 0 indicates that the symptom is not present and 10 indicating that the symptom is as bad as you can imagine. Of the questionnaires returned all participants had completed the 22 symptoms but a number of

participants had not answered all of the symptom interference items. It was decided to include these responses in the analysis as the primary objective was to assess the extent of taste changes so not having the symptom interference section completed would not affect these results.

The MDASI-HN questionnaire has guidance provided to assist with scoring the questionnaire and this guidance was followed (Rosenthal et al, 2007). The items included in the questionnaire may be scored individually or in groups of symptoms without affecting the validity of the tool. This has been made use of to look at individual scores for altered taste as well as to look for groups of symptoms that may associate with altered taste.

The symptom interference items were analysed separately and only those that had completed all responses were included in this part of the analysis.

Rosenthal et al, (2007) validated the questionnaire for use with HNC patients in a variety of circumstances including those that had surgery, RT or chemotherapy as their treatment and during treatment and follow up. They reported the following symptoms to be the most prevalent:

Symptom	% reporting symptom	Core/H&N specific symptom
Having a dry mouth	45.1	Core symptom
Difficulty swallowing or chewing	43.9	H&N specific symptom
Fatigue	40.2	Core symptom
Problem with tasting food	33.7	H&N specific symptom
Problem with mucus	32.7	H&N specific symptom
Disturbed sleep	31.7	Core symptom
Pain	30.9	Core symptom

Table 4.2 most prevalent symptoms during validation of MDASI-HN (Rosenthal et al, 2007)

As the questionnaire had been validated with HNC patients at various stages of treatment and follow up, it was not expected that the results of this study would match the findings of Rosenthal et al (2007).

Rosenthal et al (2007) state that the MDASI-HN is validated to be used in a number of ways. Scores for individual symptoms can be compared across groups of participants or alternatively symptoms can be scored in the following way:

0 – symptom not present

1-4 mild symptom

5-6 moderate symptom

7-10 severe symptom.

This method was used to compare symptom prevalence in weeks 1 and 4 of treatment across the whole sample. The sample was then split into the group who developed taste changes and the group who did not and the results compared between both groups. This was carried out to see if there were any underlying differences in the two groups in week 1 that could have been used to predict who may go on to develop taste changes. Rosenthal et al (2007) state that a score of 5 or greater may be considered to be causing significant problems for the patient. For this reason, a score of 5 or greater has been used as the cut off point for taste changes in this study, with any participant who scored themselves 5 or greater for problems tasting food in week 4 of treatment being considered to have taste changes. Although the primary objective of this study was to determine the extent and experience of taste changes during RT for HNC, it was of interest to find out if any baseline symptoms may be indicative of developing taste changes in the future and if there were any symptoms developed alongside taste changes. Once the interviews had taken place the questionnaire data was then split again to compare the characteristics of interview group with those who developed taste changes but declined to be interviewed. This was done to check if there were any differences between the participants with taste changes who were interviewed and those who declined, to ensure they were a representative sample of participants with taste changes. Any differences between these groups were borne in mind during the analysis.

The scores for each individual symptom for each participant can be totalled to give a global score of symptom distress. This is scored out of a possible score of 220 if each symptom was considered to be as bad as they could imagine, or zero if the participant did not have any of the symptoms. This method has been used to look at the changes

in total score for individual participants in weeks 1 and 4 of treatment and for those who developed taste changes and those who did not. Mean total symptom scores with the standard deviation were calculated for the whole cohort and also for the sub-group of participants who developed taste changes and the group who did not. The mean was calculated by totalling the scores from all of the participants and then dividing the answer by the number of participants. The standard deviation provides a measure of how the individual scores vary around the mean, with a low standard deviation indicating that the sample scores typically lie close to the mean and a larger standard deviation indicating a wider spread of data (Walters and Freeman, 2015). The 6 symptom interference items are also scored from 0-10 and Rosenthal et al (2007) state that these scores should be averaged to give an indication of total symptom interference. The mean and standard deviation were calculated for the whole cohort and the taste changes and non-taste changes sub-groups in the same way as for the symptom severity scores. Again, these scores were compared for the taste changes and non-taste changes groups in weeks 1 and 4 of treatment.

4.5.2 Analysis of Supplementary Questions

The supplementary questions were analysed using thematic analysis and the results presented for each individual question. The responses to these questions were used to help develop questions for the semi-structured interview.

4.5.3 Semi-structured Interview Analysis

Thematic analysis was selected to analyse the interview data, to be descriptive and explanatory regarding the experience of taste changes. Thematic analysis is unique in qualitative analytic methods as it only provides a method for qualitative data analysis and does not prescribe methods for data collection, theoretical positions, epistemological or ontological frameworks. It is a theoretically flexible method therefore making it suitable for use in this study which is underpinned by critical realist philosophy (Braun and Clarke, 2013). Themes are identified from the

transcripts and defined across the transcripts to build up a picture of the experience of taste changes.

The interviews were transcribed verbatim by the researcher as soon as possible after the interview in preparation for analysis. The interviews were anonymised and the participant given a pseudonym to protect their identity as per step one of Braun and Clark (2013) 6-phase process to carry out a thematic analysis. This allowed the researcher the opportunity to become immersed in the data, which has been recommended for more effective analysis (Quinn and Clare, 2008) and begin to develop ideas of emerging themes.

The next step was to read and become familiar with the transcripts and become fully immersed with the data. This stage was helped by the fact the researcher had transcribed the interviews herself so was already familiar with the text and had begun to develop ideas relating to themes. Notes were made of terms of potential interest and anything that may be relevant. This was done by highlighting words and chunks of text that were felt to be important. The transcripts were read through a number of times to ensure that nothing important was missed and to see if the same things were noted. When reading the data the following points were considered:

- How the participant was making sense of their experiences?
- Why might they be making sense of their experiences in the way that they are?
- In what different ways do they make sense of their experiences?
- How common sense is their story?
- What assumptions do they make when talking about the world?
- What kind of world is “revealed” through their account?

The next step was to begin coding the data – complete across entire data set – identifying aspects of the data that relate to the research question. This involved assigning a code word to chunks of text that related to the research questions in some way. This could be explaining the experience of taste changes, for example any piece of text that related to the timing of taste changes was coded “timing”. All of the texts were systematically worked through searching for any comments about the

timing of taste changes, for example, when taste changes were first noticed. It was essential that this work was carried out in a systematic way. This process was then completed for each of the coded chunks. It became apparent during this process that some of the ideas coded overlapped and were then combined into a single concept. Coding was completed by identifying anything and everything that was of interest and relevance to answering the research questions in each of the transcripts.

The next step was to search for themes. A theme captures something important about the data in relation to the research question and may be a summary statement explaining something that has been experienced (Rubin and Rubin, 2012; Braun and Clark, 2013). A code is a single idea whereas a theme is a central organising concept but will contain different ideas or aspects related to and defining the central concept. Braun and Clark (2013) describe searching for themes as an active process. It took some time to develop the themes to ensure that all the concepts fitted the theme and consider where overlapping occurred. To aid this process relevant chunks of text for each participant were recorded and these were then cut into individual pieces of paper so that they could be arranged under themes and easily moved around. These were then stored in a folder under each theme. This also gave an indication of the number of times a particular theme had been reported by participants and some participants may have revisited a theme a number of times. For example 11 participants used the phrase "I have no appetite" with participant 9 using this phrase 3 times and participant 17 on 2 occasions. In keeping with the critical realist theoretical framework a concept did not have to appear in more than one interview to be included as a theme if it was felt that this provided valuable insight into the experience of taste changes. Please see Appendix 9 for an example of this.

The next step involved reviewing themes and producing a map of provisional themes, sub-themes and relationships between them (thematic map). This is discussed in more detail in the results chapter. Consideration was given as to what supports a theme and what is original but relevant and looking for patterned responses. This is in keeping with the critical realist theoretical framework, accepting that participants will experience the same phenomenon in different ways and each version is equally valuable. Themes were then defined and, where appropriate, best and worst case

scenarios were identified. For example the range of when participants noted taste changes for the first time ranged from 2 – 20 days with a cluster of results around 10 days into treatment. This is reported in the results section by giving a case of a typical participant with taste changes and then contrasting this with the best and worst case scenario to illustrate the range of experiences. The final stage was to write up the analysis and this is reported in the results chapter and illustrated with anonymised quotes from the data to support the themes. The process of writing also helped to develop ideas. The sections of the folder where the quotes and chunks of data were stored was revisited when writing up the individual themes and the story was woven together using the participant's words as far as possible as well as using quotes to illustrate each theme.

4.5.4 Data Integration

Finally, both sets of data were considered together to provide the explanatory depth for the study. The interview data gives meaning to the questionnaire data giving an insight into the experience of taste changes as a result of RT for HNC. For example, it is widely reported that taste changes peak in week 4 of RT but less is known about what happens to taste between starting RT and week 4 and the interview data has been able to describe this.

If the data did not explain or support the questionnaire findings the critical realist approach allowed for more than one explanation of how participants managed their taste changes to be valid. Theories were developed as to why this might be the case, based upon interpretation of the interview data but also taking in to account clinical experience. The most common explanation being individuals having a different perception of the phenomenon of taste changes. The mixed methods approach supported by a critical realist philosophy has provided a comprehensive description of taste changes as experienced by patients undergoing RT for HNC.

4.5.5 Trustworthiness

Trustworthiness in mixed methods research relies upon the researcher having skills in both qualitative and quantitative research methods as well as integrating the data appropriately (Creswell and Plano Clark 2011). The trustworthiness relates to how the data answers the research questions and how the researcher demonstrates this (Creswell, 2013). Lincoln and Guba (1985) refined the concept of trustworthiness by introducing the criteria of credibility, transferability, dependability and confirmability to qualitative research to mirror the concepts of reliability and validity in quantitative research. In this study I have been clear in my methods describing how I have designed, collected and analysed the data, so that my methods can be followed by others therefore strengthening the trustworthiness of the study. I have provided examples of the qualitative analysis in Appendix 9 and all of the themes identified are defined in the results chapter.

4.5.6 Reflexivity

Reflexivity in qualitative research requires the researcher to reflect upon their role in the study, including their personal background and experiences (Creswell, 2013; Braun and Clarke, 2013). In this study the researcher was also involved in the clinical management of the participants. She purposely was not involved in recruiting patients to avoid claims of bias or coercion at that quantitative stage. However by the qualitative interview stage the researcher was well known to most of the participants. On reflection this may have helped the participants to talk freely as they had already built rapport with the researcher and trusted her and therefore felt safe expressing their opinions. Lincoln and Guba (1985) discuss prolonged engagement with participants improving the credibility and therefore the trustworthiness of the research.

The researcher is very experienced in caring for patients with HNC and this must be borne in mind when analysing the data. She has knowledge that less experienced professionals would not possess and it would not be possible to put this knowledge

aside when designing the study and analysing the data so it must be acknowledged. There is more information on the background of the researcher in the introductory chapter.

A diary was kept during the planning and data collection stages of the study and this was helpful to record why decisions were made as well as how the researcher was feeling during the interviews and any observations, such as the participant becoming upset. Lincoln and Guba (1985) recommend keeping a reflexive diary to document logistical issues, methodological decisions and the researcher's personal reflections during the research. The diary was revisited during transcribing process to add comments and aid with data analysis. Beforehand it was felt that the interview schedule might need to be changed if it was not working well in practice but this did not prove to be the case, however the diary would have assisted with this process had it been necessary .

Overall it is felt that the researcher's expertise in the field was an advantage and enabled a true report of taste changes during RT for HNC to be uncovered.

4.5.7 Presentation of Results

This study is an explanatory sequential mixed methods study and the results are presented in keeping with this methodology. An explanatory sequential study requires that the researcher first conducts a quantitative study in this case the MDASI-HN questionnaire and then builds upon these results and explains them in more detail with qualitative data (Creswell, 2014) in this case the semi-structured interviews. Finally in line with mixed methods methodology the results must be combined at some stage to answer the research question.

First the results of the MDASI-HN from weeks 1 and 4 are presented, followed by the results of those who developed taste changes and those who did not. These results are then further divided by those who were interviewed, looking for differences between the groups. Next the results of the supplementary questions and the

interview results are presented with each theme being defined. Finally the results from the questionnaire, supplementary questions and interviews are combined, including quotes from participants to show how the research questions have been answered.

4.6 Ethical Considerations and Regulatory Compliance

Ethical approval for the study was granted from Wales LREC 3 and service level approval from Velindre NHS Trust Research Risk Review Committee (See appendix 4). The completed questionnaires are stored in a locked filing cabinet along with the participant consent forms. All transcribed data is stored in a password protected file in a password protected computer. Participants in the quantitative part of the study are identified by a number to maintain confidentiality. The researcher has a master list of the participant names and numbers in a password protected file in a password protected computer. Interviews were digitally recorded and once transcribed were deleted from the recorder. When the interviews were transcribed each participant was given a pseudonym in order to anonymise any quotes and maintain confidentiality throughout the course of the study and writing up.

The Head and Neck Clinical Nurse Specialist, Review Radiographers and psychology and counselling team provided a point of contact for any patients who may have become distressed during the study as they would for any patient undergoing RT for HNC.

In the next chapter I present the results and analysis from the questionnaire and semi-structured interviews.

Chapter 5

5. Results and Data Analysis

In this chapter I present the results of the MDASI-HN questionnaire undertaken by participants in weeks 1 and 4 of treatment; the results of the supplementary questions and the semi-structured interviews as well as the demographic data. The results of the demographic data and MDASI-HN questionnaire are presented using descriptive statistics and graphs. The results are presented for the whole cohort and then for those participants who developed taste changes and finally for the interview participants. I have chosen to present the data in this way to demonstrate that the sample is representative of the population with HNC in the UK and also how the interview participants were identified and also fit this criteria. The supplementary questions and interviews were analysed using thematic analysis. Themes that were identified from the interviews are defined to support the trustworthiness of the study. At this stage I combine the data to answer the research questions and use participant's quotes to add depth to the story and support the findings showing how the interview data explains some of the findings of the questionnaire but also adds to our understanding of the phenomenon of taste changes. This is in keeping with the explanatory sequential mixed methods approach utilised in this study.

5.1 Description of Study Population

Participants were asked to complete the MDASI-HN in weeks 1 and 4 of treatment. A total of 64 patients who met the inclusion criteria were recruited to take part in the study and signed a consent form agreeing to take part. To be included in the analysis, participants must have completed and returned the MDASI-HN questionnaire in weeks 1 and 4 of treatment. From this initial sample three participants were excluded from the analysis because they did not complete both questionnaires, leaving a total of 61 patients who completed both questionnaires. Of the three who were excluded, one participant failed to return both questionnaires and two failed to return the week 4 questionnaire, all three were female. The initial

analysis is of the answers provided by the 61 participants. Figure 5.1 below shows the route participants took through the study.

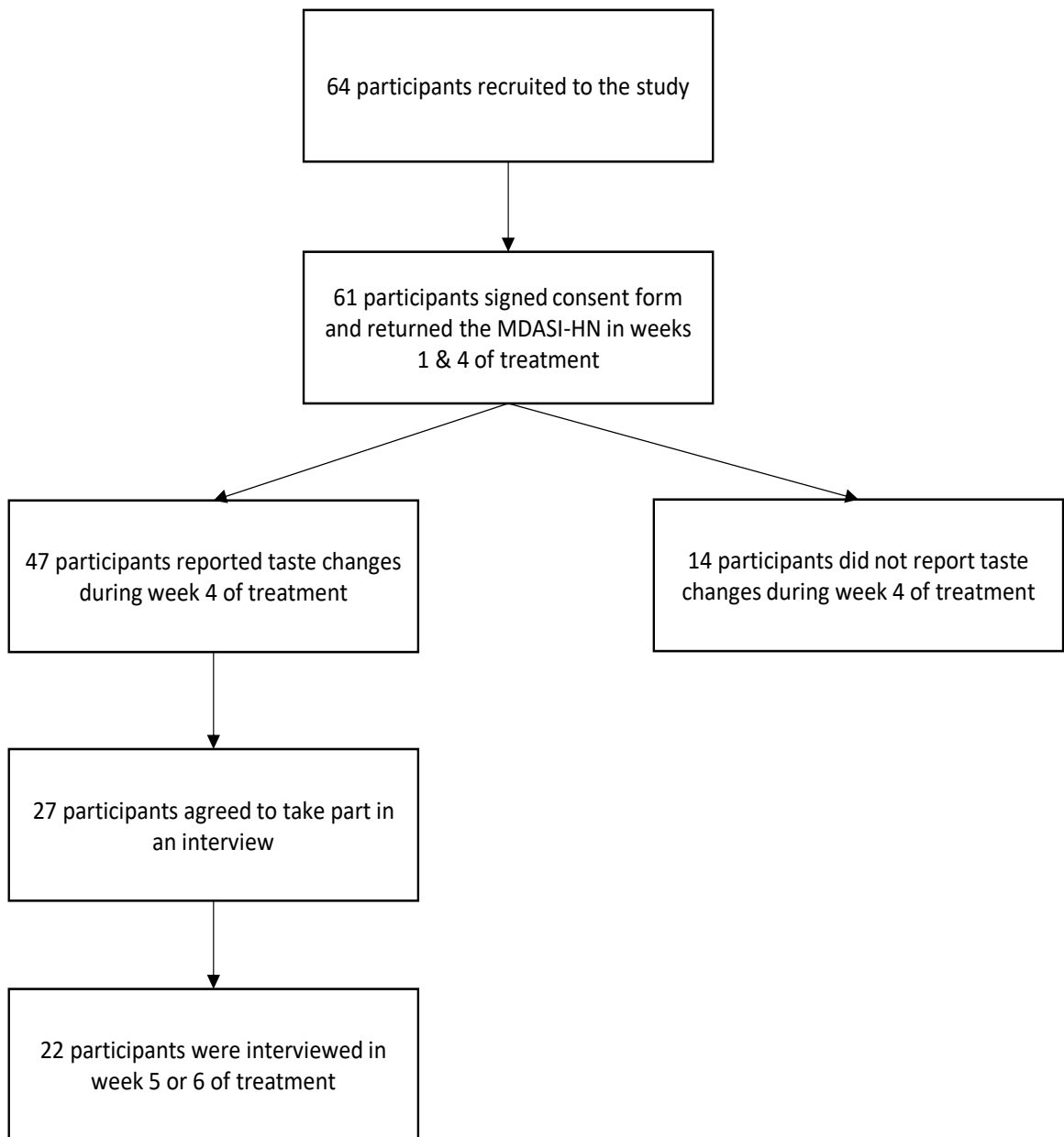


Figure 5.1 route of participants through the study

Table 5.1 below shows the characteristics of the participants in the study. Gender and age of participants is recorded along with the treatment modality they received. Thirty three participants (55%) were having chemotherapy concurrently with their RT and this is similar to the proportion seen in clinical practice. It is known that both chemotherapy and radiotherapy can affect the taste buds leading to problems tasting food, so it is important to know which treatment regime participants were receiving.

5.1.1 Characteristics of Study Population

CHARACTERISTIC		STUDY POPULATION n = 61 (%)	GENERAL HNC POPULATION
Gender	Male	48 (79)	69%
	Female	13 (21)	31%
Age		Mean 63.2years S.D. 10.2 Range 36- 88 years	Mean 62 years Peak incidence 50-70 years (CRUK, 2017)
Treatment modality	RT ONLY	28 (45)	Varies dependent upon stage of disease
	CHEMO/RT	33 (55)	Varies dependent upon stage of disease
Feeding tube	Gastrostomy	18 (30)	Not known
	Naso-gastric (NG) tube placed during treatment	15 (25)	Not known
	No tube	28 (45)	Not known

Table 5.1 characteristics of the participants

All patients at risk of developing taste changes as a result of their treatment for HNC were approached to take part in the study, so a variety of tumour sites that come

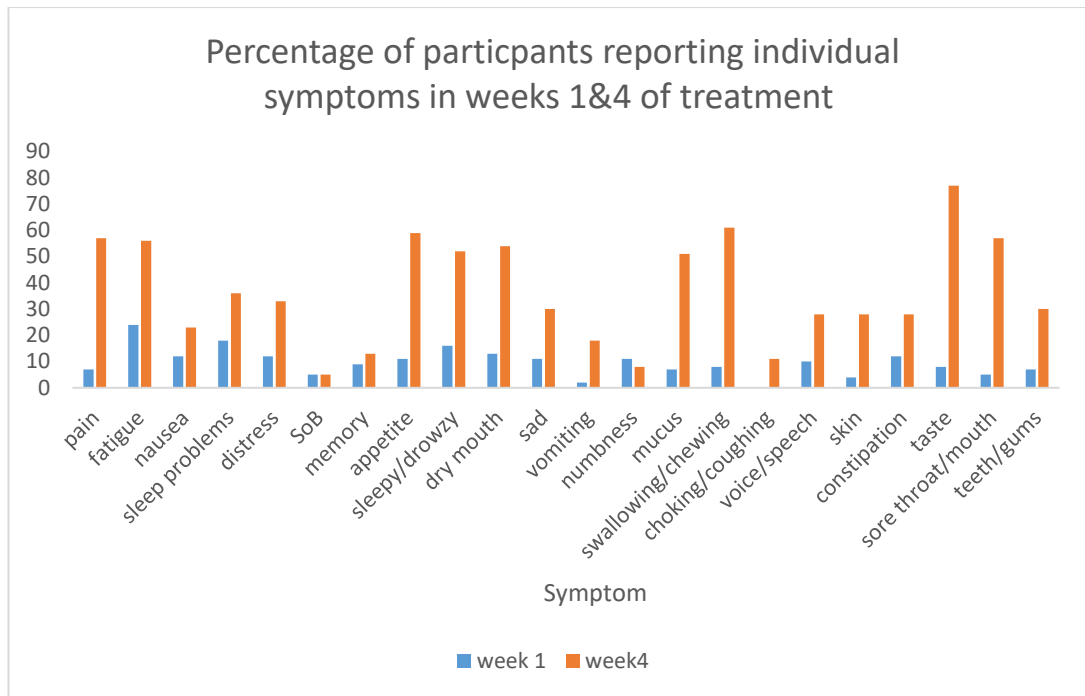
under the umbrella term Head and Neck Cancer were included in the study. The table below shows the diagnoses that were included in the sample:

Diagnosis	Number of participants n = 61 (%)
Oropharynx	32 (53)
Larynx	8 (13)
Oral cavity	7 (11)
Parotid	5 (8)
Unknown primary/neck nodes	4 (7)
Pyiform sinus	2 (3)
Ethmoid sinus	2 (3)
Nasopharynx	1 (2)

Table 5.2 diagnoses included in the study

5.2 MDASI-HN Questionnaire Results

The MDASI-HN questionnaire consists of 22 symptom distress items and a further 6 questions related to the interference caused by those symptoms known as symptom interference. A symptom was considered to be causing problems for a participant if they scored 5 or greater, as defined by the scoring criteria for the MDASI-HN questionnaire (Rosenthal et al, 2007). The incidence of individual symptoms reported by participants as scoring 5 or greater in weeks 1 and 4 of treatment are illustrated in the graph below.



Graph 5.1 percentage of participants reporting individual symptoms in weeks 1&4 of treatment

It is generally accepted that side effects and symptoms will increase during a course of RT or CRT, with symptoms reaching their peak in the final weeks of treatment and lasting for two weeks afterwards before gradually subsiding. The symptoms recorded in week 1 of treatment should be considered to be the baselines symptoms, i.e. the symptoms that the participant had when they started treatment, rather than related to RT. These symptoms could be caused by the cancer or related to previous treatments such as surgery or induction chemotherapy or as a result of any comorbidities that the participant might have had.

From the graph 5.1 above it can be seen that the most prevalent symptoms in week 1 of treatment are fatigue (24%); disturbed sleep (18%). These are both core cancer symptoms as defined by the MDASI-HN questionnaire and it is expected that H& N specific symptoms will increase in incidence the further in to the course of treatment a participant is.

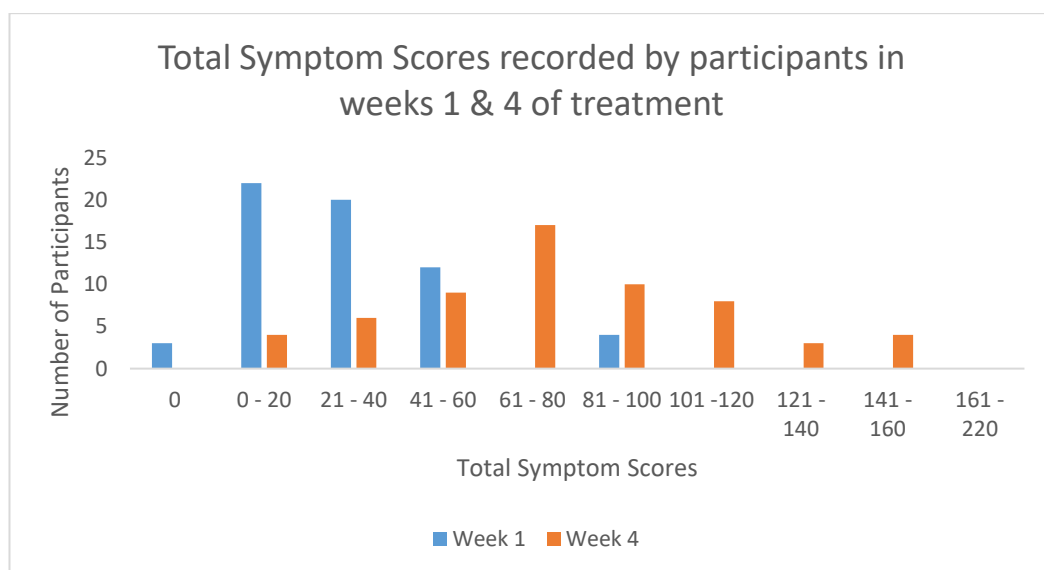
In week 4 of treatment, as expected, participants were experiencing a wider range of symptoms. The most prevalent symptoms at this stage were problems with tasting food (77%); difficulty swallowing or chewing food (61%); lack of appetite (59%); pain (57%); sore mouth/throat (57%); fatigue 56% and dry mouth 54%. The symptoms

showing the biggest change in incidence between weeks 1 and 4 are problems with taste, difficulty swallowing and sore throat with shortness of breath and numbness or tingling showing the least change. Shortness of breath and numbness or tingling are core cancer symptoms therefore would not necessarily be expected to change during treatment. Taste changes, difficulty swallowing and sore mouth or throat are core HNC symptoms and expected side effects of RT for HNC, so it is not surprising that these have increase during treatment. Fatigue and problems with appetite also increased considerably and these are core symptoms commonly associated with all cancer treatments.

5.2.1 Total Symptom Scores

A total symptom score for each participant was calculated by adding together the score they had recorded for each symptom. There are 22 items on the MDASI-HN questionnaire, therefore if the participant were experiencing the worst imaginable case for each symptom they would score a maximum of 220 points and a score of zero if they had no symptoms at all.

The graph 5.2 below shows the range of scores recorded in weeks 1 and 4 of treatment. The mean symptom score in week 1 was 28.6 with a range of 0 -93 and standard deviation of 23.1. In week 4 the mean symptom score was 78.3 with a range of 4 – 160 and standard deviation of 38.2.

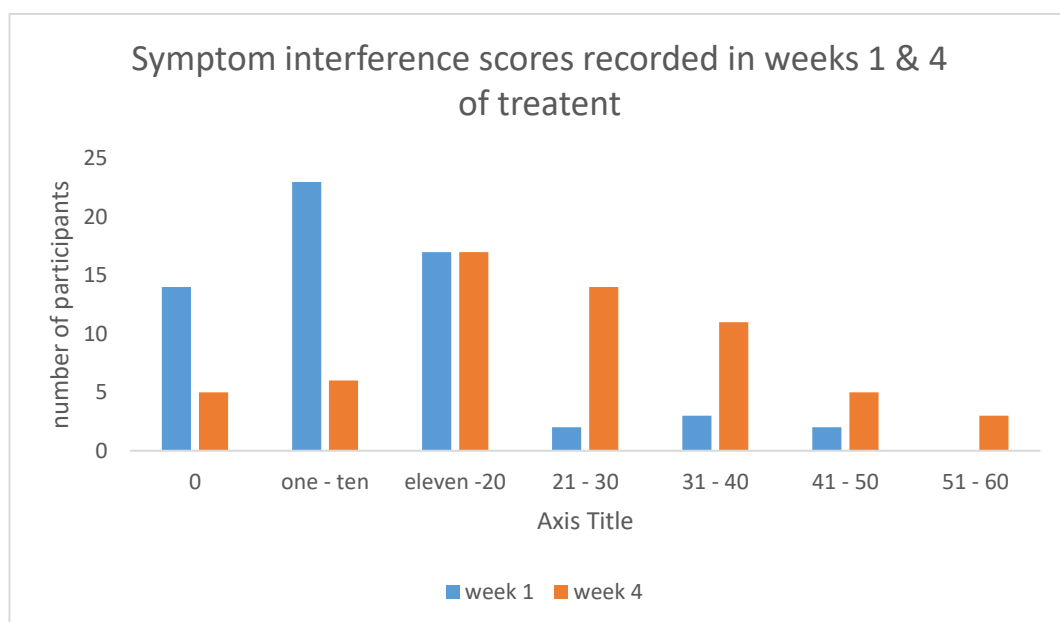


Graph 5.2 total symptom scores recorded by participants in weeks 1 and 4 of treatment

In line with participants reporting a wider range of symptoms in week 4 of treatment the total symptoms scores also increased. In week 1 of treatment three participants felt that they were not experiencing any symptoms with the rest of the sample reporting mainly mild symptoms. By week 4 of treatment no participants reported that they were not experiencing any symptoms, with a much wider range of total symptom scores being recorded.

5.2.2 Symptom Interference Scores

It was anticipated that symptom interference scores would increase alongside symptoms experienced as participants went further through treatment. The results recorded in weeks 1 and 4 of treatment are presented in graph 5.3 below.



Graph 5.3 total symptom interference scores recorded by participants in weeks 1 and 4 of treatment.

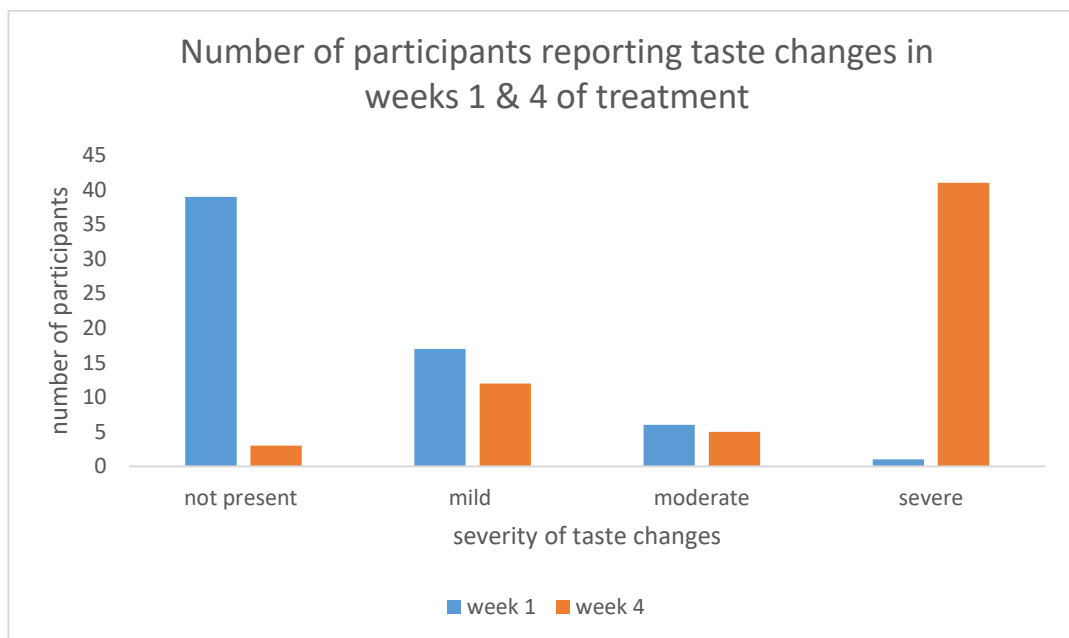
In week 1 of treatment 14 participants reported that they had no interference from their symptoms compared with only three who reported no symptoms at that point. In week 4 of treatment five participants reported no symptom interference despite all participants reporting that they had symptoms at that stage. This reflects what is

noticed in clinical practice where patients report that they have noticed side effects but they are not giving them any cause for concern.

The mean symptom interference score in week 1 was 10 with a range of 0 – 46 and standard deviation of 11, while in week 4 the mean symptom interference score had risen to 23 with a range of 1 – 58 and a standard deviation of 15.

5.2.3 MDASI-HN Scores for Problems Tasting Food

The graph 5.4 below shows the number of participants reporting problems tasting their food in weeks 1 and 4 of treatment and the severity of those taste problems.



Graph 5.4 number of participants reporting taste changes in weeks 1 and 4 of treatment

The time interval between being recruited for the study and completing the questionnaire was between 1-3 days, with many participants choosing to complete the questionnaire as soon as they were given it. In the time interval between being recruited for the study and completing the questionnaire 22 (37%) participants developed some degree of problem with tasting their food. This would not have been more than 2-4 days into their treatment as a maximum. MDASI-HN considers a score

of greater than 5 for any symptom to indicate a significant problem for the patient. Therefore, in the first week of treatment 5 (9%) participants developed obvious changes in their ability to taste food. The graph 5.4 shows that only 3 participants reported no problem with tasting their food in week 4 of treatment. For the purposes of this study a cut off score of 5 or greater is used to define taste changes, therefore 47 of the 61 participants or 77% were experiencing taste changes at this stage, with 95% of participants reporting some change to their sense of taste.

The graph 5.4 demonstrates an almost complete mirroring of the week 1 and week 4 results, with 47 participants now reporting moderate or severe taste changes. The 47 participants who reported taste changes will be termed the taste changes group from now on and the remaining 14 participants the non-taste changes group. It is interesting to note how few participants reported moderate taste changes in either week 1 or week 4 suggesting that problems with taste are either perceived to be mild or severe with little in between.

Further analysis now focusses on the 47 participants who developed taste changes in an attempt to understand more about them and whether there were any differences in them or their treatment that may have increased their chances of developing taste changes. The results of the non-taste changes group are presented for comparison.

5.3 Characteristics of Taste Changes Group

The table 5.3 below shows the characteristics of the original sample compared with the taste changes and non-taste changes groups.

CHARACTERISTIC		Whole sample N = 61	TASTE CHANGES GROUP n= 47 (% of whole sample)	NON-TASTE CHANGES GROUP n =14 (%)
Gender	Male	48 (79)	35 (73)	13 (27)
	Female	13 (21)	12 (92)	1 (8)
Age		Mean 63.2 years SD 10.2 Range 36 – 88 years	Mean 61.3 years SD 9.86 Range 36 – 82 years	Mean 69.3 years S.D. 8.85 Range 54 – 88 years
Treatment	RT Only	28 (45)	18 (64)	10 (36)
Modality	Chemo/RT	33 (55)	29 (88)	4 (12)
Feeding tube	Gastrostomy	18 (30)	17 (94)	1 (6)
	NG tube placed during treatment	15 (25)	12 (80)	3 (20)
	No tube	28 (45)	18 (64)	10 (36)

Table 5.3 characteristics of taste changes group and non-taste changes group

From the table above it can be seen that 92% of the females in the study developed taste changes. There are only a small number of females included in the study and this reflects the clinical situation where more males than female are diagnosed with HNC, however this may indicate that females are more susceptible to developing taste changes. This is explored further in the discussion chapter.

Eighty eight percent of participants having CRT developed taste changes compared with 64% of participants having RT only.

Ninety four percent of participants who had a gastrostomy tube placed prior to treatment developed taste changes. Gastrostomy tubes are placed in patients who are deemed to be more at risk of malnutrition during treatment and it is known that taste changes are a contributory factor to malnutrition during treatment (Bressan et

al, 2016). This suggests that the correct group of patients were targeted to have gastrostomy tubes placed.

Eighty percent of participants who had an NG tube placed during treatment reported taste changes and those taste changes would have been a contributory factor to them needing the NG tube being placed. Other factors that lead to the requirement of NG tube placement for feeding are sore mouth or throat, difficulty swallowing and pain which have been shown to be symptoms that also increased throughout the course of treatment.

It can be seen from table 5.4 below that 88% of participants with a diagnosis of oropharyngeal cancer developed taste changes.

Diagnosis	Number of participants n = 61 (%)	Taste changes group n = 47 (% of each diagnosis)	Non-taste changes group n = 14 (% of each diagnosis)
Oropharynx	32 (53)	28 (88)	4 (12)
Larynx	8 (13)	3 (37)	5 (63)
Oral cavity	7 (11)	5 (71)	2 (29)
Parotid	5 (8)	4 (80)	1 (20)
Unknown primary/neck nodes	4 (7)	2 (50)	2 (50)
Pyriform sinus	2 (3)	2 (100)	0
Ethmoid sinus	2 (3)	2 (100)	0
Nasopharynx	1 (2)	1 (100)	0

Table 5.4 number and percentage of participants with taste changes by diagnosis

This is perhaps not surprising as the RT treatment field will include areas of the oral cavity and pharynx that have many taste buds. Patients with oropharyngeal cancer commonly have CRT which is associated with increased risk of taste changes.

Participants with a diagnosis of oral cavity and parotid cancers would also be at high risk of taste changes for the same reasons. It is interesting to note that 37% of participants with a cancer of the larynx developed taste changes, as it is often reported that this group of patients do not develop taste changes even though in clinical practice patients having RT for laryngeal cancers report taste changes. These results support this indicating that just over a third of patients with laryngeal cancers will be affected by taste changes.

5.3.1 Most Prevalent Symptoms for Taste Changes Group

The table 5.5 below shows the main similarities and differences in the symptoms experienced by the taste changes and non-taste changes group compared to the whole sample in week 1 of treatment.

Symptom	% reporting symptom in week 1 whole group N = 61	% reporting symptom in week 1 in taste changes group n=47	% reporting symptom in week 1 in non-taste changes group n = 14
Fatigue	24*	30*	7
Disturbed sleep	18*	23*	14
Lack of appetite	11	15	0
Feeling drowsy	16*	21*	0
Dry mouth	13	15	7
Numbness/tingling	11	9	21*
Mucus	7	9	0
Constipation	12	17	0
Taste	8	9	7
Sore mouth/throat	5	4	7
Teeth/gums	7	6	7

Table 5.5 prevalence of symptoms in week 1 in the taste changes and non-taste changes groups

*denotes most frequently occurring symptoms

The group of participants who went on to develop taste changes showed a similar symptom profile to the whole sample but were slightly more likely to experience fatigue and problems with disturbed sleep. The non-taste changes group appear to have had less symptoms overall at this stage than the taste changes group.

The table 5.6 below shows the individual symptom scores recorded by the taste changes and non-taste changes group compared to the whole population in week 4 of treatment.

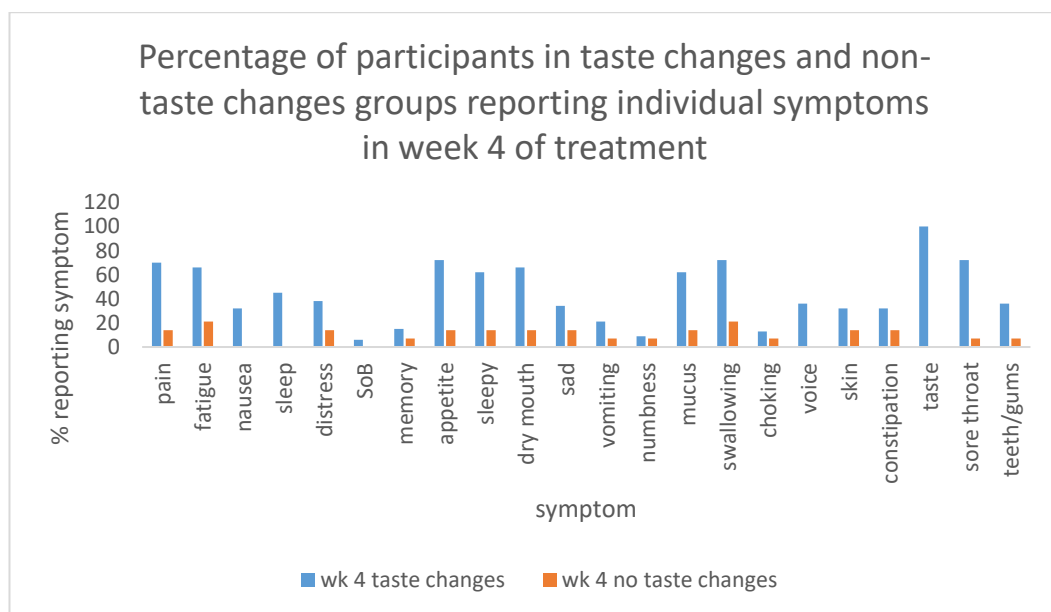
Symptom	% of participants in whole sample reporting symptom in week 4 N = 61	% of participants in taste changes group reporting symptom in week 4 n = 47	% of participants in non-taste changes group reporting symptom in week 4 n = 13
Pain	57*	70*	14
Fatigue	56*	66*	21*
Nausea	23	32	0
Sleep	36	45	0
Distress	33	38	14
Appetite	59*	72*	14
Sleepy	52	62	14
dry mouth	54*	66*	14
Mucus	51*	62*	14
swallowing	61*	72*	21*
Voice	28	36	0
Taste	77*	100*	0
sore throat	57*	72*	7
teeth/gums	30	36	7

Table 5.6 prevalence of symptoms in week 4 in taste changes and non-taste changes groups.

*denotes most frequently reported symptoms

The taste changes group had a similar pattern of side effects to the whole sample but in general had a higher incidence of these side effects, in most cases around 10% higher. Again the non-taste changes group recorded a lower incidence of other symptoms. It is beyond the scope of this study to state that particular symptoms might predict the incidence of taste changes but it appears that participants with a heavy symptom burden may be at more risk of developing taste changes. This may be explained by participants with more symptoms having more advanced cancer and therefore larger treatment fields would need to be used leading to increased treatment side effects.

The graph 5.5 below shows the difference in symptoms reported in week 4 of treatment in the taste changes and non-taste changes groups.



Graph 5.5 symptoms reported in the taste changes and non-taste changes groups in week 4

5.3.2 Total Symptom Scores for Taste Changes Group

The table 5.7 below shows that the taste changes group had a considerably higher total symptom score than the non-taste changes group.

Total symptom scores in week 4	Whole group N = 61	Taste changes group n= 47	Non-taste changes group n =14
Range	4 - 160	15 – 160	4 – 64
Mean score	78.3	90.9	35.9
Standard deviation	38.2	32.6	21.6

Table 5.7 total symptoms scores and range of scores recorded by taste changes and non-taste changes groups in week 4.

In the non-taste changes group no participant scored higher than 64, whereas in the taste changes group over 50% of participants scored higher than this. This reflects the fact that the taste changes group reported a wider range of symptoms than the non-taste changes group.

5.3.3 Symptom Interference Scores for Taste Changes Group

The symptom interference score provides a measure of how much interference symptoms are giving participants. The table 5.8 below compares the symptom interference scores for the taste changes and non-taste changes groups with the whole sample in week 4 of treatment.

Symptom Interference	Whole group week 4 N =61	Taste changes group week 4 n = 47	Non-taste changes group week 4 n = 14
Mean score	22.95	26.50	11.14
Standard deviation	14.8	14.5	8.1
Range	0 - 58	0 - 58	0 -22

Table 5.8 symptom interference scores for taste changes and non-taste changes groups in week 4.

Again the taste changes group have higher symptom interference scores than the whole group. This is not surprising given that they had higher symptom scores, so it might be expected that those symptoms would cause more interference for them. Two participants reported no symptom interference, whilst three participants

recorded scores at the top end of the scale of 51 – 60. In the non-taste changes group only one participant scored greater than 20 for symptom interference. This links in with the previous observation that this group reported fewer symptoms.

5.4 Characteristics of the Interview Participants

All of the participants in the taste changes group were invited to take part in a semi-structured interview to discuss their experience of taste changes to take place during the remaining weeks of their treatment. From the group of 47 patients with taste changes, 29 agreed to be interviewed and 22 of these patients went on to be interviewed, 17 males and 5 females. These numbers are representative of the male to female ratio in the whole study and of patients with HNC in the general population. To check that the group who agreed to be interviewed were representative of the taste changes group their symptom scores were compared. The results are presented in the table below.

	Interview group Week 1 N =22 (%)	Taste changes group week 1 N = 47 (%)	Interview group Week 4 N = 22 (%)	Taste changes group week 4 N = 47 (%)
Pain	5	9	55*	70*
Fatigue	23*	30*	59*	66*
Nausea	14	15	32	32
Disturbed sleep	23*	23*	41	45
Distress	9	13	32	38
Appetite	5	15	64*	72*
Feeling sleepy	9	21*	55*	62*
Dry mouth	14	15	64*	66*
Sadness	9	13	32	34
Mucus	5	9	55*	62*
Swallow difficulties	5	9	68*	72*

Voice	5	9	18*	36*
Skin	0	2	27	32
Constipation	14	17	27	32
Taste	5	9	100*	100*
Sore throat/mouth	0	4	68	72
Teeth/gums	0	6	23	36

Table 5.9 symptom prevalence in interview group compared to taste changes group in weeks 1 and 4

It can be seen from table 5.9 that the interview group had less severe symptoms than the whole group with taste changes. It is likely that participants who has milder symptoms were more likely to agree to be interviewed. However, the symptom profile for both groups is similar and the top five reported symptoms for each group are the same. In addition to taste problems there are problems with appetite, swallowing difficulties, sore mouth or throat, dry mouth and pain. The biggest differences between the two groups are observed for problems with voice; 36% in the taste changes group, compared with 18% in the interview group and pain 70% in the taste changes group and 55% in the interview group. It is highly likely that participants who had more pain and concerns about their voice were less likely to agree to be interviewed. These differences should be borne in mind when analysing the interview data.

5.5 Conclusions from Demographic Data and MDASI-HN Questionnaire

The main findings are summarised below:

- 77% of all participants had developed problems tasting food as defined by the MDASI-HN questionnaire during week 4 of treatment.
- 88% of participants having CRT developed problems with tasting food
- 64% who were having RT only developed taste changes.
- 92% of female participants developed taste changes compared with 73% of males. This difference in incidence has not been reported in previous studies.

- 88% of participants with a diagnosis of oropharyngeal cancer developed taste changes compared with 71% of participants with oral cavity cancers and 37% of those with laryngeal cancers.
- 80% of participants who had an NG tube placed during RT reported taste changes were a problem for them.
- 9% of participants noticed some changes in the way their food tasted before the end of week 1 of treatment.
- 95% of participants reported some degree of change in their taste in week 4 of treatment even if it was not bothering them.
- Fatigue (24%) and problems sleeping (18%) were the most commonly reported symptoms in week 1 of treatment.
- Problems tasting food (77%); difficulty chewing or swallowing (61%); lack of appetite (59%); pain (57%); sore mouth or throat (57%); fatigue (56%) were the most commonly reported symptoms in week 4 of treatment.

It is worth noting that participants who did not experience problems tasting food reported fewer symptoms overall.

5.6 Supplementary Questions Results

Participants who scored 5 or greater for problems with tasting food in week 4 of treatment were asked to complete a series of supplementary questions. It was hoped that participants who did not want to be interviewed would still be able to give a more in-depth report of their experiences, therefore gathering as much information as possible to understand how participants managed their taste changes. Some patients answered the questions despite scoring less than 5 on the MDASI-HN questionnaire and these responses have been excluded from the analysis. Not all participants with taste changes answered all of the questions. The 47 participants who reported a score of 5 or greater for taste changes in week 4 were included in the analysis. All answered at least one of the 5 supplementary questions and these results are presented below. Nineteen of the 22 interview participants answered all of the supplementary questions. One participant did not answer questions 4 or 5 and

two participants did not answer either question 4 or 5. Participants are identified by their study number at this stage as they were only given pseudonyms if they took part in an interview.

Thematic analysis was selected as an appropriate method for analysing the open-ended questions (Braun and Clarke, 2013).

Question 1

Are you able to taste any foods?

Yes – 49%

No – 45%

Not answered – 6%

Almost half of the participants who reported taste changes could not taste anything at all. Participants were then asked to list any foods that they were able to taste, with the most common responses are summarised in the table below.

Response	Number (%) giving response
Nothing	18 (38)
Sweet or very sweet things	12 (26)
Everything is salty	3 (7)
Everything is bland	3 (7)
Sharp foods	4 (9)
Citrus fruits	2 (4)
Puddings (e.g. trifle, custard, rice pudding)	12 (26)
Porridge/cereal	6 (13)
Pasta	4 (9)

Table 5.10 main responses to question 1 of the supplementary questions

Some participants gave more than one response to this question for example they may have been able to taste sweet and sharp foods. The biggest response was that participants couldn't taste anything at all. Some reported that although they could

taste certain foods, they did not taste normal. All respondents had a very limited and specific list of foods that they could eat. Overall, the impression was one of foods that could be tolerated rather than enjoyed.

Participant 24 reported that they could taste a very specific and limited list of foods:

“Weetabix with sugar, butter (not margarine) on bread, fish cooked in butter, treacle sponge cake and leek and potato soup (home-made).”

Question 2

Do you find the texture of some foods puts you off eating them?

Yes - 62%

No - 26%

Not answered - 12%

Participants were asked to list any food or textures of food that they found off-putting. The most common responses are summarised in table 5.11 below

Response	Number (%) giving response
Everything	5 (11)
Bread	11 (23)
Meat	8 (17)
Thick liquids	7 (15)
Hard/rough foods	5 (11)
Food with bits in	5 (11)
Anything that needs chewing	5 (11)

Table 5.11 summary of the main responses to question 2 regarding texture of food

Almost two thirds of patients found the texture of some or all foods off-putting. Two patients commented that the more you chew food the worse the taste becomes, and your brain tells you not to swallow it. Participant 28 reported:

“I have gone over to puree diet as mouth too sore to chew food. I find the texture of pureed food not very nice at all, but I have to eat something. I hold my nose while eating so cannot taste or smell.”

Again, the responses to this question give the impression of food being tolerated and also an understanding that nutrition is essential not enjoyment.

Question 3

Do you find the smell of some foods puts you off eating them?

Yes – 28% (28% of males and 50% of females)

No – 66%

Not answered – 6%

Participants were asked to list some smells they found off-putting, with the common responses being fried foods, vegetables cooking, and any food cooking. Around one third of the participants who reported taste changes could not tolerate the smell of any food cooking and had to stay out of the kitchen and away from the dining table when the rest of the family were eating.

Two participants reported that they didn't find smells off-putting but did find them disappointing as food smells normal making you think you would enjoy it, but it tastes awful.

Participant 5 didn't find the smell of food off putting but commented that:

“The food smells nice, but you don't want to taste it.”

Question 4

What advice, if any have you been given to help you cope with taste changes?

Twenty eight percent of participants did not answer this question. It is not known if this is because they had not been given any advice, or if the advice they had been given was not helpful. The responses are reported in table 5.12 below.

Response	Number (%) giving response
None	6 (13)
Keep trying foods	10 (21)
Eat what you can manage	8 (17)
Soft or smooth foods	5 (11)
Use the mouthwashes	4 (9)
Think of food as medicine	3 (7)
Use the supplement drinks	3 (7)
Advice from the dietician/team	3 (7)

Table 5.12 advice participants have found to help with taste changes

It is of interest that 13% of participants reported that they had not been given any advice to help them cope with taste changes, as one of the aims of this study is to be better able to advise patients regarding taste changes in the future. This is in addition to the 28% who chose not to answer this question, meaning over 40% of participants potentially had been given no information or no information that they found helpful.

Question 5

What advice would you give to someone else going through the same treatment who has taste changes?

Twenty six percent of participants did not reply to this question, but those that did respond were overwhelmingly positive with their advice and encouragement to others who may be going through the same treatment. The most common response (34%) was to keep trying/try everything and persevere or something similar. The other common responses are summarised in table 5.13 below.

Advice participants would give to another patient	Number (%) giving response
Keep trying different foods	16 (34)
Try liquidy foods	6 (13)
Try different foods/be open-minded	7 (15)

It's part of the treatment/think of food as medicine	3 (6)
Get on with it!/you have to eat	5 (10)
Listen to the advice form the team	3 (6)
Don't know	4 (9)

Table 5.13 responses to supplementary question 5

Participant 39 gave the following response:

“To be open minded to foods that you normally wouldn't eat- try different things. And eat as much as you can when you feel like eating! “

Much of the advice given was very practical, such as the advice from participant 44:

“Persevere. Make sure food is not too salty or too acidic. Eat slowly and chew food slowly.”

Participants were also very honest and acknowledged that they were learning themselves what worked and what did not. The following response is from participant 43:

“I don't know, I'm experimenting myself.”

This response also gives some insight to the difficulties faced by patients experiencing taste changes and knowing how best to cope with this.

5.6.1 Key Findings from Supplementary Questions

The supplementary questions have provided an insight into the experiences of the participants who reported taste changes but declined to take part in an interview.

Over 50% of participants who had taste changes could not taste anything at all with the remaining participants having only a limited number of foods they could tolerate.

Over 60% of participants also found textures of food off-putting, particularly anything with bits in it that required extra chewing. Ninety two percent of female participants with taste changes also found the texture of food off putting.

Approximately one third of participants found the smell of food unpleasant or off-putting particularly fried foods. Females were more likely than males to find the smell of food off putting 50% females compared to 28% of males.

Forty percent of participants did not feel that they had been given any advice to help them cope with taste changes during treatment. This needs to be addressed for future patients.

Participants wanted to provide practical and moral support to future patients but often were not sure themselves what helped.

The supplementary questions also supported the mixed methods methodology used in the study, linking the quantitative questionnaire with the qualitative interviews. In this case using an explanatory sequential mixed methods methodology, the supplementary questions and interviews served to explain the MDASI-HN questionnaire responses.

For those patients who agreed to be interviewed their questionnaire was taken into the interview and where appropriate their supplementary question responses were probed further to understand more about their experiences.

5.7 Interview Results

Of the 47 participants who developed taste changes twenty nine agreed to take part in an interview, with 22 going on to taking part in a semi-structured interview to discuss how their taste had been affected. Seven participants were not interviewed for the following reasons: four were not able to arrange a mutually convenient time for the participant and interviewer; two became too unwell to be interviewed; and one was cancelled twice due to bad weather. All interviews took place in either week 5, 6 or 7 of treatment while the participant was still having treatment or in the first week after they had completed their treatment and side effects were still at their worst. It was important that the interviews were conducted while participants were experiencing problems tasting food rather than speaking from memory. The interviews lasted an average of 28 minutes with a range of 14 minutes to 45 minutes.

The interviews were audio digitally recorded and transcribed verbatim by the interviewer as soon as possible after the interview. The interviews were then anonymised with participants being given a pseudonym.

5.7.1 Characteristics of the Interview Group

The table 5.14 below demonstrates that the interview group had similar characteristics to the whole study population, having similar gender split and average age and also similar proportions having feeding tubes. The proportion of participants having RT only is slightly higher in the interview group than the whole sample. These proportions are also similar to the whole population who experienced taste changes indicating that the interview population are representative of both patients with HNC undergoing RT and patients who develop taste changes.

CHARACTERISTIC		INTERVIEW POPULATION n = 22 (%)	WHOLE SAMPLE N = 61 (%)
Gender	Male	17 (77)	48 (79)
	Female	5 (23)	13 (21)
Age		Mean 62.1 years Range 36 – 82 years S.D = 9.5	Mean 63.2years S.D. 10.2 Range 36- 88 years
Treatment modality	RT	12 (55)	28 (45)
	CRT	10 (45)	33 (55)
Feeding tube	Gastrostomy tube	5 (23)	18 (30)
	NG tube	5 (23)	15 (25)
	No tube	12 (54)	28 (45)

Table 5.14 showing characteristics of interview sample compared with the whole study population

The distribution of diagnoses of patients in the interview sample was similar to that in the whole study population. Patients with oropharyngeal cancers are the biggest group in the whole study sample and this is reflected in the interview sample. Therefore, it can be assumed that the interview sample is representative of the population of patients with HNC.

Diagnosis	Number of participants (%)	Whole sample (%)
Oropharynx	13 (59)	32 (53)
Parotid	2 (9)	5 (8)
UKP neck nodes	2 (9)	4 (7)
Nasopharynx	1 (4.5)	1 (2)
Oral cavity	2 (9)	7 (11)
Larynx	1 (4.5)	8 (13)
Nasal Cavity	1 (4.5)	2 (3)

Table 5.15 diagnosis of participants in the interview sample and whole study population

All participants who were interviewed scored either 9 or 10 for problems with tasting food on the MDASI-HN in week 4 of treatment, indicating that they were experiencing severe problems. Questions were used to guide the interview (see appendix 7), but participants were encouraged to talk freely about their experience of taste changes. The main themes covered in the interview were timing of when taste changes occurred, how the participant was affected, how they managed, what if anything, was helpful, emotional impact of taste changes and effect upon family members and what motivated the participant to continue eating.

5.8 Interview Analysis

Once the interviews had been transcribed they were read and re-read a number of times to get a feel for the content. Notes were made and common themes identified along with examples of what defined a theme, as discussed in the methods chapter. Key quotes that illustrated the theme were gathered to be used in writing this thesis to ensure that the story of taste changes was told using the participant's words wherever possible. These quotes are used later in the chapter to answer the research questions

5.8.1 Themes and Definitions

The main themes are outlined below, along with a description of what defines that theme.

5.8.2 Timing of Taste Changes

The majority of participants felt that taste changes had happened sooner than they had been warned to expect them. They also reported that taste changes had not occurred in the way that they had been led to believe; for example food did not taste of cardboard. All of the participants sought advice from the interviewer regarding how long their taste would take to recover, suggesting they had not been informed of this prior to treatment, or needed reassurance.

5.8.3 Description of Taste Changes

Participants used vivid terminology to describe how food tasted to them. They also described what it was like trying to make yourself eat when your taste is affected. Words such as “rancid”; “oily”; “soapy” and “awful” make it easy to understand why patients cannot “just eat it” as has been suggested by some members of staff and relatives in the past. It is not a case of food tasting bland or not quite right, it actually tastes horrible and in normal circumstances this would be a warning not to eat the food as there is something wrong with it. It may be argued that it is more surprising that patients manage to continue eating when food tastes “rancid” or “oily”.

5.8.4 Disruption to Daily Life

This theme included not being able to eat meals with the family, not meeting friends for coffee, as well as not being able to eat meals that they would usually enjoy. Boredom and isolation were also components of this theme and the monotony of eating from a limited list of foods that could be tolerated.

5.8.5 Making Sense of the Situation

This theme included participants reasoning that although things are bad currently it won't last forever. They also reasoned that it was worth putting up with the pain of

the current situation for the hope of a cure and better times in the future. Acceptance was a common feature of this theme, such as the participant accepting that they would not be able to eat their usual meals and being willing to make adjustments.

5.8.6 Psychological Impact

The psychological impact of taste changes was clear both explicitly and implicitly in most interviews. It is difficult to be sure that taste changes were the only cause of the psychological issues noted but they were certainly a component of the problem. Also characterised in this theme were the frustration, anxiety and low mood and resilience.

5.8.7 Having a Plan

Having a plan was an important part of getting through the day for participants with taste changes. Knowing what needed to be done, when to take medication and use mouthwashes and planning what to eat at each meal. Having a plan relates to getting through the day but also on a broader outlook having a plan of what to do after treatment and having something to look forward to.

5.8.8 Sharing the Burden

Participants spoke with gratitude of the support they received from family members, friends and healthcare professionals. They showed concern for patients who might not have that support available to them. It did not seem to matter who provided this support so long as it was available to them.

5.8.9 Coping Strategies

Coping strategies appear to be one of the most important themes for participants. These were explicit for some participants and implicit for others; for example some participants spoke of how they had managed at other times of adversity and applied the same principles here. Others had a determination to carry on no matter what. Avoidance strategies were also used along with strategies such as imagining what the food would normally taste like. Seeking advice from family members or healthcare professionals was important for many participants and this also links in with the theme of “having a plan.” Participants sought the help of others to help them devise and execute a plan.

5.8.10 Motivation to Continue Eating

This theme outlines the reasons participants gave for continuing to eat even though their food tastes bad. It includes ideas such as not even thinking that not eating is an option and a determination to carry on. Strong motivators were wanting to avoid having a feeding tube and the participant wanting to preserve their swallowing function. There was also a strong survival instinct apparent for some participants who associated not eating with giving up on life. They were prepared to do whatever it takes to get through treatment. They tended to have a positive outlook and be able to see beyond what they were going through at the time.

5.9 Conclusions of Interview Results

The interviews have proven to be an effective tool to gather information about the experience of taste changes during RT for HNC. Participants were able to describe vividly their experiences. They valued having support and someone to share their burden, although it seemed to matter less who provided this support. It was clear that participants required accurate information regarding taste changes including when they would occur, what they would be like and how long they would last. They

realised the value of having a plan of how they would manage during treatment but acknowledged that the plan would need adjusting as circumstances changed. Individual coping strategies were important in how they managed and also strongly linked to their motivation to continue eating.

These results are now analysed in conjunction with the results from the questionnaire section of the study.

5.10 Analysis and Integration of Results

This thesis addresses the four main research questions:

- What is the experience of taste changes during RT for HNC?
- What is the extent of taste changes and which patients are more likely to develop taste changes?
- How do patients manage these taste changes?
- What motivates patients to continue eating when their food tastes horrible?

The results from the quantitative and qualitative sections are now analysed, integrated and presented to answer these questions. Some of the themes were common to more than one of the research questions, for example individual determination to carry on was concerned with the management of taste changes and motivation to carry on eating. The data from the quantitative and qualitative strands has provided more depth and detail than either would have on their own. The findings are summarised in the table below.

Research question	Interview Themes and MDASI-HN data that answer the question
The experience of taste changes	<ul style="list-style-type: none"> • Sooner than expected • Description of taste • Typical story of taste changes • Support and sharing the burden • Disruption to daily life • Making sense of the situation • Psychological impact – frustration, anxiety, low mood and isolation

	<ul style="list-style-type: none"> • Body image • Resilience
The extent of taste changes	<ul style="list-style-type: none"> • MDASI-HN symptom severity and symptom interference • Extent and timing – sooner than expected • Who gets taste changes • Diagnosis • Treatment modality • Demographic data
Management of taste changes	<ul style="list-style-type: none"> • Symptom management • Having a plan • Determination • Practical advice and issues • Coping strategies • Supplementary questions
Motivation to continue eating	<ul style="list-style-type: none"> • Avoid tube feeding • Fear of losing my swallow • Survival instinct • Determination to carry on • Acceptance

Table 5.16 the research questions and themes that answer these questions

5.11 The Extent of Taste Changes Experienced by Participants

The extent of taste changes experienced by the participants is covered in detail earlier in the chapter however to summarise only 5% did not report any changes in their ability to taste food during week 4 of treatment. In week 1 of treatment 22 (37%) of participants reported that they had developed some degree of altered taste. This is sooner than has been reported in the literature and was explored further in the interviews with participants.

There were only a small number of females recruited for the study, however it appears that they were more likely to develop taste changes than males undergoing the same treatment.

The average age of the participants who did not develop taste changes is higher than the average age of those who developed taste changes. The significance of this is not known, however it is known that sense of taste diminishes with age, so older patients

may have poorer sense of taste to start with. All participants received the same dose of RT regardless of their age, so this effect is not related to the RT dose delivered.

Eighty eight percent of participants having CRT developed taste changes compared with 64% of participants having RT only. Splitting this into male and female participants, 100% of females having CRT developed taste changes compared with 82% of males again suggesting that females experience more taste changes than males.

Ninety four percent of participants who had a gastrostomy tube developed taste changes suggesting that the correct group of patients had gastrostomy tubes placed.

Eighty percent of participants who had an NG tube placed during treatment reported taste changes and those taste changes would have been a contributory factor to them needing the NG tube being placed.

5.12 Site of Cancer in Participants who Developed Taste Changes

Eighty eight percent of participants with a diagnosis of oropharyngeal cancer developed taste changes. Participants with a diagnosis of oral cavity and parotid cancers would be at risk of taste changes as all of these diagnoses have treatment fields that include tissues containing taste buds. It is of interest that 37% of participants with a cancer of the larynx developed taste changes as it is often reported that this group of patients do not develop taste changes, even though clinical practice would suggest that they do. Taste buds are distributed in the pharynx and upper oesophagus so radiation treatment to these structures would also be expected to lead to problems with tasting food.

From the interview group 9 (40%) participants stopped taking any food orally, becoming reliant either on their NG tube or gastrostomy tube for their nutrition. The remaining 13 (60%) participants carried on eating sufficient food orally to not require enteral feeding or used a combination of tube and oral feeding. Given that they all had scored themselves either 9 or 10 for problems tasting food it appears that this is not a good predictor of who will continue eating and who will stop. This does

however reflect clinical practice where patients report that everything tastes awful but some continue to eat and others stop eating and become feeding tube reliant. These 9 participants were made up of 3 females and 6 males, so approximately 12% of males became tube reliant compared to 23% of females, suggesting that females are more likely to develop problems tasting food which then leads to them becoming tube dependent. However, this observation may be unreliable due to the small number of female participants in the interview group. When taking the taste changes group as a whole the proportion of males and females who had NG tubes placed was similar with approximately 60% of males and females in the taste changes group either having an NG tube placed or having a gastrostomy tube.

The MDASI-HN was selected for use in this study because of its reliability in reporting taste changes in patients undergoing treatment for HNC. It has been noted from clinical practice that some patients continue to eat when they have taste changes whereas others stop. It was hoped that the measure of symptom interference might help to uncover why this is the case. It was also hoped that there might be some baseline symptoms that would predict which participants would go on to develop taste changes. However this proved not to be the case. The symptoms that developed alongside taste changes were the expected symptoms of RT for HNC such as having a dry mouth, problems with mucus in the mouth or throat, difficulty swallowing or chewing food, pain and fatigue. Therefore the results of the MDASI-HN have not been helpful for this purpose, they have however been successful in identifying participants with the greatest problems with taste changes so that they could be offered an interview. The results of the MDASI-HN are presented earlier in the chapter with a selection of these included in the main part of the thesis as relevant.

As can be seen from the graph 5.4 above the majority of participants recorded taste changes as not present, mild or severe at both time points with a score of 5 or 6 used less frequently. This indicates that for most participants who developed taste changes they described them as severe. All of the participants who were interviewed scored either 9 or 10 for taste changes, with a score of 10 indicating that the problems tasting food were as bad as could be imagined. This is important as it

ensured that these participants with the worst taste changes were interviewed about their experience. Participants only needed to have scored 5 or greater to be included in the taste changes group however of the 47 participants reporting taste changes only six of them scored themselves a 5 or 6 for problems with tasting food in week 4 of treatment, with the rest scoring 7-10. All of the interview participants recorded a score in the range of 7-10 for problems with tasting food.

The other symptoms scored on the MDASI-HN questionnaire did not provide any insight to which symptoms might be associated with the development of taste changes, with expected side effects of RT for HNC increasing throughout the course of treatment. Taking all of this in to a count it appears that factors such as site of cancer and treatment modality are much more important predictors of who will develop taste changes than the presence of other symptoms. The mostly likely person to develop taste changes is someone having CRT for oropharyngeal cancer.

The symptom interference scores are intended to give a measure of how much any symptoms have interfered with the participant's activity, mood, work, relationships, walking and enjoyment of life. It might be anticipated that participants with more symptoms or more severe symptoms would report the greatest symptom interference.

Interestingly the participants who reported the worst problems with taste and who had stopped eating recorded some of the lowest symptom interference scores. They also recorded some of the lowest changes in symptom interference between weeks 1 and 4 of treatment. In fact some of the participants from the interviews who reported some of the worst problems with tasting food and who had stopped eating had lower symptom interference scores as shown in the table below. The five participants included in table 5.17 below were not eating any food at the time of their interview and could not even consider trying food. They were all dependent upon tube feeding for their nutrition.

Participant	Name	Total symptom score week 1 Range 0 - 220	Total symptom score week 4 Range 0- 220	Symptom interference score week 1 Range 0 – 60	Symptom interference score week 4 Range 0 – 60
6	Diane	37	175	5	58
14	Angela	47	95	24	23
32	Tony	8	101	9	43
35	Lewis	57	86	18	22
50	James	25	59	7	3

Table 5.17 total symptoms scores and symptom interference scores for participants who stopped eating

There appears to be less consistency in the interview group between those who talk about having severe problems with tasting food and the non-taste changes group, with the non-taste changes groups recording little symptom interference at either stage. For example Diane reported the highest scores for symptom severity of the interview cohort in week 4 of treatment and also one of the highest scores for symptom interference. Angela reported similar symptom interference in week 4 as week 1 despite symptom severity increasing. Yet neither of them could eat anything at all and both were dependent upon their gastrostomy tubes for feeding. This may be explained by the fact that Diane found the situation more distressing than Angela, although that did not appear to be the case from their interviews. Alternatively, Angela may have been utilising a different coping style to Diane, such as denying the severity of her experience.

Tony reported both increased symptom severity and symptom interference in week 4 of treatment, whereas, James who had a small increase in symptom severity in week 4 recorded very little symptom interference despite not being able to eat anything and having a NG tube placed for feeding.

It seems that neither symptom severity nor symptom interference scores are good predictors of who will continue to eat. There are a number of explanations for this such as some participants may not have understood the questions, although there is little evidence of this. Participants may have been in denial or distancing themselves

from their symptoms as part of their coping mechanism. This will be explored further in the discussion chapter.

Diane and Tony’s report of symptoms are closer to what would be expected with increased symptom severity leading to greater symptom interference.

These results are contrasted with those of participants who appeared to be coping better and had continued to eat oral diet despite taste changes.

Participant	Name	Total symptom score week 1 Range 0 - 220	Total symptom score week 4 Range 0- 220	Symptom interference score week 1 Range 0 – 60	Symptom interference score week 4 Range 0 – 60
19	Louise	25	87	17	37
22	Dai	0	19	0	0
24	Paul	25	122	9	31
49	Tom	40	74	11	34

Table 5.18 symptom severity and symptom interference scores for selected participants who continued eating.

Paul recorded on of the largest increase in symptom severity between weeks 1 and 4, however he appeared to be managing these symptoms well, being regimented with his medications and meals. Dai was the only participant to report taste changes and no symptom interference. Other than scoring himself 9 for taste changes the remainder of his symptom severity score was made up of scoring 1 or 2 for symptoms such as dry mouth, pain, cough and sore throat. Both Paul and Dai appeared to have an acceptance of their situation and the side effects experienced and worked to find a way to manage their symptoms. Other participants who appeared to be managing well also demonstrated this acceptance and a resilience to cope with their current situation.

It appears that the participant’s perception of their situation and their ability to cope with it might be a better indication of who will continue to eat than scores from the MDASI-HN questionnaire. This should be considered in conjunction with the patient’s diagnosis and treatment modality when assessing the risk for the incidence of taste changes. These ideas are explored further in the discussion chapter.

5.13 The Extent and Timing of Taste Changes

During the interview, participants were asked if they could remember when they first noticed their taste had been affected and what that was like for them. The interview data provides more in-depth information as to when taste changes are first observed.

The MDASI-HN results tell us that taste is affected somewhere between week 1 and week 4 of treatment. The interview gave the participants the opportunity to discuss this in more detail. Most participants described food not tasting quite right initially and then for some this worsened until they felt they could not taste anything at all. The results are summarised in tables 5.19 and 5.20 below.

When were taste changes first noticed	Number of responses (%)
Treatment 1 – 5 (week 1)	4 (18)
Treatment 6 – 10 (week 2)	12 (55)
Treatment 11 – 15 (week 3)	1 (4)
Treatment 16 – 20 (week 4)	3 (14)
Could not remember	2 (9)

Table 5.19 timing of taste changes

Seventy three percent of participants had noticed their taste had been affected by the end of the second week of RT, indicating that a high proportion of patients will have their taste affected before the other common side effects of RT for HNC, such as mucositis, dry mouth and difficulty swallowing begin to be a problem. This suggests that the majority of patients who develop taste changes begin to notice changes to their taste early on in treatment, as early as the end of week one. Ninety

one percent of participants who had problems tasting their food had noticed these changes by the end of week 4 of treatment and the remaining 9% could not remember precisely when they first noticed changes. There was a range of responses in the way that participants reported their taste changes. Some reported that foods did not taste right, others reported not being able to taste anything at all and others reported that everything tastes bad.

Interview participants were asked if their taste had gone completely and if so when they thought this had happened. Some participants reported this without having to be asked directly. The results are summarised in table 5.20 below.

Taste completely gone	Number of responses (%)
Treatment 10 – 15 (week 3)	8 (38)
Treatment 16 – 20 (week 4)	12 (57)
Treatment 21 – 25 (week 5)	1 (5)

Table 5.20 time when taste had gone completely

Ninety five percent of participants reported their taste had gone completely by the end of week 4 of treatment. It is unlikely that taste will begin to improve until at least 2-3 weeks after treatment is completed meaning that they will not be able to taste food for 6 weeks as a minimum and after that there may only be a slow recovery. This provides insight into the extent of the problem and how long patients are potentially going to struggle with their nutrition due to taste changes.

Most participants reported that they noticed minor taste changes initially but then their taste changed quickly from day to day. Foods that were acceptable one day were not the next day. Participants described their taste going through phases, metallic through to neutral and for some participants becoming very unpleasant Julia explained:

“The second week it was okay, not normal, but okay, then it went completely. Citrus was the last thing to go.”

The majority of participants felt that initially the altered taste was bearable but quickly became unbearable with a number of participants admitting to giving up

trying things. By the time the interviews took place approximately half of the participants described having no taste or everything tasting bland with the other 50% of participants describing everything being unpleasant or horrible.

Louise described this very vividly:

“My taste is totally affected, I have no taste at all. It went quickly, and it is changing all the time. It’s quite a soapy taste now and the dry mouth makes everything worse. Everything was salty for a while, but that has gone, and everything is soapy now.”

One participant who didn’t have problems tasting food until week 4 of treatment reported that their taste had gone completely by the end of that week, indicating a sudden complete loss of taste in contrast with the majority of participants who noted taste changing day to day.

Steve remembered very specifically when he first noticed his taste changing: *“The taste started to change at the end of week 2. We had a meal with some friends and it didn’t taste good. It’s difficult to describe, metal, gone off. I still had a mild sweet taste and was able to taste fruit, but it wasn’t nice. By the end of week 3 it had gone completely. It was awful then.”*

Tom who first noticed altered taste after 2 days of treatment said:

“I was warned to expect it. I noticed it from day 2 really. A bitter sour taste developed in my mouth. It ebbed and flowed since week 2 then started to dominate. The taste is in my mouth even when I’m not eating.”

To summarise the extent and timing of taste changes:

Seventy seven percent of participants reported taste changes in week 4 of treatment. Three quarters of these had reported marked taste changes by the end of week 2 of treatment.

Eighty eight percent of participants having CRT reported taste changes and 64% of patients having RT only reported taste changes.

Participants with a diagnosis of oropharyngeal cancer having CRT were most at risk of developing taste changes during treatment.

Females were more likely than males to develop taste changes but were not more likely to require tube feeding.

The MDASI-HN score for problems with tasting food is not a good indicator of whether patients will continue to eat.

5.14 The Experience of Taste Changes during Treatment

Participants were able to describe in detail how their taste was affected and the impact it had upon them. A number of themes were apparent across each of the interviews as summarised in the table above and these are presented below. The stories fell into categories of the typical participant with taste changes and those who appeared to be managing better than average and those who really struggled to cope with the effects of taste changes. Having their taste affected was something that had a major effect upon them. There is also evidence of them gaining knowledge and skills in learning to tolerate taste changes as time passes.

All interview participants reported that they had been informed before treatment that the RT would affect their taste buds but had no idea what the reality of that would be like. Elaine said:

“I was warned but I didn’t realise what it would be like. It’s worse than I thought. I thought I would just be able to put up with it.”

Some participants were contradictory in that they reported that they knew what to expect and then went on to say that they had no idea what it would actually be like. Most felt that it would not have been possible for them to understand the full implications beforehand because it is not like anything they have ever experienced previously. Rhys reported:

“It was explained to me that I would lose my taste, but I didn’t realise what it would be like. I don’t think anyone could have told me.”

This information can be used by staff caring for patients having RT for HNC to prepare future patients more effectively. The results suggest that staff are informing patients

that taste changes will occur but failing to convey the full extent and impact that taste changes will potentially have for the patient. This may be because they do not want to worry patients unduly as well as a lack of understanding of the impact of taste changes. Most participants reported that taste changes occurred sooner than they expected suggesting again that they could have been better prepared. Louise reported:

"I do what I can. Two small meals a day and try to have some other things too. I get so bored. I keep trying things and then remembering why I don't have them anymore. It's because they taste so horrible."

Although participants reported that they felt well prepared some of their comments suggest that they were lacking information regarding the timing and severity of taste changes.

Participants were able to voice effectively what their experience of taste changes was like, such as food tasting "gone off" and the sour taste in the mouth even when not eating. This provides insight in to the patient experience of what it is like to eat when experiencing taste changes due to radiotherapy. The words used by participants: "unpleasant", "nothingness" and "non-existent" being some of the milder words and "rancid", "oily", "soapy", "awful", "horrible" and "indescribable" providing graphic examples of what they had to overcome. All of these words provide insight as to how unpleasant it must be trying to eat food described in this way. There is nothing that makes these foods sound appetising. In fact under normal circumstances these are all descriptions of food that most people would chose to avoid. For those participants who describe all foods as tasting this way it becomes easier to understand why they would find it so difficult if not impossible to eat. Stories such as these will be used to explain to staff how difficult it is for patients to eat when they have taste changes.

The typical story of the experience of taste changes covers the themes of, support and sharing the burden, disruption to daily life and making sense of the experience, as well as the psychological impact of taste changes. This story has been developed to demonstrate the common elements from the stories that participants portrayed in the interviews.

Participants spoke about how much they appreciated the support of family members and healthcare professionals alike. Although, this could be a double edged sword in some cases leading to feelings of guilt and being a burden when they were not able to eat the lovely meal that their loved one had prepared for them. In some cases spouses struggled to understand why the patient could or would not eat what was usually their favourite meal, suggesting that the patient “just eat it anyway” as they know they would usually enjoy it. Those participants who had supportive spouses and family members spoke of how they did not know how they would manage without them and the support being invaluable. However, there were also examples of participants feeling guilty because they could not eat meals cooked for them and feeling a burden. Tom said:

“My wife buys nice things to tempt me. I don’t like waste. I was brought up to clean my plate, only take what you need. The cost and effort gone in to it. It’s upsetting.”

Others reported feeling pressure when asked what they would like to eat when in reality they didn’t fancy anything at all. It appears that family members struggled to understand that there was nothing that would taste acceptable at that point. Owen said:

“My wife tries to tempt me with things, it looks nice, but I know I will spit it out as soon as I put it in my mouth. It’s not worth trying things now.”

This contrasted with the views of two participants who lived alone and although they had the pressure of cooking for themselves, they felt that they were doing quite well because they could eat what they wanted when they wanted without fear of upsetting anyone.

Some acknowledged that they must be hard to live with because of the difficulty eating or knowing what they might be able to eat at any given time. Abdul found the regular review clinic appointments reassuring. He acknowledged that once the side effects started, he would have panicked if he hadn’t been reassured that this was all normal and expected. Others spoke of feeling cared for and that knowing that others were caring for them made them want to take care of themselves.

In some cases the weekly review appointment served more as a warning to participants that they were being monitored. Eileen reported that she if it wasn't for the fact that she was weight each week, she knew that she would not have made so much effort to keep eating. Louise said:

"It's difficult for carers, they try their best, but they don't know what to say, what to make for you. They make you something nice and you can't even look at it"

She expressed guilt and frustration at this but there was just no way could she eat anything at that stage as it all tasted so bad. She had managed this by being very clear with family and friends that they were welcome to visit her but please do not bring food because she would not be able to enjoy it.

Meal times take longer than usual and become a battle ground between spouses with the supporting partner becoming upset when the patient is not able to eat the meal that has been lovingly cooked for them. This leads to feelings of guilt and frustration in the patient.

Participants described boredom associated with the lack of taste. Firstly, with being restricted to so few foods they were able to tolerate and also with the relentlessness of the situation they found themselves in and the lack of structure in their day

Louise talked about marking time and how the day is defined by meals times. She said:

"The days are long, twice as many hours in a day as I need".

She went on to say:

"I don't eat meals anymore, just have what I can when I can. It's difficult, porridge: just goes down; custard: just goes down no chewing. Yoghurt makes my mouth claggy and frothy – not nice, won't go down."

Other participants also described the boredom associated with the lack of taste. Firstly, with being restricted to so few foods they were able to tolerate and also with the relentless and repetitive nature of the symptoms and treatment. Peter reported:

"It's harder than I expected and the monotony has got me down."

Angela also spoke of the boredom associated with limited foods that she found acceptable:

“eating the same things. Milky things are easier, stick with what you know you can eat.”

Steve echoed this:

“Just forced it down, it gets boring. I make do with what I know I can manage.”

Many participants described losing the taste for savoury foods first making it difficult to plan what to have at meal times and therefore losing the daytime structure. Bob talked about losing taste for savoury foods:

“Savoury was affected more than sweet initially and then gradually everything has become unpleasant, you don’t want to eat at all”

Owen described a similar course:

“I lost the taste for savoury foods first but could still taste sweet foods, then lost everything”.

It seems that once participants could no longer taste savoury foods they struggled to know what they wanted to eat at meal times. Savoury or umami sense of taste appears to affect appetite more than the other senses of taste. Most meals are based around a savoury dish and once participants no longer knew what they wanted to eat, meal times began to fade away and with them the structure of the day.

Participants also spoke of food to sustain their body and carrying on as normal and sticking to routine and meal times, for example, Edward still attended a lunch club when his RT appointments permitted, saying:

“I still attend lunch club when I can, try to carry on as normal. I eat because its meal time and I want to get better.”

Richard said:

“I can eat most things, they have no taste. I eat because it’s meal time. I get used to not being able to taste. It would almost be strange to taste now.”

There was a strong suggestion both explicitly and implicitly that there was no longer any enjoyment in food and meals times and eating was considered entirely a basic necessity to stay well and keep alive.

Some participants were so repulsed by the taste of food that they could not consider putting it in their mouth. Tony described the emotions associated with a typical mealtime:

“I’m anxious because I know I have to eat but I can’t. It’s not unwillingness, its inability to do it – physically can’t do it..... Texture is horrible, anything with lumps or granules in it, very reluctant to swallow. It breaks my heart if I struggle to get it down and then it comes back up”

Tony went on to describe what it was like trying to swallow something:

“You move the food around your mouth, but you can’t make yourself swallow it. You don’t want to, you don’t have the where with all, no feeling that I want to swallow it.”

This is an interesting observation because normally when food tastes bad it is a warning to avoid it as it might be harmful to you. So, Tony’s response might be considered a more normal response to the situation he finds himself in than those participants who continue to eat even though the food tastes bad. Taking Tony’s response along with the words used to describe how horrible food tastes it is surprising that more patients do not stop eating.

These observations demonstrate the disruption to daily life as patients lose their sense of taste they either avoid meal times or do not take part in them with their family. They avoid meeting friends for coffee so that they do not subject themselves or their friends to the reality of how much life has changes for them.

Participants demonstrated that they learned as they went along what worked and rationalised that it wasn’t forever. They had to go through bad times now for the reward of better times in the future. They showed acceptance of their situation and a willingness to make changes so that they could manage their symptoms and continue eating.

The psychological impact of taste changes runs through many of the themes, with the emotional toll on participants apparent when they discuss meal times, what it's like not to be able to taste food and the support they have received.

Guilt was commonly expressed during the interviews both overtly and explicitly in the way that participants spoke.

There was the obvious guilt at not being able to eat food that is lovingly prepared for them. Guilt about the waste of good food. Guilt at not being able to overcome the bad taste and eat food that they knew had nothing wrong with it. Guilt about having to rely upon a feeding tube. There was a suggestion that participants felt that they had let down both their loved ones and healthcare professionals in not being able to do better with their nutrition.

Participants reported frustration with their situation and at not being able to overcome the bad taste to make themselves swallow. Many participants reported that the first mouthful of food tasted okay but the more they chewed food or the longer it remained in their mouth the worse the taste became. Steve said:

"Liquidy foods that don't need much chewing are easiest. The first chew is okay, after that the taste goes."

This was very frustrating as it made participants think they would be able to taste food only for the taste to disappear or become unpleasant after a couple of mouthfuls.

Many participants spoke of the anxiety they experienced in relation to meal times. Tony recalled sitting in his chair watching the clock as it moved, round to meal time, knowing that his wife would soon be asking what he wanted to eat and then seeing the disappointment on her face when he couldn't eat it. Many participants acknowledged that it would be easy to become low in mood and feel like giving up but had things that kept them motivated to keep going. Others admitted that they had in fact given up trying food because it was a hopeless situation.

More than a third of the interview participants talked about feeling isolated as a result of not eating due to taste changes. This was usually because they did not want

to socialise rather than friends or family avoiding contact with them. The female participants were more likely to voice this than the male. They talked about missing meeting friends for coffee and avoiding family mealtimes. Angela spoke of the boredom associated with this:

"I get bored. We are a foody family, I miss coffee with friends, the social side. I'm isolated, isolate myself. It's a long old day."

Anna summed this up very eloquently with the following quote:

"I no longer meet people for food. I tried to carry on initially but what's the point? I don't subject myself to it anymore..... I'm usually quite a positive person. It feels lonely but I just get on with it."

There was a sense that participants were isolating themselves because they had no enjoyment in social gatherings but also protecting friends and family from seeing their suffering. This also served to protect themselves from the evidence of their own suffering and how much their life had changed.

Bob who was coping well and managed to continue eating acknowledged that it would be easy to hide in a corner, but he would not allow himself to do that. He lives alone and still cooked a meal for himself every day and had meals with his sister and brother-in-law.

On the other hand Ernie who also lived alone said:

"I wouldn't eat in front of other people now."

He felt it would be too embarrassing to eat with friends or family because of the process he had to go through but also felt it might be awkward for them to see him like this.

Isolation was also associated with a strong sense of loss, again with participants sometimes choosing not to do things and at other times feeling that they had been taken away from them.

James felt it was not worth trying things now as he knew they would taste horrible. However, he acknowledged that he was worried saying:

“I’m worried about the weight loss and loss of physical shape.”

He went on to explain:

“I need my muscles to do my job, I am a builder, I wouldn’t be able to lift anything at the moment. I don’t like the weight loss. I’m looking forward to finishing and building my body and body strength back up.”

In fact he said this three times during the interview indicating that it was a major concern for him. His concern about his body image and his loss of identity were very apparent and obviously distressing for him but food tasted so bad he still could not make himself eat. Despite this obvious concern regarding his body image James was still not able to make himself eat. This gives some insight in to how bad food must taste when the apparent motivators of body strength and returning to work were over ridden by the inability to swallow such fowl tasting food. All of these issues obviously add to the burden for patients going through treatment.

Participants who continued to eat demonstrated great resilience in the way they continually adjusted what they were doing as the side effects progressed and their ability to taste food worsened. They reasoned that this was a short term problem and by getting through this now they had a better times to look forward to in the future. Abdul said:

“I keep telling myself it won’t be forever and it’s making me better.” If it had to be like this forever I would be down. I hope to get back to normal.”

Dan said:

“I want to be here for a few years yet. You just got to get on with it. It is what it is, get on with it. I’ve never been defeatist, you know what I mean, if I think I can do it, no matter how hard I’ll stick with it until I’ve done it. I did it after my stroke and heart attack and I’ll do it after this.”

5.15 How do Participants Manage their Taste Changes

It was anticipated that by understanding more about how participants manage their taste changes that this information could be adapted to support future patients. Information from previous patients is frequently valued by current patients as the advice is felt to be particularly relevant coming from someone who has been in a similar situation. As previously stated some patients appear to be coping better than others and having a greater understanding of this would be beneficial to help support patients in the future. Responses from the supplementary questions proved to be a rich source of data in answering this question.

Participants managed their taste changes with a combination of determination to carry on, good symptom management, having effective coping strategies including being willing to adapt to their current situation. These are discussed in further detail below.

Participants spoke of their determination to carry on eating and get through the treatment. Many participants appeared to treat eating as a personal challenge they had set themselves and suggested that they would see it as a personal failure if they became reliant upon tube feeding. This determination appeared to give some participants a focus and ensured that they planned how they would manage and helped them to stick to the plan or make adjustments if they could not.

Owen described the talk he gives to himself:

“stop whingeing and keep yourself well. I use grim determination. It tastes bad but it won't do you any harm.”

He demonstrated great determination and resilience to carry on eating despite everything tasting bad.

As previously stated RT and CRT for HNC causes a wide range of side effects. Participants felt that if their symptoms such as pain and thick secretions were well controlled it was easier for them to tolerate taste changes and continue to eat. Paul explained:

“Getting the medication just right before eating is important for me. I am very sensitive to pain and if I have pain and no taste I struggle.....”

James found it helpful to write down his medication so that he knew what he had taken and when the next doses would be due:

“I write down my medicine and supplement drinks so I know what I have had and keep on track”

He hadn't done this initially and things became very difficult for him because he was missing out pain medication and therefore was struggling to eat.

Other participants reported that clearing thick secretions and using mouthwashes prior to eating helped with taste and made it easier to be able to swallow food. If other symptoms were well controlled they were more likely to be able to overcome the taste of food and their nutrition would be improved.

Participants reported that altering their diet so that they ate foods that they could taste or at least found tolerable helped to increase the amount they ate. Almost half of the participants who reported taste changes said could not taste anything at all. In the supplementary questions participants were asked to list any foods that they were able to taste with the biggest response being that participants couldn't taste anything at all. Some reported that although they could taste certain foods, they did not taste normal. All respondents had a very limited and specific list of foods that they could eat. Overall, the impression was one of foods that could be tolerated rather than enjoyed. This has been presented in more detail earlier in the chapter.

Participants reported that they found softer foods that did not require chewing easier to tolerate. The more they had to chew their food the worse the taste became. Most participants had discovered this for themselves, frequently reporting that the first mouthful of food tasted okay and then the taste would either disappear or turn bad. Steve said:

“Liquidy foods that don't need much chewing are easiest. The first chew is okay, after that the taste goes.”

Semi-solid or liquid type foods were better tolerated as they were easier to move around the mouth and spent less time in the mouth so that bad taste was less noticeable. Many reported that the longer you had to chew food the worse the taste became. Owen suggested the following approach:

“Blend things, the smoother they are the better and then straight down without tasting it. The more you chew the worse the taste becomes.”

This method ensures that patients get adequate nutrition, however, it has implications for the swallow muscles as they are at risk of atrophy if they are not exercised sufficiently during treatment. This is explored further in the discussion chapter.

Another of the supplementary questions asked what advice you would give to someone else going through the same treatment who has taste changes.

Those that responded were overwhelmingly positive with their advice and encouragement to others who may be going through the same treatment. The most common response (34%) was to keep trying/try everything and persevere or something similar. Other common responses were to try “liquidy” foods, to think of food as medicine and listen to the advice from the professionals.

Participant 39 gave the following response:

“To be open minded to foods that you normally wouldn’t eat- try different things. And eat as much as you can when you feel like eating! “

Much of the advice given was very practical and honest. Participants acknowledged that they were learning themselves what worked and what did not. The following response is from participant 43:

“I don’t know, I’m experimenting myself.”

This response also gives some insight to the difficulties faced by patients experiencing taste changes and knowing how best to cope with this. The response acknowledges that taste is changing and the need to keep adapting what you are eating as you get further through treatment.

Participants spoke of the value of having a plan to help them through the treatment and this took various forms. Participants who were coping well had a regime of when to take medications and mouthwashes to help them manage their side effects. They found that this approach of taking supportive medications at set times kept them on track so that they could continue eating and drinking. Some spoke of the support from their spouses in helping them produce this plan and then stick to it, by reminding them it was time to do things. Angela said:

“My husband is very encouraging, I don’t know how I would have managed without him. He keeps me on track. I would keep putting things off. I can’t believe how brilliant he has been.”

Other participants found this a strain if they could not manage to stick to the regime with encouragement from family members being perceived as nagging or adding to their anxiety. Rhys said:

“My wife worries. I see her face when I don’t eat. She tries really hard but nothing is working.”

Having a plan for some participants was more about plans for what they wanted to do after treatment and things they were looking forward to in the future such a family celebrations or holidays. These proved to be strong motivators to keep participants going when things got tough.

This study was not designed to assess participants coping strategies, however, it became apparent during the interviews and when analysing them that individual coping strategies made an impact on how patient experienced and managed taste changes. Some participants spoke of other adversities that they had faced and how they coped then. They used similar strategies now. For example Dan had previously had a stroke and a heart attack and had recovered better than had been expected because he was determined to recover. He felt that using strategies that had served him well in those situations would see him through this too. They also reasoned that they had experienced hard times before and found a way out, so they would do the same again. James had brought up his four young children on his own and been through some very dark times when he first found himself in that situation. Although

he acknowledged that tolerating taste changes and the cancer diagnosis was hard, it wasn't the hardest thing he had, had to face in his life, therefore he would persevere and get through it.

5.16 Motivation to Continue Eating

One of the most interesting observations from clinical practice and one of the main motivations for doing this research is how some patients continue to eat when they experience taste changes whereas others find the taste of food so bad they stop eating. This study has shown that the scores from the MDASI-HN for problems with eating do not predict who will continue to eat and who will stop with participants scoring themselves 9 or 10 for problems with tasting food, some carrying on eating and others unable to eat anything. One of the main aims of this research was to understand more about this to see if any strategies utilised by the patients that continue to eat could be adapted to help those that stop eating. The main reason that participants gave for continuing to eat was a determination to do so. This was motivated by different things for different participants with the common themes being, wanting to avoid having a feeding tube; fear of losing their swallow muscles, survival instinct (you have to eat), wanting to stay well and not wanting to let down family members or healthcare professionals. Individuals who continued to eat despite taste changes exhibited great resilience. Alongside this resilience participants also demonstrated acceptance of their current situation and a willingness to make adaptations to how they would normally behave, what they would usually eat and how they live their lives. They spoke of doing what you have to do to get through the treatment.

Many interview participants were obviously working very hard to maintain an adequate nutritional intake. One of the main motivations for continuing to eat was the desire to avoid having a NG tube placed or to avoid using the gastrostomy tube that had been placed prior to starting treatment. Eileen said:

“I am fearful of needing a feeding tube. I had one after surgery. I’ve got to eat. It’s difficult to fit in everything that I have to do.”

Participants felt it would be a personal failure to resort to tube feeding and those that continued to eat took a pride in continuing to do so. Some participants were quite poorly nourished but still did not want to use their tube, despite the fact that doing so would have aided their nutrition. Peter said:

“I don’t want a feeding tube and that keeps me going on days when I can’t be bothered.”

Fear of losing their swallow and not regaining it after treatment was the other main reason participants gave for carrying on eating. This was a common motivation for participants who were still carrying on eating small amounts of food, despite getting most of their nutrition via their gastrostomy tube. Patients are warned of the risks of their swallowing muscles becoming atrophied if they stop having oral intake during RT and do not do swallowing exercises provided by the SLT. This fear obviously weighs heavily on some patients leading to them refusing tube feeding when it would be in their best interest to accept it. Rhys said;

“I was brought up not to complain, just get on with it. I keep swallowing, don’t want to lose my swallow. It would be easy to just rely on the tube though.”

Eating is a basic need related to survival. A strong instinct of eating to survive was demonstrated by participants with some being surprised to learn that others stopped eating because the taste of their food was so bad. Participants voiced their concerns that stopping eating was akin to giving up and that was not something that they were prepared to even think about doing. They spoke of eating because you need nutrition to survive and that the taste of the food was secondary. Dan said:

“My motivation – I want to get better. I’m strong willed, persevere. I am worried about the weight loss.”

Some participants were able to put the taste aside and realise that the food still had the nutritional value even if it tasted bad. Richard said:

“I don’t add salt and pepper, there’s no point. I’m determined to eat, but I’m not excited to eat, it’s a necessity.”

This contrasts with those participants who alluded to the fact that food that tasted bad could not be good for you.

Acceptance of their situation rather than fighting against it was an important quality for participants. If they could accept their situation they were able to make changes to enable them to cope with their current situation. Patients who were unable to change from their usual eating habits were more likely to struggle with nutrition.

5.17 Summary of Key Findings of Study

The key findings of the study combining the results from the MDASI-HN questionnaire, supplementary questions and the semi-structured interviews are summarised below.

Seventy seven percent of participants developed taste changes as defined by scoring 5 or greater on the MDASI-HN questionnaire. This rose to 88% in patients having CRT and is 66% in patients having RT alone. Only 5% of participants reported that their taste was not affected at all.

Patients having CRT for oropharyngeal cancer are more likely to develop taste changes (88%) than other tumour sites, with oral cavity and parotid tumours also at risk. Thirty seven percent of participants with laryngeal cancers developed taste changes.

Females are slightly more likely to develop taste changes than males, although this does not mean they are more likely to stop eating.

Taste changes are first reported towards the end of week 1 of treatment. This is early than has been reported previously and earlier than patients are warned to expect them.

Patients need accurate information about taste changes including, when to expect them, what they will be like and how long they are likely to last.

Patients manage taste changes with a combination of good symptom management, finding a plan that works for them and determination.

A “liquidy” diet is better tolerated by patients with taste changes, as food spends less time in their mouth.

Acceptance of the situation and adaptability appear to be key skills that patients need to utilise to help them get through the treatment.

Individual coping styles are an important factor in how patient’s manage taste changes.

Patients are motivated to continue eating by fear of losing their swallow, wanting to avoid tube feeding and a strong survival instinct and determination to eat.

Participants self-reporting of the severity of taste changes using MDASI-HN is not a good predictor of who will continue to eat. Other factors such as site of tumour, treatment modality and individual coping styles also play an important role in predicting who will develop taste changes and continue with oral diet.

In the next chapter I discuss the results from the study and what these mean for patients with HNC and healthcare staff caring for them and how they relate to current literature.

Chapter 6

6. Discussion

In this chapter I discuss the key findings from the study, explore what these results mean and why they are important for patients with HNC and healthcare staff caring for them. I also discuss how these results might be used in clinical practice and the strengths and limitations of the study.

6.1 Summary of Key Findings

The key findings from the study are summarised below:

- Seventy-seven percent of participants in the study developed taste changes, rising to 88% in participants having CRT and 66% in participants having RT alone.
- Patients having CRT for oropharyngeal cancer were most likely to develop taste changes.
- Females are slightly more likely to develop taste changes than males.
- Taste changes were first reported by participants during week 1 of treatment. This is earlier than has been reported previously in the literature and earlier than patients were warned to expect them.
- Patients need accurate information about taste changes including, when to expect them, what they will be like and how long they are likely to last.
- Patients manage taste changes with a combination of good symptom management, finding a plan that works for them and determination to get through the situation they find themselves in.
- A “liquidy” diet is better tolerated by patients with taste changes, as liquidy food has to spend less time in their mouth.
- Acceptance of the situation and adaptability appear to be key skills that patients need to utilise to help them get through the treatment.

- The individual approach to coping is an important factor in how patients manage their taste changes.
- Patients are motivated to continue eating by fear of losing their swallow, wanting to avoid tube feeding and a strong survival instinct and determination to eat.
- There did not appear to be any association between participants recording a high score in MDASI-HN for problems with tasting food and who will continue to eat.

I have addressed the key findings of the study in relation to how each answers the research questions, meet the research objectives and how they relate to the current literature.

6.2 Extent of Taste Changes

As previously stated 77% of participants developed taste changes during treatment, rising to 88% for participants who had CRT. This is consistent with the findings of other studies (Irvine et al, 2014; Hovan et al, 2010; Ruo Redda et al, 2006), who reported the incidence of taste changes in patients undergoing RT or CRT for HNC as being between 55-95% in. Previous studies have reported taste changes that were measured using chemical and electrogustometry with some also including a patient reported measure (Maes et al, 2002; Shi et al, 2004). This study has only used patients reported measures of taste changes and has reported results consistent with those obtained using objective measures. It is known that objective measures are time consuming and rarely used clinically. The results from this study suggest that taste changes can be accurately assessed using a patient reported tool. This is quicker, effective in clinical practice and uses less resources than other measures and has demonstrated comparable results to studies using other measures such as chemical or electrogustometry (Maes et al, 2002, Shi et al, 2004, Baharvand et al, 2013). Using a patient self-report questionnaire also ensures that this troublesome side effect is not overlooked by staff supporting patients, directing them to discuss the issues giving patients most concern.

When deciding upon an appropriate sample size for any study it is essential that the number of participants recruited will provide valid answers to the research question (Hunt and Lathlean, 2015). A larger sample is more likely to provide a representative sample of the whole population, however this needs to be balanced against the risk of too large a sample wasting resources and participants time (Hunt and Lathlean, 2015; Creswell and Plano Clark, 2011). This study has a sample size of 61 participants which compares favourably with the sample sizes of other studies assessing taste changes and improves the quality of research. Maes et al (2002) in their study looking at the time scale of loss and recovery of tastes caused by RT used both objective and subjective measures and had a sample size of 73 participants. Baharvand et al (2013) in their study looking at taste alteration and impact on QoL after RT for HNC used a sample size of 22 and Fernando et al (1995) in their prospective study looking at the effect of HNC irradiation on taste dysfunction employed a sample size of 26 participants for both objective taste testing and used a subjective taste questionnaire. Shi et al (2004) in their study looking at acute and late radiation damage to the four basic tastes and volume of tongue irradiated used a sample size of 118 with 100 participants in group A having most of the tongue irradiated and 18 in group B where the RT fields did not include the tip of the tongue. They concluded that if the tip of the tongue was not included in the RT field then taste changes were not observed during RT. This has proven to be incorrect by others (Mirza et al, 2008; Irune et al, 2014). In this study 61 participants completed the MDASI-HN at two time points, week 1 and week 4 of treatment with 22 participants taking part in interviews. In this study no account was taken of the precise positioning of treatment fields as this was not one of the objectives. However, all participants would have had a wide range of their taste buds included in their treatment volume, as it would not be possible to treat the tumour sites included in the study without covering tissues containing taste buds.

6.3 Timing of Taste Changes

Few studies have looked at the timing of taste changes during RT (Porter et al, 2011; Shi et al, 2004) with many choosing to look at taste changes after treatment and in particular the time it takes for taste to recover (Baharvand et al, 2013; Maes et al, 2002). This study has provided more detailed evidence of the timing of taste changes during RT.

Most participants felt that they had started to notice taste changes sooner than they had been warned to expect them. This is surprising because a number of studies have found that problems tasting food is one of the earliest symptoms to appear in patients having RT for HNC, often preceding symptoms such as oral mucositis, (Vissink, 2003 and Rou Redda and Allis, 2006, Epstein et al, 2016), although they do not report a specific time scale for this. Others have suggested that taste changes do not become apparent until weeks 3-4 of treatment (Irvine et al, 2014; Conger, 1973 and Shatzman and Mossman, 1982). In clinical practice patients are generally told to expect taste changes after approximately 10 days of treatment. Some of this may be explained by the fact that taste changes have only been measured at specific time points during treatment. For example if taste changes are reported in week 3 but this was the only time point that they were measured, it is not possible to know from this type of study when taste changes were first observed by the patient. In this study the MDASI-HN was given to participants in week 4 of treatment as this was when the literature suggested that taste changes are at their peak. If participants were going to develop problems with taste changes it was felt that they would be present by week 4 of treatment. The interviews then provided more detail regarding when taste changes occurred, as participants were asked to describe when they first noticed taste changes and how they progressed. These findings support the use of mixed methods methodology to explore taste changes with the interview results providing more detail to the findings of the questionnaire. This has proven valuable in understanding more about when taste changes are first noticed by patients and how they typically develop over time as well as the earliest and latest presentation. This study has shown that 17% of participants reported taste changes in the first week of

treatment (that is before #5 of RT) and 73% of participants reported taste changes by the time they had 10 treatments. Therefore, almost three quarters of participants who went on to develop taste changes reported noticing changes as early as the end of the second week of treatment. This is important because patients may become concerned that they are experiencing side effects sooner than they had been warned. This might lead them to worry that their side effects are worse than they should be or that something has gone wrong, therefore leading to unnecessary anxiety for them. Mishel (1988) noted that patients become concerned when symptoms do not follow the pattern that they have been told to expect. All participants felt that they had been well informed regarding side effects but then went on to say that taste changes occurred sooner than they had expected. Donovan and Glackin (2012) found that patients need a knowledgeable and competent person to provide support and guidance during radiotherapy and this would include giving accurate advice regarding problems tasting food.

It was mainly older studies with less modern RT techniques (Mossman et al, 1979; Schwartz et al, 1993) that have reported taste changes started later in treatment suggesting perhaps that healthcare staff are not up to date with most recent information and are therefore not advising patients appropriately. These older studies have relied upon objective measures of taste and it may be that studies using subjective taste measures are identifying taste changes sooner than objective measures are able to identify them. It is unlikely that older RT techniques led to taste changes occurring later, in fact more modern RT techniques such as IMRT and VMAT may be expected to lead to later occurrence of taste changes. This poor provision of information can increase the psychological distress experienced by patients at this time (Rose and Yates, 2013). Patients should be informed that problems tasting their food might be one of the first symptoms they experience during RT and they might become apparent during the first week.

Conversely, all participants who developed problems tasting their food had noticed problems by the end of the fourth week of treatment. Most had noticed a gradual change and deterioration in their taste until it went completely or they found that everything tasted horrible. It can be assumed that if patients are going to have

problems tasting their food they will have developed problems by week four of treatment. If they haven't developed problems by then they are almost certainly not going to develop them. A small number of participants reported limited problems up until week four and then their taste went completely within a matter of days. This has not been reported in any other studies. However, the gradual change and worsening of taste was a much more common scenario.

Eighty-eight percent of participants having chemotherapy as well as RT developed taste changes in this study, supporting the findings of other studies (Irvine et al, 2014; Hovan et al, 2010). It is not surprising that adding chemotherapy increases the risk of taste changes as both treatment modalities are known to affect the sense of taste. McLaughlin and Mahon (2014) conclude that RT is the main culprit for the cause of taste changes in patients undergoing CRT for HNC. While RT has a direct effect upon the taste buds, chemotherapy is known to affect the sense of taste in different ways, such as influencing enjoyment of different foods and appetite (Boltong and Campbell, 2013). This highlights the impact for patients undergoing CRT regimes being exposed to two treatment modalities that affect the sense of taste in differing ways. Patients should be informed of the increased risk of experiencing taste changes with CRT regimes.

It appears from this study that female patients are slightly more likely than males to develop taste changes 92% (12 female participants) compared with 73% (35 male participants). The differing incidence between males and females experiencing taste changes has not been reported in other studies and this requires further investigation to see if this is in fact the case. Studies have shown that in the general population females tend to have a better sense of taste than males (Soter et al, 2008) but it is not known how this might affect the way RT alters their sense of taste. It has been suggested that women may have more taste buds than men, leading to their sense of taste being superior to that of males under normal conditions (Soter et al, 2008). It may be considered that females have more taste buds damaged by RT because they had more taste buds to start with leading to a slightly higher incidence of taste changes. There are not any studies that have specifically looked at the incidence of taste changes in males and females with HNC, however, Ng et al (2004) and others

have reported that taste is affected by hormonal changes such as pregnancy and menopause suggesting that females may be more prone to experiencing taste changes.

Participants having CRT for oropharyngeal cancer were the group most likely to experience taste changes (88%). McLaughlin and Mahon (2014) in their meta-analysis of the relationship among impaired taste and treatment site concluded that tumour site is a poor predictor of problems with taste. They acknowledged that more modern RT techniques such as IMRT and VMAT may change this perception as these techniques involve shaping the RT beam more precisely to the tumour volume therefore reducing the amount of normal tissues treated. Their study included participants who had conventional RT as well as IMRT and they reported differences in the incidence of taste changes between the two groups, although this did not reach statistical significance. In this study all of the participants had VMAT and the findings suggest that although tumours of the oropharynx, oral cavity (71%) and parotid (80%) have a bigger risk of developing taste changes, all tumour sites in the head and neck region are at risk of developing taste changes. This is relevant to staff caring for these patients and patients with all HNC diagnoses should be asked whether they are experiencing problems tasting food when they are seen for their routine review during RT. Experience from clinical practice suggests that staff do not expect patients having RT for laryngeal cancers to develop taste changes, whereas this study has suggested that 37% of them do experience problems tasting food. Taste buds are located in the throat and upper oesophagus (Epstein and Barasch, 2010) and therefore patients having RT for laryngeal cancers should be warned that there is a 1 in 3 chance of them developing problems tasting their food as there will be taste buds included in their treatment volume. This will help to avoid unnecessary worry for this patient group should they develop taste changes. It has been shown that patients are better able to cope with side effects if they are well informed regarding which side effects they are likely to experience and how severe they might be (Haisfield-Wolfe et al, 2012).

In this study 94% of participants who had a gastrostomy tube placed before starting treatment reported taste changes. This is important because when the MDT are

deciding which patients might benefit from having a gastrostomy tube placed prior to treatment they are deciding upon which patients are more likely to struggle with oral intake as a consequence of their HNC and its treatment. The factors considered when making this decision include the patient's current nutritional status, diagnosis, recommended treatment plan and position of RT beams (NICE, 2017). This high percentage of participants with a gastrostomy tube who reported taste changes suggests that the correct patients were targeted for needed tube feeding. Taste changes are associated with diminished appetite which has a high risk of leading to weight loss and malnutrition (Maes et al, 2002; Irune et al, 2014), therefore the risk of being affected by altered taste and how the patient might cope with taste changes should be included in the factors likely to lead to the need for tube feeding. Bressan et al (2017) in their systematic review and meta-synthesis of the life experience of nutritional impact symptoms during treatment for HNC include taste changes as well as dysphagia, oral mucositis and dry mouth as being the most important nutritional impact symptoms. Eighty percent of patients who required an NG tube to be placed during treatment reported taste changes, again suggesting that taste changes are a risk factor for needing tube feeding. Alvarez-Camacho et al (2015) report that taste and smell changes are strongly associated with reduced QoL in both tube fed and non-tube fed patients.

6.4 The Experience of Taste Changes

By understanding more about the experience of taste changes as a result of RT and CRT for HNC staff would be in a better position to advise future patients on how to manage this side effect. Having a deeper understanding of what patients are experiencing would help devise effective treatment plans and have improved understanding of what is helpful for patients and what works for them in practice. As previously stated there has been limited research looking at the experience of taste changes in patients with HNC undergoing RT and less still where taste changes have been the sole focus of the study. Many studies have included taste changes along with other common side effects such as mucositis, dysphagia and xerostomia as the

main focus of the study (Donovan and Glackin, 2012; Larsson et al, 2007). Some of these studies have suggested that problems with taste and other side effects should be studied individually in an effort to understand more about the experience (Irvine et al, 2014; Hovan et al, 2010). However, it has become clear that singling out taste from other side effects of treatment for HNC is not straightforward as taste is so strongly linked with other side effects such as sense of smell, appetite and nausea.

Participants were able to describe the experience of taste changes using vivid terminology which upon listening to and reflecting upon made it very clear how difficult this side effect is to tolerate. Describing the taste of food as “rancid”; “oily”; “soapy” and “awful” make it easy to understand why patients cannot “just eat it” as has been suggested by some members of staff and relatives in the past.

In addition to the descriptions of what food tasted like there were a number of themes that were common to the participant’s experiences of taste changes. The themes identified in this study are disruption to daily life; sharing the burden; making sense of the situation and the psychological impact. These are similar to the themes identified in studies looking at the side effects of RT for HNC in general (Donovan and Glackin, 2012; Lang et al, 2013). Donovan and Glackin (2012) undertook a literature review of the lived experience of receiving RT for HNC. Their research focussed on RT for HNC in general rather than taste changes specifically. The themes uncovered were: “waiting and uncertainty”; disruption to daily life”; “RT environment and processes”; “side effects from RT”; “psychological wellbeing” and “support”. There is a clear overlap of themes between the two studies suggesting that it might be difficult to assess individual side effects of treatment due to the fact that different side effects occur at the same making it difficult to be sure which side effect is causing a particular effect or whether the multiple side effects together cause the effect. Either way, the results are similar and guide us to the ways in which patients require support. Lang et al (2013) undertook a systematic review and meta-analysis of the psychological experience of living with HNC and identified the following six themes: “uncertainty and waiting”; “disruption to daily life”; “diminished self”; “making sense of the experience”; “sharing the burden” and “finding a path” again showing considerable overlap with the themes identified in this study and others. Bressan et

al (2017) in their review of nutritional impact symptoms in patients undergoing RT for HNC concluded that nutritional symptom experiences do not occur in isolation, suggesting that acknowledging the patients eating difficulties and challenges can help to develop appropriate management and support to best manage symptoms in a timely manner. It appears that although individual symptom knowledge is important, due to the overlapping nature of symptoms it is not always possible or necessary to know which individual symptom is the cause of the patients' problems. It is however, important to be able to identify the problem as the patient perceives it and support them in managing the symptoms and effects in a way that will be helpful for them.

6.4.1 Support and Sharing the Burden

The need for support and someone to share the burden of their experiences was a strong theme running through most of the interviews. Participants spoke of valuing the support they received from staff and family members alike. As well as being a positive experience, some participants found this support to be a source of anxiety and guilt if they felt they could not manage to do what others expected of them, feeling they had let them down in some way. This has been noted in other studies looking at how patients cope with the demands of RT for HNC (Donovan and Glackin 2012; Haisefield-Wolfe et al, 2012)

Those participants who had a spouse or other significant person involved in their care spoke with gratitude of the support they were given, often voicing that they did not know how they would cope without them. Undoubtedly, the family member helped the participant to plan their days, making sure they did their mouthwashes regularly, taking their medication when it was due, cooking meals for them and providing general support. This support was valuable for patients, helping them to keep on top of their symptoms and reminding them of all the things they need to do. The advice given to patients undergoing RT for HNC involves them carrying out mouthwashes at least 4 times a day, regular analgesia and other medications to manage side effects,

managing a gastrostomy tube and administering nutritional supplements via the tube, exercises from the SLT and attending daily for RT. All of this is at a time when they are feeling exhausted from their treatment, it is not difficult to see how having a significant person help manage all of this is beneficial.

However, there was a negative side to this support with participants feeling guilty if they could not eat the meal that had been lovingly cooked for them. This sometimes led to conflict with the spouse suggesting that their partner should forget about the taste and just eat the food that had been prepared for them. This approach is obviously borne out of worry and frustration at seeing their loved one become increasingly malnourished and not knowing how else to help other than cook meals that their loved one would usually enjoy. Participants spoke of dreading meals times as they knew they would be expected to eat something and it would lead to worry for their partner when they either could not say what they wanted to eat or were simply unable to eat anything. These situations lead to anxiety for both the patient and their partner (Haisefield-Wolfe et al, 2012; Larsson et al, 2007; Roing et al, 2007). Lang et al (2013) report that spouses or partners took on the main burden of emotional and practical support, taking on tasks such as telephone calls and collecting prescriptions. Utilising a critical realist framework has enabled the acceptance of conflicting views to each be equally valid, with individual participants holding differing views at different times. For example sometimes finding family support valuable and at other times feeling guilty for not being grateful for this support.

Participants also spoke of their appreciation of the care and advice provided by members of the MDT. One participant stated that having everyone care for him, encouraged him to care for himself too, not wanting to let the healthcare professionals down. They were doing their best, so he must do his best too. Again, for some participants this care was perceived as pressure, when they had not been able to do what was expected of them. For example, they knew they would be weighed when they attended clinic and they felt that there would be disapproval if they had lost weight again, adding to the pressure they felt. This was reflected by Lang et al (2013) who report that relationships with healthcare professionals are

vitaly important for patients who are feeling vulnerable. Patients rely upon healthcare professionals for information, guidance and reassurance (Lang et al, 2013, Donovan and Glackin, 2012; Larsson et al, 2007), so it is essential that all of these are correct, appropriate, and timely and tailored to the individual. Patients look to members of staff to be the expert in the treatment that they are receiving and it is vital that information provided is accurate and provided in way that is accessible for the patient. Although there were positive and negative aspects of having support, the main feeling was of gratitude and appreciation. This reflects the findings of Larsson et al (2007) who spoke of patients needing a “hand to hold” to guide them through their treatment. It did not appear to matter if this were a family member or healthcare professional so long as that individual were knowledgeable, competent and familiar with what the patient was experiencing.

6.4.2 Disruption to Daily Life

Most participants with taste changes were struggling to eat regular meals having to rely upon eating what they could manage when they could manage it. It often meant they could not have the same meal as the rest of the family and in some cases could not bear the smell of food cooking. Participants spoke of avoiding meal times because they did not want to subject their families to watching them eat. The taste of some foods made them gag and retch and they did not want to expose others to this. Meal times are not just about nutrition and participants spoke of missing the social aspect of meeting friends for coffee and this has been observed in other studies (Roing et al, 2007; Haisefield-Wolfe et al, 2012). McQuestion et al (2011) spoke of food not only to sustain life but also as a vehicle to interact and socialise with others and also to receive comfort. Their study looking at the changed meaning of food after treatment for HNC identified physical, social and emotional loss in patients. Some participants initially carried on meeting friends and family for meals or coffee in an attempt to continue with the social side of these occasions. However, most stopped this quite soon, suggesting that there was no point in subjecting themselves to this. It was often presented as the patient protecting their loved ones from what they

were going through, although there was a strong suggestion that they were also protecting themselves and did not want to be reminded about how much their life had changed. Roing et al (2007) in their phenomenological study looking at the effects of RT on the mouth described patients protecting their family and friends by not eating in front of them and not wanting to let them know how bad things were.

Although participants spoke of disruption to their daily life in relation to taste changes there was a sense that they were talking about the wider disruption to their lives caused by attending daily for RT. Lang et al (2013) talk about patients with HNC having their lives disrupted physically, emotionally and socially. Donovan and Glackin (2012) state that it is difficult distinguish a single element that is responsible for disruption that patients experience, suggesting that feelings of fear, treatment side effects and eating problems all contribute.

6.4.3 Making Sense of the Situation

Participants were trying to make sense of the situation they found themselves in and how they were going to manage this new situation. There was evidence of them learning as they went through treatment and of adjusting to a new normal. Participants demonstrated acceptance of their circumstances and set about finding what worked for them. They showed a willingness to try new ways of doing things and in doing so appeared to be managing their symptoms more effectively. Conversely, some participants were not able to adjust, trying to eat the foods that they would normally eat even though this was clearly not working for them. These participants appeared not to have accepted their situation and therefore were not able to move on by adapting to their current situation. From the results of this study it is not possible to say if these participants were refusing to accept their situation or whether they just had not had sufficient time to process and accept their current situation. It is known that lack of acceptance and disengagement are commonly used coping strategies for patients with HNC (Haisfield-Wolfe et al, 2012; Morris et al. 2017). The use of disengagement style coping strategies are associated with

increased psychological distress and reduced QoL (Sherman and Simonton, 2010; Haisefield-Wolfe et al, 2012). It is known that patients will take different amounts of time to come to terms with their illness or any other changes in their life and will concentrate their efforts on the issue that is causing them the most distress (Lang et al, 2013; Larsson et al, 2007). This should be borne in mind when caring for patients with HNC, particularly what coping strategies they appear to be using and are they effective for them. Staff should support patients to develop effective coping strategies.

6.5 Management of Taste Changes

As previously stated, it appears from clinical practice that some patients cope better with taste changes than others, with some patients continuing to eat despite not being able to taste their food. The third research question in this study was to explore how participants manage their taste changes, so that this information could be adapted to advise and support future patients. There is no previous research that specifically addresses how patients undergoing RT for HNC manage taste changes. The lack of synchronicity between what food looks like, smells like and tastes like is understandably a difficult hurdle for patients to overcome. A number of participants in this study spoke of the disappointment they felt when their food looked and smelt delicious and then tasted horrible. Hovan et al (2010) suggest that nutritional counselling may be helpful to some patients in minimising the symptoms of taste changes at least early on in a course of treatment. However, it is known from clinical practice that taste changes during RT are constantly changing and this was alluded to by participants in the interviews. Many participants spoke of having a plan but being prepared to adjust the plan because taste was changing all the time. What worked today might not work in a few days' time, so be prepared to make adjustments. The management of taste changes relied upon participants and their loved ones being very methodical in their approach to finding out what worked and what did not work for them. Acceptance of the situation and adaptability appear to be key skills that patients need to utilise to help them get through the treatment.

Morris et al (2017) noted that social support was associated with better emotional adaptability to cancer and HNC patients who lacked social support may be at greater risk of psychological distress. They also found that facilitating patients in adapting to their situation reduced stress for some patients. Staff should be aware that patients with limited social support may be less able to cope with symptoms and at greater risk of psychological distress.

The supplementary questions in week 4 of treatment proved to be a rich source of practical information about which foods participants found more acceptable when experiencing taste changes. It is noted that often the first mouthful of food doesn't taste too bad but the more the food has to be chewed the worse the taste becomes. Participants had managed this by choosing "liquidy" foods that required less chewing and therefore spent less time in their mouth, suggesting foods such as porridge and puddings were more acceptable. This has not been reported in any previous studies of HNC patients having RT and is valuable information for future patients. This needs to be considered alongside the need to maintain a good swallow function for patients. SLT advice is for patients to continue with a textured diet as long as they are able (Paleri et al, 2014) and NICE guidance (2017) supports this. However, the alternative would be tube feeding if the patient is not able to tolerate oral intake, which would potentially have a worse functional outcome for the swallow. So long as patients continue with their swallowing exercises this "liquidy" diet should not be detrimental to their swallow in the longer term and would have clear benefits nutritionally during treatment and recovery.

6.6 Motivation to Continue Eating

No previous studies have been identified that looked specifically at what motivates or enables patients to continue eating when they have taste changes. As previously stated all of the interview participants scored themselves either 9 or 10 on the MDASI-HN for problems with tasting food. Despite this some of them continued to eat while others were not able to eat anything and became dependent upon tube feeding. It seems that this score alone is not a good indicator of who will continue to

eat and who will not. Although the MDASI-HN does not claim to be able to predict who will stop eating, it might be assumed that if the participant is reporting that their problems tasting food are as bad as imaginable this would impact upon their ability to eat. Other studies have found that problems tasting food is key issue for patients who become malnourished during treatment (Bressan et al, 2017; Boltong and Campbell, 2013). This suggests that factors other than the way food tastes impact upon the patient's ability to carry on eating. Common responses to the question "what makes you carry on eating?" were wanting to avoid tube feeding or fear of losing their swallow. In addition to this a small number of participants appeared to have not considered that stopping eating was an option and were surprised to hear that some patients did in fact stop eating. These patients appeared to view stopping eating as giving up on survival, suggesting it was a strong belief for them that you do not give up on life, with one participant stating "that would be the wrong thing to do, wouldn't it?" This so called "survival instinct" is often talked about in relation to cancer survivorship and appears to be anecdotal and quite difficult to study. Rosenbaum and Rosenbaum (2012) noted that strong survival instinct appeared to be related to positive mental attitude and the ability to deal with problems as they arise, which seems to align with having effective coping strategies. Considering that nutrition is an essential component of life, the view that stopping eating is giving up on life is understandable on one level; however, ingesting food that tastes bad could also be viewed as going against what is necessary for survival. Participants went some way to explain this by stating that they told themselves that they knew there was nothing wrong with the food so they just had "to get it down". Others reasoned with themselves that the food looks like it should, smells like it should and were able to imagine the taste as it would normally be and therefore eat the food. There were few participants who were able to do this and those that were able, admitted that this method got more difficult over time. None the less these participants demonstrated great resilience in being able to do this and a strong survival instinct whichever way it was utilised was a key factor for participants who continued to eat despite having taste changes. McCarter et al (2018) in their study investigating the impact of a dietician-delivered health behaviour intervention to reduce malnutrition in HNC patients found the themes of survival and support to be very important. The main

message of their intervention was the need to “eat to live”. Although their study wasn’t specifically looking at taste changes, patients in the study frequently reported that taste changes were one of the barriers to eating. They also found that patients were motivated to eat to survive. Their intervention delivered in an empathic and supportive way was beneficial in improving nutrition during and after treatment.

Participants wanted to avoid tube feeding if possible and sited this as a strong motivator in carrying on eating. Even participants who had a gastrostomy tube placed prior to starting RT were keen to avoid using it, appearing to see this as some sort of failure if they had to give in and use the tube. Despite acknowledging that the tube had been placed to support their nutrition during treatment they wanted to avoid using it. This has been observed in other studies (Corry et al, 2008), although 90% of patients report that they were relieved to use the tube once they had started using it, they were reluctant to use it initially. This may have been because they did not want to admit that their eating had reached a point where they could not take in enough nutrition to support their body, therefore seeing tube feeding as a last resort. In some cases this served to make participants eat enough or take enough supplement drinks to ensure they maintained their body weight but for others they lost weight and still refused to use the tube. For some participants the taste of food was so bad that even the thought of avoiding having to use a feeding tube was not a stronger enough motivator to keep them eating.

Patients with HNC are encouraged to continue swallowing food for as long as possible during RT. It is accepted that the side effects of RT for HNC including taste changes make eating difficult (Bressan et al, 2017). If patients become dependent upon tube feeding, the muscles used for swallowing, particularly the pharyngeal constrictor muscles, can lose their function making swallowing impossible or unsafe with the patient being at risk of aspiration (Paleri et al, 2014). Radiotherapy treatment is planned to avoid the pharyngeal constrictor muscles where possible (Dale et al, 2016) to reduce the risk of these structures becoming damaged and losing their function in the longer term. Despite all of this patients are understandably very concerned about the risk of never being able to swallow solid food again and becoming permanently reliant upon tube feeding. In the case of taste changes, fear of losing their swallow

seems to be a powerful motivator in keeping them swallowing at least some food. However, it can also have a negative impact on some patients if they refuse to use a gastrostomy tube but also do not eat sufficient food to maintain their weight. In doing this they run the risk of becoming malnourished and struggling to cope with the effects of treatment (Corry et al, 2008), ending up with the worst of both worlds, risking losing their swallow as well as not eating enough. Corry et al (2008) found that the majority of patients wanted to avoid a feeding tube and before side effects started they found it hard to believe that they would need to rely upon a feeding tube. Once they had become reliant upon a feeding tube, 90% of patients would recommend a feeding tube to other patients. This reflects what participants reported in this study and also what is seen in clinical practice. There is clearly a need for healthcare professionals to improve the ways in which the need for tube feeding is explained to patients.

Patients should be advised to continue eating as long as they are able and to do their swallowing exercises but should also be encouraged to have an NG tube placed or use their gastrostomy tube if they have one in situ (Paleri et al, 2014; Corry et al, 2008). Careful explanation is needed to ensure that the patient does not feel that they have failed if they need to use a feeding tube to maintain good nutrition.

Both wanting to avoid using a feeding tube and fear of losing their swallow were quite negatively portrayed as reasons to carry on eating and it appeared that other factors also came into play as motivators for participants. It did not appear that either or both of these were the only factors indicating who would carry on eating and who would find taste changes too difficult to overcome and therefore stop eating.

6.7 Factors that Lead to Patients Stopping Eating

This study has demonstrated that the patient's self-reported score for problems with tasting food is not a good indicator of who will continue to eating during RT or CRT for HNC and who will not. Soter et al (2008) in their study with over 400 participants who presented with taste and smell disorders tested the use of a questionnaire to

determine if participants could accurately self-report taste disorders compared to using whole of mouth taste testing. Participants were required to respond “easily”, “somewhat” or “not at all” to questions such as “I can detect salt in chips, pretzels or salted nuts” to detect if they could taste salt in this case. They found that participants could not self-report accurately compared with the results of the whole of mouth taste testing. These findings were confirmed by McLaughlin (2013) who also reported that patients could not accurately predict which part of their taste was affected. Whilst it may be argued that what the patient reports is what they are experiencing, this demonstrates that where taste is concerned there are many variables at play, such as enjoyment of food, appetite and desire to eat, indicating that perhaps relying upon a single measure is not sufficient. This again suggests that the use of subjective measures is more effective at measuring taste changes than objective measures as well as being easier to carry out in clinical practice.

This study has shown that female patients having CRT for oropharyngeal cancer are at the highest risk of developing taste changes, 88% in this study. However, that alone is not enough to predict that this group will be more likely to stop eating. In this study, of the 13 females included, only 4 of them were having CRT, all of them developed taste changes and 3 of them stopped eating and became tube dependent. From the male cohort 28 participants were having CRT and 23 of them developed taste changes of these 14 stopped eating. It appears from this study that females are more likely to develop taste changes, however, this result needs to be treated with caution due to the small numbers of females in the interview cohort. Research from other disciplines (Soter et al, 2008, Doty, 1978) has suggested that females have a more sensitive sense of taste and smell than males and are therefore more likely to be affected by taste changes. They have found that females consistently outperform males in both whole of mouth taste tests and regional taste tests for all taste qualities. Doty (1978) found that females had more taste buds on the anterior tongue than males. This is an area that needs further study. The number of females in this study is too small to draw any conclusions but there is a definite association that demands further investigation. In the meantime staff caring for these patients should

bear in mind the possibility that females are more likely to develop problems tasting their food.

Although this study is focussed upon taste changes it appears that patients who reported multiple side effects in addition to taste changes are more likely to stop eating. This was demonstrated by participants who has scored highly for both symptom disturbance and symptom interference and had become gastrostomy tube dependent for their nutrition. This finding is unsurprising but should still serve as a warning to staff caring for these patients.

6.7.1 Coping Style

Everyone has different coping styles that they utilise and chose the most appropriate one that they think will help in a particular situation. Morris et al (2017) highlight the relationship between psychological distress and coping strategies in patients with HNC. Lazarus and Folkman (1984) define coping as a dynamic process involving cognitive and behavioural efforts to manage internal or external demands of disease. They identified three basic coping styles: task-oriented; emotion-oriented and avoidance oriented. Participants in this study spoke of other difficult times in their lives and how they had coped then, indicating that they were drawing upon strategies that had served them well previously. They drew upon those experiences to help them navigate their way through treatment for their HNC. For example Dan had learned to eat again after his stroke and the fact that he had recovered better than expected then helped him to believe that he would get through this too. It is sometimes felt that some coping styles are more effective than others (Lazarus, 1993, Dunne et al, 2016). Patients may chose a coping style that is common for them, for example ignoring a problem and hoping it goes away might be effective in some circumstances but not others (Morris et al, 2017). Taste changes are not going to go away in the short term so ignoring the fact that you cannot eat and are becoming malnourished is not going to be effective in this situation, as the participant cannot stop eating for that length of time without coming to harm. However, ignoring the

fact that you cannot taste food and eating it anyway proved to be a successful coping strategy for some participants.

Bressan et al (2017) talk about different coping strategies employed by patients with HNC and the relationship between coping style and psychological distress. They conclude that disengagement or avoidance coping strategies led to increased psychological distress in HNC patients, whereas, Elani and Alison (2011) in their study looking at coping and psychological distress conclude that coping strategies vary according to the level of psychological distress. Although there is lack of consensus on the direction of the relationship between coping styles and psychological distress there is agreement that a relationship exists (Morris et al, 2017). However, engagement coping strategies were not consistently effective in reducing psychological distress. The participants that took part in the interviews fell into a group who appeared to feel quite hopeless about their circumstances, saying things like, it's not worth me even trying to eat something because I know I won't be able to. They had anticipated that they were going to fail so they didn't even try to eat anything, definitely displaying signs of disengagement and avoidance. All of the participants who had stopped eating displayed this trait to some extent. There were other participants who were having the same treatment regime and scored similarly for symptom severity and distress and yet they carried on eating. They remained more engaged with their treatment and the management of any side effects and appeared to be more accepting of their situation and the need to make changes to their diet so that they could continue to eat. These coping strategies appear more effective in managing taste changes. Of course people will have times when they are better able to engage with these more effective strategies and times when they feel less able to do so. Elani and Alison (2011) report that patients with higher levels of anxiety were more likely to "blame themselves", resort to "wishful thinking" and use avoidance strategies. It should also be said that coping strategies are not inherently good or bad and will depend upon the context that they are being applied to (Morris et al, 2017). Participants who engaged problem focussed coping styles that involve actively doing something and also those who sought social support tended to cope better (Morris et al, 2017; Elani and Alison, 2011). Connor-Smith et al (2007) broke

these active coping styles down in to primary control coping strategies and secondary control coping. Primary control coping strategies involve actively doing something to change the situation, such as planning what you will do and actively seeking support, both of which were demonstrated by participants such as Paul and Tom who were both coping very well. Secondary control coping strategies involve acceptance and reappraisal, such as acceptance of the situation and willingness to make changes to reflect this. Again these traits were demonstrated by participants, with Louise and John reflecting this in the way they spoke of their experiences, suggesting that you had to “do what you had to do” to get through treatment.

Therefore coping strategies demonstrated by patients may serve as an indication to staff of those patients who may be less able to manage their taste changes. This study did not undertake any measure of coping strategies, however there appears to be a relationship between coping strategies and ability to continue eating that requires further investigation. Coping strategies should not be considered in isolation as it is accepted that an individual’s coping strategies might change over time and also people can be supported to develop more effective coping strategies.

6.8 Recommendations for Clinical Practice

There are a number of recommendations for clinical practice and for staff caring for patients with HNC undergoing RT.

All patients should be informed of the risk of them developing taste changes during treatment, including when they might occur, what they will be like and how to manage this problem.

All patients should be assessed regarding problems with tasting food at each review clinic appointment. This should include a formal assessment of problems tasting food and how that is impacting the patient bearing in mind that some patients tolerate taste changes better than others. All members of the MDT should be educated to do this given the widespread MDT working within the HNC team.

Appropriate advice on managing taste changes should be provided. Healthcare staff

should also make an assessment of the patients coping style and the support available to them to assist with producing an appropriate care plan for the patient.

At the end of treatment all patients with taste changes should be given advice regarding how long taste changes might take to improve and informed that they might never return to normal.

In doing this patients should be better informed and cared for during and after treatment.

6.9 Limitations of the Study

It appears that individual coping strategies are very important in determining which patients will carry on eating and who will not. This study did not set out to assess coping styles specifically and it should be remembered that coping styles are not inherently good or bad. Different styles work more or less effectively for individuals at different times. However staff caring for patients undergoing RT for HNC should be aware that some coping styles are associated with coping less well.

Taste changes and poor nutritional intake are associated with reduced QoL and as such this study could have been improved by the addition of a QoL tool, such as the University of Washington QoL questionnaire. It had been hoped that the symptom interference scores from the MDASI-HN would have served a similar purpose but this did not prove to be the case as there was no relationship demonstrated between high symptom interference score and problems with tasting food. Had used a QoL instrument been used it would have been able to assess the impact of taste changes upon QoL.

It appears that females may be more at risk of developing taste changes than males but it is not possible to draw a definite conclusion regarding this as the number of females in the sample is small.

This study was carried out in a radiotherapy department with patients who were predominantly white which although is representative of the local population of

patients with HNC, it should be borne in mind that results may not transfer to patients of other cultures which may have different associations with food and eating.

The trustworthiness of the study has been strengthened by clearly defining the steps taken in designing, conducting and analysing the research. The themes identified have been defined and supported with quotes for clarity. Under normal circumstances the analysis would have been conducted by more than one researcher to aid the trustworthiness however the requirements of the Professional Doctorate qualifications do not permit this.

It should also be borne in mind that the researcher was also heavily involved in the care of the participants during their treatment and this could potentially introduce bias to the study. Although measures were put in place to reduce this as much as possible it is not possible to know how much effect this had. Reflexivity has sought to make clear the impact of the researcher and her values and beliefs in relation to the research and the clinical care that she provides for this patient group.

Finally, it should be acknowledged that the side effects associated with RT for HNC are extensive and inter-related so was not always possible to know that participants were only discussing the impact of taste changes and may have been discussing their experience in general. This was mitigated for as much as possible by reminding them that the study was focussed on taste changes and during the interview guiding them back to taste changes if it was felt that they had diversified.

6.9 Conclusions

Mixed methods has proven to be a suitable methodology for investigating taste changes caused by RT for HNC providing more detail than either qualitative or quantitative methodologies alone would have done. Utilising a critical realist framework has allowed for a range of responses in how participants manage their taste changes to be considered equally valid.

Individual coping strategies appear to have a large effect upon how patients tolerate and manage their taste changes, with active coping styles appearing to be more effective. Patients may favour a particular coping style and disengagement coping styles in particular should alert staff that the patient may not be coping well and experiencing psychological distress requiring support.

Previous studies have recommended that research should focus on taste changes specifically rather than the combined side effects of RT for HNC, however it seems that the themes associated with taste changes are similar to the themes identified in studies looking at side effects in general. These themes show a particular overlap with studies looking at the effects of nutritional impact symptoms including oral mucositis, dry mouth and problems swallowing as well as taste changes.

Acceptance of their current situation and being willing and able to adapt and work with healthcare professionals to manage their taste changes appear to be key skills that patients need to tolerate taste changes. Healthcare staff should develop ways of engaging with patients to support a good working relationship with patients ensuring that they are able to understand and adapt advice to find a way that works for them. This is particularly important as participants spoke of how they valued their relationship with staff.

In the next chapter I outline the conclusions and recommendations from the study.

Chapter 7

7. Conclusions and Recommendations

7.1 Conclusions

In this chapter I restate the main aims and key findings of the research. I highlight why this work is so important and make recommendations for clinical practice.

Losing the ability to taste food is a common side effect of RT and CRT for HNC. Not being able to taste food properly leads to patients having reduced appetite, weight loss and malnutrition as well reduced QoL (Bressan et al, 2016). Patients who stop eating run the risk of their swallowing muscles becoming atrophied and not regaining normal function following treatment when other side effects have recovered and their cancer has been cured (Paleri et al, 2014). This in turn may lead to patients being dependent upon tube feeding for the rest of their life. My primary motivation for doing this research was to have a better understanding of why and how some patients with HNC who have taste changes manage to carry on eating whereas others are not able to. In doing so healthcare staff would be better placed to advise future patients experiencing problems with tasting food. To understand more about this topic four research questions were developed.

Firstly, what is the extent of taste changes as a result of RT or CRT for HNC? This was assessed by asking participants to complete the MDASI-HN questionnaire in weeks 1 and 4 of treatment and looking at the incidence of taste changes in comparison to tumour site and treatment received. The overall incidence of taste changes was 77% in the study population, rising to 88% in participants who had CRT and 65% in participants who had RT only. Participants who had CRT for oropharyngeal cancer were most likely to experience taste changes (88%). The incidence of taste changes was slightly higher in females (92%) than males (73%) although the numbers in this study are too small to draw conclusions, this is an area where further research is recommended. See section 6.2

The literature review also provided current information regarding the extent of taste changes and how they are measured.

The second question addressed the experience of taste changes for patients undergoing RT for HNC. Participants were able to graphically describe the experience of taste changes providing valuable insight into the problems they have to contend with. Food described as “oily” or “rancid” left little doubt as to why participants found it so hard to continue eating, if anything making it more surprising that some participants manage to continue eating anything at all.

Participants spoke of taste changes occurring sooner than they had been warned to expect.

Participants attempted to make sense of their situation, reasoning that they had to go through bad times now with the hope of better times in the future. Participants also spoke of the importance of support networks and it did not seem to matter who provided this, so long as there was someone to share the burden. They also spoke of the psychological impact of taste changes making reference to isolation, boredom, frustration, low mood and demonstrating great resilience in dealing with all of this. See section 6.4

The third research question focussed on how participants manage their taste changes. This is important because it provides information regarding what works and does not work for patients with taste changes. The supplementary questions provided answers to this question. The advice provided was very practical and encouraging for future patients. See section 6.5. The importance of good symptom management was highlighted along with having a plan of what to do when but also being willing to deviate from the plan if it stopped working for you.

Coping strategies appear to be very important in the way participants manage taste changes. Although this study did not set out to assess coping strategies it became apparent that individual coping strategies either inherent or learned from other experiences had a great impact on how participants managed. The ability to accept and adapt to their current situation were important skills for patients to develop. See section 6.7.1

The fourth question addressed what motivates patients to continue eating when food tastes awful. No previous studies were identified that looked at this specifically. In this study all of the participants interviewed scored themselves either 9 or 10 on the MDASI-HN for problems with tasting food indicating that their problems were severe. However, as in clinical practice some of them continued to eat and others could not even contemplate putting food on their mouth becoming reliant upon tube feeding. This has demonstrated that patient self-reported toxicity grading was not a good indicator of who will continue to eat and who will not, suggesting that other factors must be involved in this. See section 6.6

Strong motivators in keeping participants eating were wanting to avoid tube feeding and fear of losing swallowing function in the longer term. This suggests that both of these were considered worse to the patient than eating food that tastes bad. See section 6.7.

Many participants demonstrated a determination to carry on eating no matter what. Some did not appear to have considered not eating to be an option and for others it was strongly linked to survival and not wanting to give up. Put very simply they reasoned if you don't eat you will not survive.

Mixed methods methodology supported with a critical realist framework has proven to be a successful way to investigate the experience of taste changes in patients undergoing RT for HNC. The research questions clearly have quantitative and qualitative components suggesting that a mixed methods approach would be appropriate. However, it is not possible to know before data has been collected and analysed that it will be possible to integrate the results effectively. This methodology has proven successful at a number of stages. Firstly, the use of supplementary questions to seek the opinions of participants with taste changes but declined to be interviewed lead to a wider range of opinions and thoughts being gathered giving more strength to the responses. The question that asked participants how they managed their taste changes was particularly useful. The supplementary questions provided a good link between the quantitative and qualitative sections of the study. Secondly, the interviews proved to be successful in explaining the findings of the MDASI-HN questionnaire, such as the timings of when taste changes occurred. This

is important because participants reported that taste changes occurred sooner than they had been warned to expect them leading to some anxiety and concerns that things had gone wrong. This information will be used to inform future patients what to expect during treatment.

Critical realism was the theoretical framework that guided the research. This was effective because it supported the technical aspects of HNC treatment and the fact that taste changes were caused in the same way for each participant, but acknowledged that how this was experienced was different for each participant being filtered through their own experiences, beliefs and values. Critical realism also supports mixed methods methodology supporting the use of more than one method to answer the research questions in a meaningful way.

7.2 Recommendations

7.2.1 Clinical Practice

Patients should be provided with clear information regarding the likelihood of them developing taste changes, including the risk with the type of treatment they are having, their tumour site, when this is likely to occur and an idea of what it will be like as well as tips for managing taste changes. This should be provided before they start treatment and reinforced at their review clinic appointments during treatment. Patients should be asked at each review clinic appointment if they have any problems tasting their food and how much distress it is causing them.

An assessment of patients coping strategies should be made and appropriate support offered to help them develop a plan that works for them if their coping strategies do not appear to be effective. See section 6.8

Healthcare staff should be educated to provide patients with appropriate up to date information. Patient stories developed from this study could be adapted to support this training. An information leaflet will be developed to reinforce this information.

7.2.2 Future Research

Future research should focus on how long taste changes take to resolve after treatment has been completed. All of the interview participants asked this question during their interview. In my clinical role I run a late side effects clinic and see patients 6, 12 and 24 months after RT. Clinical practice suggests that many patients still have quite marked taste changes six months after treatment, whereas for others their taste has returned to normal. Current research has focused on the quantitative measure of taste changes which has been shown not to match what patients report they can taste subjectively. Better designed studies addressing this would provide improved quality patient information regarding which patients might find taste recovering sooner than others. For example does taste recover sooner in patients who have had RT alone compared to those having CRT?

Further investigation of whether females are more at risk than males of developing taste changes is also warranted. This study did not have large enough numbers to assess this, although there is an indication that this might be the case. It is known that females have more taste buds than males (Doty, 1978; Soter et al, 2008)) so this could be a causative factor.

It had been hoped that the symptom interference score would have provided insight into the impact of taste changes, however this proved not to be the case. Future research should measure the impact of taste changes on QoL in this patient group more formally. The impact of different coping styles and how these impact on psychological distress and QoL also demand further investigation. Other studies have suggested a relationship between coping styles and how patients manage treatment side effects (Morris et al, 2017; Elani and Allison, 2011).

7.3 Final Reflections

Undertaking this research has been challenging alongside a busy full time clinical role but the information gained has already been utilised to help patients in practice. For example, patients are advised that foods that require less chewing may be more acceptable for them and as it is known that liquid foods do not exercise the swallow much in the same way as more solid food, patients are encouraged to do swallowing exercises. In doing this it reduces their fears of losing their swallow, maintains good nutrition and reduces reliance upon tube feeding. I also consider what coping style the patient appears to be favouring and adjust the information I give to them accordingly, whilst also suggesting other approaches that might be beneficial.

Previously I have felt frustrated at not being able to support patients with taste changes appropriately and whilst I still don't necessarily have all the answers being able to provide evidence based advice feels more satisfying. Having an appreciation of patients as individuals helps to support them to develop a plan that works for them.

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APPENDICES

Appendix 1

STUDY PROTOCOL version 1.0 (June 2017)

Exploring the experience of altered taste during radiotherapy for head and neck cancer.

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Abbreviations/glossary

CRT – concurrent chemotherapy and radiotherapy

HNC – head and neck cancer

IMRT – Intensity modulated radiotherapy

MDASI-HN – MD Anderson symptom inventory head and neck module. A validated tool for assessment of symptom burden in treatment of head and neck cancer

MDT – Multidisciplinary team

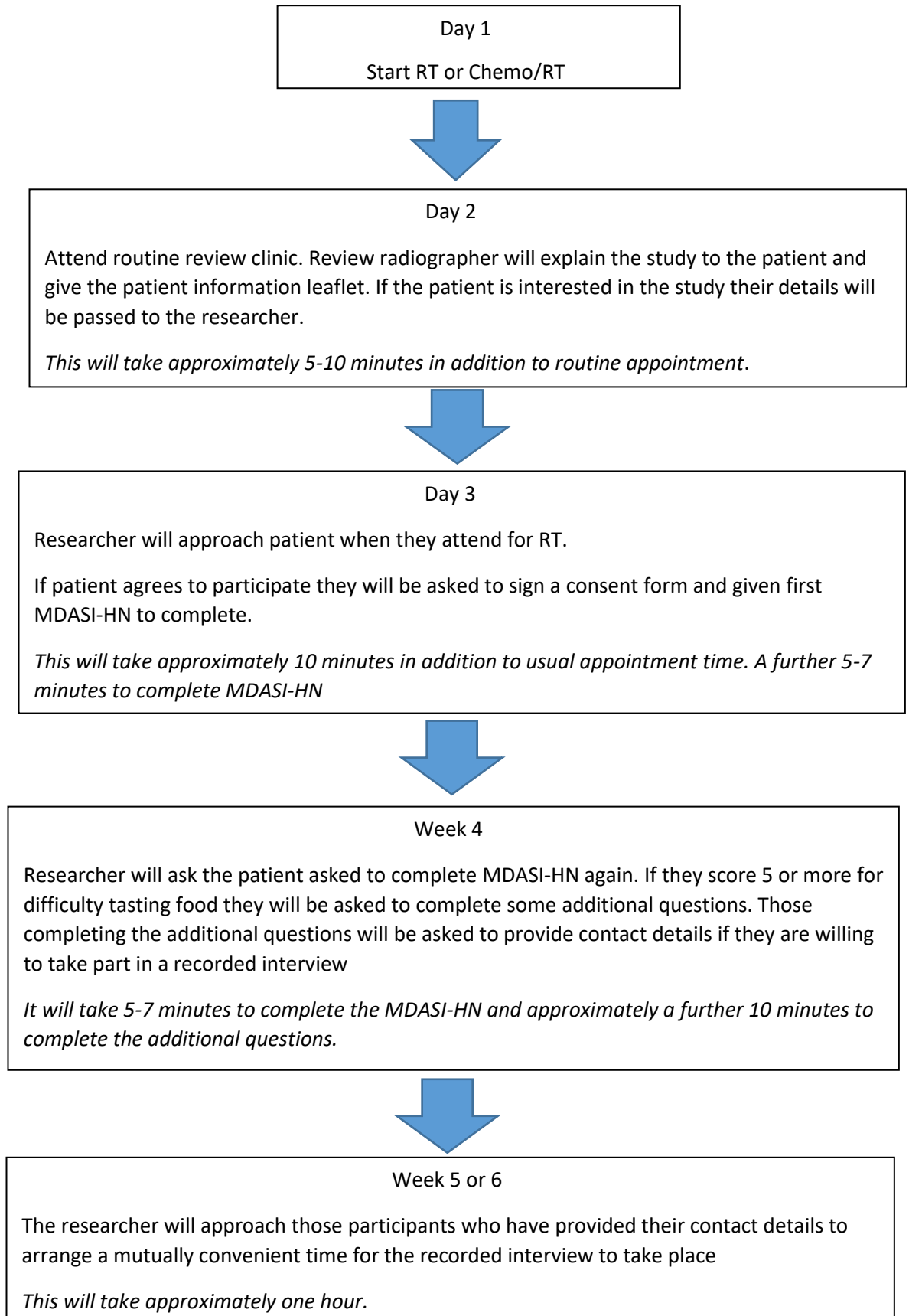
NG tube – naso gastric tube. A feeding tube placed through the nostril into the stomach to provide nutrition for patients who are unable to swallow.

QoL – Quality of life

RT – Radiotherapy

VMAT – Volumetric arc therapy

STUDY FLOW CHART



Lay Summary

Radiotherapy for head and neck cancer causes side effects that make the treatment difficult to tolerate. These side effects including sore mouth or throat, thick saliva, dry mouth, altered taste and difficulty swallowing. Improved radiotherapy techniques and better symptom relief have helped to reduce side effects. Taste changes have not improved, with some patients stopping eating due to everything they eat tasting awful, despite not having swallowing problems. This leads to malnutrition which may require hospital admission for tube feeding so that they can complete their treatment.

This study will recruit patients undergoing radical radiotherapy who are at risk of developing taste changes. Taste buds are widespread throughout the mouth and throat, so patients having radiotherapy to any of these regions will be included. They will be approached to take part in the study when they attend their routine review clinic appointment on day 2 of radiotherapy. The researcher will meet them on day 3 of radiotherapy and if they agree to take part they will be asked to complete the MD Anderson symptom inventory-head and neck module. Those that return the questionnaire will be asked to complete the MDASI-HN again in week 4 as it is known that this is when taste changes reach their peak. Those scoring greater than 5 for altered taste on the MDASI-HN will be asked to complete additional questions about the nature and impact of their taste changes. Finally, they will be asked to take part in an interview to discuss the impact of altered taste and how they coped with it. The interview will take place between weeks 5-7 of radiotherapy.

The study will be undertaken in the radiotherapy department at Velindre Hospital. Approximately 250 patients a year are treated for head and neck cancer. The study will run over six months with approximately 65 patients being recruited for the questionnaires and up to 30 patients being recruited for interview.

Data will be analysed with the aim of producing a leaflet to inform future patients and the multidisciplinary team about the impact of taste changes and how they may be helped.

1. Background

McCarthy-Leventhal (1959), a doctor and accomplished cook, who also had head and neck cancer, writing from personal experience, described taste changes following radiotherapy as “blindness of the mouth” and of staff failing to understand the difference between “food” and “diet”. She goes on to explain the impact of this on the patient: “Exhaustion and despair set in, and the already debilitated patient feels that it is all not worthwhile”. These comments closely resemble an interaction that the researcher had with a patient recently in clinical practice. Tony ((2015), not his real name) reported *“I’m fed up of all this. I can’t eat, I haven’t been able to taste any food for over a month now. Everything I put in my mouth feels and tastes foul. Why would I want to eat anything that makes me feel like that? I just want to feel better and go back to work. If I had known, it was going to be this bad I wouldn’t have agreed to have it.”*

These comments are profound for several reasons; firstly, the realisation that from the patient perspective little seems to have changed in the intervening 57 years and secondly the vivid description of the impact of taste changes on the individual. There is a lack of research into patients with head and neck cancer (HNC) experiences of taste changes due to radiotherapy (RT). Observations from clinic practice reveal that some patients cope better than others with these taste changes. Some patients carry on eating even though they cannot taste their food, whilst others refuse to eat anything, becoming malnourished and having to rely on enteral feeding, either via a gastrostomy tube or a nasogastric tube. Whilst other side effects such as mucositis and pain also impact upon nutrition, for some patients these side effects are well controlled and they are physically able to swallow but choose not to because they are so badly affected by taste changes. By developing a deeper understanding of HNC patient’s experiences of taste changes during radiotherapy, staff will be better placed to support patients in developing strategies to cope with this distressing side effect. Patients who are malnourished struggle to tolerate their treatment and take longer to recover afterwards. This leads to increased hospital admissions for enteral feeding and reduced quality of life (QoL) for the patient.

2. Rationale

HNC and its treatment cause distress due to the diagnosis and side effects associated with its treatment (Larsson et al, 2007 and Haisefield-Wolfe et al, 2012). These side effects interfere with the basic human needs of eating, breathing and speaking (Ruo Redda and Allis, 2006 and Bahravand et al, 2013). RT is used to treat over 60% of patients with a diagnosis of HNC (Donovan and Glackin, 2012). It is a gruelling treatment given daily over 6-7 weeks, usually on an outpatient basis. The common side effects associated with RT for HNC are mucositis, difficulty eating, taste changes, xerostomia, pain and sore skin (Baharvand et al, 2013 and Ruo Redda and Allis, 2006). Once RT is completed these side effects generally resolve in time, although some do not fully settle and become long term or late side effects. Taste changes are often one of the first side effects to develop during RT and may take a considerable time to improve after completion and in some cases, never fully recover (Ruo Redda and Allis, 2006). Studies have reported that up to 95% of patients having RT for HNC experience taste changes (Schwartz et al, 1993; Kamprad et al, 2008; Irune et al, 2014). These studies have been mainly of a quantitative nature, focussing on which of the five sense of taste have been most affected: sweet, sour, salty, bitter and umami (Baharvand et al, 2013; Ruo Redda and Allis, 2006; Epstein and Barasch, 2010). This is usually measured utilising either chemical or electro-gustometry, which are rarely carried out in clinical practice as it is difficult and time consuming. Subjective measures of taste changes are more commonly used and may be argued to be of more use, as these are patient reported and capture the patient's own perception of their ability to taste different foods.

Taste buds are anatomical structures located throughout the oral cavity, pharynx and upper oesophagus (Ruo Redda and Allis, 2006). Loss of taste is greatest from week four of RT until two months after completion of RT (Maes et al, 2002). Recovery of taste is slow with improvement being noted up to 24 months after RT is completed and in some cases never fully recovering (Mossman et al, 1982, Yamashita et al, 2006). There is no standard accepted way that taste changes should be assessed, although it is suggested that in clinical practice, objective as well as subjective measures should be used

(Irvine et al, 2014). It may be argued that the effect of taste changes on the patient is of greatest concern, as it affects their nutritional intake and therefore their ability to cope both physically and emotionally with this rigorous treatment.

There is little qualitative research into taste changes associated with RT for HNC, most concentrating on the impact of RT in general and the effect upon nutritional intake (Donovan and Glackin, 2010; Larsson et al, 2007; Rose-Ped et al, 2003 and Gamble, 1998).

The more modern RT techniques of Intensity Modulated RT (IMRT and Volumetric Arc Therapy (VMAT) have helped to improve some of the late toxicity associated with RT for HNC but have done little to improve acute toxicity, including taste changes (Yamashita et al, 2006; Irvine et al, 2014). It is necessary to include the tissues containing taste buds in the radiotherapy treatment volume, therefore, taste changes will continue to be a problem.

Taste changes have a major impact on the QoL of HNC patients, being associated with weight loss due to reduced appetite, nausea and altered eating habits, leading to malnutrition (Epstein and Barasch, 2010; Irvine et al, 2014). Taste changes are also associated with reduced enjoyment of food, leading to social isolation, avoiding family meal times and social gatherings (Baharvand et al, 2013; Boltong, 2013). This malnutrition leads to increased hospital admissions for feeding tubes to be placed and longer recovery times after treatment has been completed. A recent audit in my department has shown that approximately one third of HNC patients require NG feeding. Semba et al (1994) noted that patients with taste changes had a worse outcome than those who could continue to eat and maintain good nutrition.

It has been suggested that dietary counselling is the best way to deal with taste changes (Ruo Redda and Allis, 2006; Epstein and Barasch, 2010). However, it is noted from clinical practice that some patients will not eat anything, therefore advising them how to adjust their diet is not helpful or effective.

Hovan et al (2010) in their systematic review of taste changes induced by cancer therapies, concluded that management strategies are required to help patients cope and state that studies are required to clarify our understanding of this side effect. Epstein et al (2016) state that there is limited study in

oncology patients despite the significant impact that taste has on oral intake and general physical and social well-being. An improved understanding of the experience of taste changes will help clinicians to support these patients during treatment leading to improved nutrition and quality of life.

Therefore, the following research question has been developed:

“What is the extent and experience of altered taste during radiotherapy for head and neck cancer?”

3. Research Aims and Objectives

This study aims to achieve a better understanding of the extent and experience of taste changes for patients undergoing radiotherapy and concurrent chemoradiotherapy (CRT) from their perspective.

- The MDASI-HN will provide information about the extent of altered taste in this patient group and symptom burden.
- The supplementary questions will provide information about the nature of taste changes and how patients cope during treatment.
- The semi-structured interviews will give more detail and help improve understanding of patient experience of altered taste.

Analysis of the data collected will help to develop management strategies for future patients who experience altered taste.

4. Study Design

An explanatory sequential mixed methods approach has been selected for this study. Schneerson and Gale (2015) suggest that sequential mixed methods can be used when the results of one method are used to plan the next method. Integration can occur at any stage of the research process, during data collection, analysis or interpretation (Creswell and Plano Clark, 2011). The quantitative data will be used to select participants to be interviewed for the qualitative part of the study. The data from the quantitative and qualitative parts will be analysed separately initially and then combined to help with interpretation of the results (Schneerson and Gale, 2015). A pragmatic approach has been selected for this study. Pragmatism is a world view

associated with multiple methods of data collection to best answer the research question (Creswell, 2014). The pragmatic approach focuses on the practical implications of the research and emphasises the importance of conducting research that best addresses the research question (Chenail, 2011). Tashakkori and Teddlie (2003a) suggest that pragmatism is the best philosophical foundation for mixed methods research and suggest the use of different paradigms, but to honour both quantitative and qualitative methods and be explicit about when each is being used (Creswell and Plano Clark, 2011). Pragmatism draws upon many ideas, including employing “what works”, using diverse approaches and valuing both objective and subjective knowledge and in doing so mirrors the approach adopted in clinical practice when supporting patients through their treatment for HNC. The combination of quantitative and qualitative approaches fits with the role of the therapeutic radiographer, having the highly technical role of delivering radiotherapy accurately and the patient care and support aspect of the role being more qualitative in its approach. The therapeutic radiographer undertaking on-treatment review utilises quantitative tools to assess treatment toxicity and adopts a pragmatic approach in advising and supporting patients. Patients are individual and need supporting in different ways to get them through their treatment.

The ontological beliefs associated with mixed methods research are “reality is what is useful, practical and works”. The epistemological beliefs focus on reality as known through using many tools of research that reflect objective and subjective evidence (Chenail, 2011).

4.1 Methods

Participants will be asked to complete the MD Anderson Symptom Inventory Index- Head and Neck (MDASI-HN) in week one and again in week four of RT. Completing the questionnaire in week one will provide baseline data on symptoms being experienced at the start of treatment. The MDASI-HN was designed to measure symptom burden of HNC treatment symptoms and the impact of those symptoms on daily life (Rosenthal et al, 2007). The instrument consists of 13 general cancer symptom burden questions and nine items

specific to HNC. The questionnaire takes 5-7 minutes to complete. The reliability coefficient for the HNC specific items was 0.83 and tasting food was among the most prevalent severe symptoms in the initial psychometric testing of the instrument (Rosenthal, 2007). The MDASI-HN uses a 0-10 scale, where 0 indicates that the symptom is not present and 10 being as bad as you can imagine. The 11-point scale gives participants the opportunity to report the level of altered taste that they are experiencing and therefore the magnitude of distress experienced. A score of 5-6 indicates the symptom is causing moderate distress, with a score of 7 or greater indicating severe distress (Rosenthal et al, 2007). For these reasons the MDASI-HN has been selected for this study. Other validated questionnaires were considered but rejected as they did not discriminate between the level of altered taste being experienced. Patients who score themselves as 5 or above for altered taste in the MDASI-HN in week 4 of RT will be asked to complete some supplementary questions that ask for more detail about the impact of their altered taste (See appendix 3). These questions have been developed in consultation with patients undergoing RT for HNC, members of the MDT caring for these patients and clinical experience. These questions ask about the effects of altered taste including asking about any foods they can taste or not; any advice they have found helpful and any advice they would give to another patient going through the same treatment. Finally, they will be asked to provide their contact details if they would be willing to be interviewed about their experience of taste changes.

The supplementary questions have been developed because the MDASI-HN, although better than the other validated questionnaires, does not ask for any detail on how the patient has been affected. These questions have been developed to understand more about the impact of taste changes during RT for HNC.

The semi-structured interview will be carried out in either week 5 or 6 of RT at a time convenient for the participant and the researcher, usually either before or after their RT. The questions for the semi-structured interview will focus on the impact of taste changes for the patient and will be developed from the replies to the MDASI-HN, input from current patients and answers to the supplementary questions. It is important that the interview is carried out while

the participant is still experiencing taste changes. They will be encouraged to speak freely about their experience and given prompts if necessary. Semi-structured interviews have been selected as they are recommended when the researcher knows enough about the topic to guide the interview but needs answers to these questions (McIntosh and Morse, 2015).

4.2 Data Analysis

Descriptive statistics will be used to analyse demographic data, such as age and histological diagnosis of participants and data from MDASI-HN in weeks 1 and 4.

Data from the supplementary questions in week 4 will be analysed to produce themes and categories to shape the questions for the semi-structured interviews.

Once the individual analysis has been done, this will be followed by analysis across both parts of the study using an explanatory approach. The interview data may be utilised to give meaning to the questionnaire data.

The MDASI-HN will be analysed using the guidance provided by Rosenthal et al (2007).

The interviews will be transcribed by the researcher as soon as possible after the interview takes place. This allows the researcher the opportunity to become immersed in the data leading to more effective analysis (Quinn and Clare, 2008). Interview data will be analysed using a pragmatic approach. First the full transcript will be read to get a feel and general understanding of the content. Then it will be re-read making notes about the themes that are being discussed and uncovered. These themes will then be grouped into categories. This will be done for each interview individually and then they will be looked at together so that common themes and ideas can be developed. McIntosh and Morse (2015) suggest that semi-structured interviews are best interpreted through categorical analysis, although the nature of this topic is likely to have an interpretive element.

5. Study Setting

The study will take place in the radiotherapy department at Velindre Cancer Centre. Patients with head and neck cancer attend the department daily for their radiotherapy treatment. Once a week they are seen in the radiotherapy review clinic by members of the multidisciplinary team including review radiographers, dietician and speech and language therapist. At this appointment, the team assess how the patient is tolerating treatment and offer advice on coping with any side effects. The patient also has the opportunity to discuss any issues that are affecting them at that time. A holistic approach is taken to patient care in the review clinic. The first review clinic appointment takes place on day 2 of RT.

It is anticipated that the study will run over a period of six months. Approximately 250 patients a year are treated with RT for HNC. It is anticipated that greater than 50% of patients will agree to complete the MDASI-HN, with fewer agreeing to be interviewed. Not all patients will develop taste changes and therefore would not be eligible for interview. However, it is accepted that up to 95% of patients undergoing RT for HNC will develop taste changes so it is not anticipated that many patients would not be eligible for interview.

It is hoped that over the 6-month period of the study 60-70 patients will complete both questionnaires and if 50% of these agree to be interviewed, 30 participants will take part in the recorded semi-structured interview.

6. Sample and Recruitment

Participants will be recruited when they attend review clinic on day 2 of RT. The review radiographer will approach all patients at this appointment and if they are interested in taking part and do not already have altered taste, they will be given the patient information leaflet (see appendix 1) and their details will be passed to the researcher. The researcher will approach the patient on day 3 of RT to answer any questions and take written consent (see appendix 2) if they agree to participate. The participant will be given the first MDASI-HN at this point and asked to complete it as soon as possible, either in the department or take it home and return it to the researcher the next day when they attend for RT.

6.1 Study Population

The study population is a purposive sample of any patients undergoing radical RT or chemo/RT for 6 weeks or more for a diagnosis of primary HNC who are at risk of developing taste changes because of this.

Inclusion criteria

Any patient over 18 years of age undergoing radical RT or concurrent chemo/RT of 6 weeks or more duration for a diagnosis of primary HNC who is willing to complete the MDASI-HN

- Taste changes are a possible side effect of planned treatment

Exclusion criteria

- Patients who have pre-existing taste changes or taste loss
- Patients who are unable to understand or speak English
- Patient does not have a diagnosis of primary HNC
- RT given with palliative intent
- Has had RT to head and neck region previously

Taking a pragmatic approach, every patient who is eligible will be approached to take part in the study. It is anticipated that during the period of the study over 70 patients could be recruited for the questionnaire part of the study.

When deciding upon the sample size for the semi-structured interviews the following criteria were considered:

- Nature of the data
- Quality of the data
- Scope of the study
- Sample specificity
- Amount of information obtained from each participant
- Qualitative method and study design used (Malterud, 2016; Morse, 2000).

Taking all of this in to account a sample size of 20 has been set for the semi-structured interviews, although it is acknowledged that this may change as it is not possible to know the quality of data collected before the interviews have taken place. Participants may be less likely to agree to being interviewed than complete the questionnaires because the burden associated with the interview

is greater and will be carried out at a time when the participant will be at the peak of their treatment reaction.

7. Ethical and Regulatory Compliance

Ethical approval for the study will be sought from REC and service level approval from Velindre NHS Trust Research Risk Review Committee.

The completed questionnaires will be stored in a locked filing cabinet. All transcribed data will be stored in a password protected file in a password protected computer. Participants will be identified by a number to maintain confidentiality. The researcher will keep a master list of patient names and numbers in a password protected file on a password protected computer. Interviews will be audio digitally recorded and once transcribed will be deleted from the recorder.

Participants confidentiality will be maintained throughout the study and when publishing results. Participant quotes will be anonymised and a pseudonym used when attributing quotes.

There is a possibility that the participant may become distressed during the interview, in which case the participant will be directed to the person most appropriate to deal with the problem e.g. a member of the review team, Rebecca Bailey Head and Neck CNS or a member of the psychology and counselling team. This adheres to departmental practice for any patient who becomes distressed during RT.

Patients with HNC may have difficulty communicating and will be given as much support as possible during the interview. They may have a dry mouth or copious thick saliva, so drinks will be made available and tissues and they will be encouraged to take as much time as they need and to take a rest if required. Patients who have a laryngectomy and therefore no voice will be included in the study and may write their answers if this is easier for them.

8. Dissemination

The results of the study will be shared with the multidisciplinary team in the annual South Wales Head and Neck Cancer study day. This will ensure that healthcare professionals caring for HNC patients with taste changes across the network will be informed of the results. It is anticipated that a paper will be

produced for publication in a journal such as Supportive Care in Cancer. A paper will be produced for Radiography Journal and an abstract submitted for the annual Radiotherapy Conference.

One of the main aims of the study is to produce a patient information leaflet to provide advice on managing taste changes. These results will also be shared with charities that provide information for patients. The aim is to ensure that as many professional and carers groups as possible are informed of the results.

Appendix 2

PATIENT INFORMATION SHEET (version 0.3 June 2017)

Exploring the experience of taste changes during radiotherapy for head and neck cancer.

You have been invited to take part in this study. Before you decide it is important that you understand why this study is being done and what it will involve. You will be undergoing a course of radiotherapy to treat your head and neck cancer. One of the possible side effects of this treatment is altered taste. There is a lack of research looking at the impact of altered taste during radiotherapy.

What is the purpose of this study?

The purpose of this study is to understand the patient's experience of altered taste during radiotherapy and how they have managed this. The results will help to support patients undergoing treatment in the future.

Why have I been invited to take part?

You have been invited to take part because you are having radiotherapy for your head and neck cancer. As a result of this radiotherapy your sense of taste may become altered.

Do I have to take part?

It is up to you to decide whether to take part or not. Your review radiographer will explain the study to you and go through this information sheet with you. If you are interested in taking part in the study your details will be passed on to the researcher, who will contact you the next day when you attend for radiotherapy. You are free to withdraw from the study at any time, without giving a reason. The standard of care you receive will not be affected whether you decide to take part in the study or not.

What will happen to me if I take part?

If you agree to take part, you will be asked to sign a consent form and be given the MD Anderson Symptom Inventory- Head and Neck (MDASI-HN) to complete. This questionnaire usually takes less than 10 minutes to complete and asks you about how you have been affected by the treatment you are receiving. You may complete the MDASI-HN in the radiotherapy department or if you prefer you may take it home to complete and return it when you attend for radiotherapy the next day. The first questionnaire measures your

symptoms at the start of treatment. You will be asked to complete the same questionnaire again during week 4 of treatment. If you score greater than 5 for problems with tasting food at this time you will be asked to complete some extra questions about how your taste has been affected. Finally, if your taste has been affected you will be asked if you are willing to take part in an audio-recorded interview to discuss your experiences. You may complete the questionnaires and decide not to be interviewed.

If you agree to be interviewed, the interview will take place in the radiotherapy department on a day convenient for you and the researcher, during either week five or six of your radiotherapy treatment. You will not have to make any extra visits to the hospital.

What will happen if I agree to be interviewed?

The researcher will meet you on the agreed date and time and before starting the interview will confirm that you are still happy to take part in the study.

The researcher will ask you about your experience of taste changes, such as “how has your taste been affected?”, “are there certain foods that you have found easier to eat than others?”, “how have you managed your taste changes?”, “Is there any advice you would give to someone else going through the same treatment?”.

The interview will be digitally audio-recorded and will last up to an hour. It is not anticipated that the interview will cause distress, but should you become distressed during the interview or afterwards, the researcher will advise you to contact the review radiographers or your clinical nurse specialist for further support. The researcher will remind you of their contact details if you do not already have them. If you feel the need, you can stop the interview at any point and any data collected will be destroyed if you wish, in accordance with Cardiff University policy.

Throughout the interview you can take a comfort break or refreshment break if you wish. Refreshments will be made available for you.

Should you divulge any information during the interview that raises concern over your treatment, or regarding your personal welfare or safety the researcher would be unable to keep the information confidential. The

researcher would have to notify your consultant or GP in line with Velindre NHS Trust safeguarding policy and Cardiff University guidelines.

What will happen to the questionnaires and the recording of the interview?

Your confidentiality will be protected at all times. Any personal data collected about you will be securely destroyed within three months of completion of the study.

The completed questionnaires will be stored in a locked filing cabinet in Velindre Cancer Centre. Anonymised data from the questionnaires will be transferred to a password protected spreadsheet for analysis. This spreadsheet will be stored on a password protected computer at Velindre Cancer Centre.

The recorded interviews will be transcribed and stored on a password protected computer at Velindre Cancer Centre. The interview will then be deleted from the recorder. Only the researcher, supervisors and auditors will have access to the data, which will be stored securely for 15 years and destroyed securely afterwards in accordance with Cardiff University guidelines.

What are the possible disadvantages and risks of taking part?

If you agree to take part it will take you approximately 5-7 minutes to complete the questionnaire on each occasion. If you develop taste changes and agree to be interviewed, the interview will take up to an hour, so you be at the hospital for longer on this occasion, which may cause you some inconvenience.

If any unaddressed issues are uncovered during the interview you will be seen by a review radiographer who will either answer your questions or signpost you to the most appropriate person to deal with the issue.

Alternatively, you may prefer to contact your clinical nurse specialist.

What are the possible benefits of taking part?

The study may not benefit you but it is hoped that the information collected during the study will help improve the care of future head and neck cancer patients who develop taste changes during radiotherapy.

Expenses and payments

There is no financial reward for taking part in the study.

What if there is a problem?

If you have any complaint about the way you have been dealt with during the study or any possible harm you might suffer it will be addressed. If you have a concern about any aspect of this study, please ask to speak to the researcher who will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through:

Dr. Kate Button

████████████████████
██
████████████████
████████████████████████████

Will taking part in the study be kept confidential?

Yes, any information, including direct quotations that may be used in the study report or publications will be anonymised. The researcher will follow ethical and legal practice and all information about you will be handled in confidence. All data collected in the study will be processed, stored and destroyed following Cardiff University policies.

Information collected about you during the study may be used to support other research in the future, and shared anonymously with other researchers with ethical approval.

What will happen if I don't want to carry on in the study?

You can withdraw from the study at any time without giving a reason. This will not have any impact on your medical care during treatment or afterwards. We would like to keep any data already collected but will destroy it if you wish, unless it has already been analysed in which case this may not be possible.

Involvement of your consultant and General Practitioner (GP)

Your consultant and GP will not be informed of your participation in the study as it has no impact on your current or future medical care. Your head and neck cancer consultant is aware that the study is taking place.

What will happen to the results of the study?

The results of this study will be written up and submitted for a doctoral thesis. It is anticipated the results will be presented at Velindre NHS Trust meetings and other conferences. It is anticipated that the results will be submitted for publication in peer reviewed cancer journals. If you wish, a summary of the findings can be sent to you. Please provide the researcher with your contact details if you would like a summary of the research findings.

Who is organizing and funding the research?

This is a student study and will be submitted as part of a Professional Doctorate in Advanced Healthcare Practice award. It is sponsored by Cardiff University and has no funding associated with it.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Wales Research Ethics Committee 3.

Thank you for taking the time to read this information sheet.

Further information and contact details

If you require further information, please contact:

Jane Mathlin MSc, DCR(T), IP

[Redacted]

[Redacted]

[Redacted]

[Redacted]

e-mail: jane.mathlin@wales.nhs.uk

Appendix 3

IRAS ID: 224517

Participant Identification Number for this trial:

CONSENT FORM

Title of Project: **Exploring the experience of altered taste during radiotherapy**

Name of Researcher: Jane Mathlin

1. I confirm that I have read the information sheet dated June 2017 (version 0.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Cardiff University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I give consent to take part in an audio-recorded interview if I develop taste problems during treatment.

5. I give consent for the researcher to use anonymised quotes from my interview in reports or publications.

6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature

Appendix 4 Ethical Approval



Velindre NHS Trust Headquarters
Pencadlys Ymddiriedolaeth GIG Felindre

2 Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff
CF15 7QZ

Tel/Ffon : (029) 2061588
www.velindre-tr.wales.nhs.uk

*Correspondence to: Mrs Sarah Townsend, Research and Development Manager, Velindre NHS Trust,
Research & Development Office, Velindre Cancer Centre, Velindre Road, Whitchurch,
Cardiff, CF14 2TL
Email: Sarah.Townsend@wales.nhs.uk
Tel: 029 20 615888 ext: 4670*

Mrs Jane Mathlin
Radiotherapy Department
Velindre NHS Trust
Speech and Language Therapy Department
Velindre Cancer Centre
Cardiff
CF14 2TL

26th October 2017

Dear Mrs Mathlin,

2017/VCC/0017: Exploring the extent and experience of altered taste during radiotherapy for head and neck cancer

In line with the Trust R&D permissions process I am pleased to award R&D permission to commence the above study in the Cancer Centre.

Supporting Documentation as listed

Document:	Subtitle:	Version:
REC favourable opinion letter and all correspondence	224517 17-WA-0309 Favorable opinion with additional conditions 16 10 2017	
Research participant consent form		v1.1, 18 Oct 2017
Summary CV for Chief Investigator (CI)	J Mathlin	21 Sep 2017
Supervisor's CV	Nicholas Courtier	
Supervisor's CV	Jane Hopkinson	
Non-validated questionnaire	M. D. Anderson Symptom Inventory - Head & Neck (MDASI- HN)	© 2000

Mae'r Ymddiriedolaeth hon yn croesawu gohebiaeth yn y Gymraeg
This Trust welcomes correspondence in Welsh



Document:	Subtitle:	Version:
R&D Form (Parts A-D) (signed/authorised pdf or hard copy)		24 Oct 2017
Research participant information sheet (PIS)		v1.1, 18 Oct 2017
R&D Application checklist		
REC form	Draft	20 Sep 2017
Interview schedules or topic guides for participants	Sample interview questions	v1, 18 Sep 2017
Written final confirmation from the organisation(s) acting as sponsor	Cardiff University sponsorship in principle letter	24 Aug 2017
Research protocol		v1.0, 29 Jun 2017
Non-validated questionnaire	Further questions about how your taste has been affected	v1, 18 Sep 2017
Site-Specific Information form checklist	V NHST, Radiotherapy Department Velindre Hospital	
Site-Specific Information Form (signed/authorised pdf or hard copy)	V NHST, Radiotherapy Department Velindre Hospital	24 Oct 2017

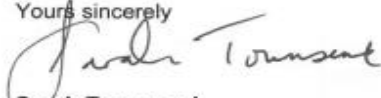
It is the responsibility of the PI to ensure that the study is being carried out to the correct protocol and amendments are assessed proportionate to the scale of the amendment and the risk and liabilities of the Trust.

Approval lapses if the project does not commence within 12 months of approval. The Committee reserve the right to information on the progress of the project at any time and should receive a progress report six monthly and a written report on completion. Random audits may be carried out to ensure that projects comply with the clinical guidelines for research. Any serious adverse incidents relating to the project should be reported to the R&D office and a Clinical Incident Form completed.

On completion of the project please inform the R&D office.

All correspondence should be forwarded to Sarah Townsend, R&D Manager, Research & Development Office, Velindre Cancer Centre, Velindre Road, Whitchurch, Cardiff, CF14 2TL.

Yours sincerely




Sarah Townsend
Research and Development Manager and Sponsor Representative

Appendix 5
Scoping Review Search Strategy

#	Searches	Results
13	8&12	48
12	9 or 10 or 11	19395
11	exp taste acuity/	0
10	exp taste/	19148
9	exp dysgeusia/	327
8	3 and 7	10361
7	4 or 5 or6	63474
6	((oral or mouth) adj3 (cancer* or tumo\$r*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	15155
5	(head and neck cancer*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	17347
4	(head and neck neoplasms).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	45889
3	1 or 2	183237
2	radiation therapy.mp. or radiotherapy/	86259
1	Exp radiotherapy/	155209

Appendix 6 MDASI-HN Questionnaire

 Draft	Date: <input type="text"/> / <input type="text"/> / <input type="text"/> (month) (day) (year)	Study Name: _____
	Subject's Initials: _____	Protocol #: _____
PLEASE USE BLACK INK PEN	Study Subject # <input type="text"/>	PI: _____
		Revision: 07/01/05

M. D. Anderson Symptom Inventory - Head & Neck (MDASI-HN)

Part I. How severe are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been *in the last 24 hours*. Please fill in the circle below from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	NOT PRESENT										AS BAD AS YOU CAN IMAGINE	
	0	1	2	3	4	5	6	7	8	9	10	
1. Your pain at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
2. Your fatigue (tiredness) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
3. Your nausea at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
4. Your disturbed sleep at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
5. Your feeling of being distressed (upset) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
6. Your shortness of breath at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
7. Your problem with remembering things at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
8. Your problem with lack of appetite at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
9. Your feeling drowsy (sleepy) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
10. Your having a dry mouth at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
11. Your feeling sad at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
12. Your vomiting at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
13. Your numbness or tingling at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
14. Your problem with mucus in your mouth and throat at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
15. Your difficulty swallowing/chewing at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	



Date: / /
 (month) (day) (year)

Study Name: _____

Subject's Initials: _____

Protocol #: _____

Study Subject #

PI: _____

Revision: 07/01/05

PLEASE USE
BLACK INK PEN

	NOT PRESENT										AS BAD AS YOU CAN IMAGINE	
	0	1	2	3	4	5	6	7	8	9	10	
16. Your choking/coughing (food/liquids going down the wrong pipe) at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Your difficulty with voice/speech at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Your skin pain/burning/rash at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Your constipation at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Your problem with tasting food at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Your mouth/throat sores at their WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Your problem with your teeth or gums at its WORST?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Part II. How have your symptoms interfered with your life?

Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items in the last 24 hours:

	Did not Interfere									Interfered Completely	
	0	1	2	3	4	5	6	7	8	9	10
23. General activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Mood?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Work (including work around the house)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Relations with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Walking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Enjoyment of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix 7

SAMPLE INTERVIEW QUESTIONS

The questions for the semi-structured interviews will be developed using information noted in clinical practice and incorporating the answers from the supplementary questions but are likely to cover the following areas:

- Please can you tell me how your taste has been affected during your treatment?
- How has having altered taste affected you during treatment?
- Has this stopped you doing anything?
- Are there some foods that you can taste better than others?
- Have you found the texture of some foods off-putting?
- How have you managed your taste changes?
- Has having altered taste affected you emotionally?
- Is there any advice you would give to someone else going through this treatment?
- Is there any advice you have been given that you have found particularly helpful?

The interview will start with the researcher explaining the purpose of the interview to the participant and making sure that they are still willing to take part. Probes and encouragement will be used throughout to ensure that questions are answered fully and the personal impact is uncovered.

Participants will be given plenty of time to answer and drinks and tissues will be made available, along with comfort breaks as it is acknowledged that participants will be interviewed at a time when they may be experiencing a build-up of mucus from the radiotherapy and may be experiencing pain.

The interview will be cut short if the participant is finding it too uncomfortable to carry on.

**Appendix 8
MDASI-HN Results**

Week 1 results

WEEK 1 MDASI-HN	NUMBER OF PARTICIPANTS REPORTING SYMPTOM NOT PRESENT SCORE 0 (%)	NUMBER OF PARTICIPANTS REPORTING MILD SYMPTOM SCORE 1 – 4 (%)	NUMBER OF PARTICIPANTS REPORTING MODERATE/SEVERE SYMPTOM SCORE 5 or greater (%)	Core or Head and Neck specific symptom
Pain	27 (44)	30 (49)	4 (7)	Core
Fatigue	15 (25)	31 (51)	15(24)*	Core
Nausea	38 (63)	15 (25)	8 (12)	Core
Problems with sleeping	22 (37)	27 (44)	11 (18)*	Core
Distress	26 (43)	28 (46)	7 (12)	Core
SoB	43 (70)	15 (25)	3 (5)	Core
Memory	34 (56)	21 (34)	6 (9)	Core
Appetite	30 (50)	24 (39)	7 (11)	Core
Feeling sleepy/drowsy	20 (33)	31 (51)	10 (16)*	Core
Dry mouth	25 (41)	28 (46)	8 (13)	Core
Sadness	26 (43)	28 (46)	7 (11)	Core
Vomiting	57 (93)*	3 (5)	1 (2)	Core
Numbness/tingling	40 (66)	14 (23)	7(11)	core
Mucus	33 (54)	24 (39)	4 (7)	H&N
Problems swallowing	35 (57)	21 (34)	5 (8)	H&N
Choking	52 (85)*	9 (15)	0	H&N

Voice	36 (59)	19 (31)	6 (10)	H&N
Skin	48 (79)*	11 (18)	2 (4)	H&N
Constipation	36 (59)	17 (28)	8 (12)	H&N
Taste problems	39 (64)	17 (28)	5 (8)	H&N
Sore throat	40 (66)	18 (29)	3 (5)	H&N
Teeth/gums	43 (70)	14 (23)	4(7)	H&N

Table 1 scores recorded on MDASI-HN by participants in week 1 of treatment

Symptom Interference Scores

Symptom Interference	Activity Score	Mood Score
Mean score	5.43	4.65
Range	0 - 24	0 – 23
Number scoring 0 (%)	21 (34)	19 (31)
Number scoring 1 – 10 (%)	28 (46)	33 (54)
Number scoring 11 – 20 (%)	9 (15)	7 (11)
Number scoring 21 – 30 (%)	3 (5)	2 (4)

Table 2 symptom interference scores for activity and mood items in week 1 of treatment

Week 4 results

Symptom	Number scoring 5 or greater for symptom (%)	Number reporting symptom not present (%)	Core/HN symptom
Pain	35 (57)*	6 (10)	Core
Fatigue	34 (56)*	4 (7)	Core
Nausea	14 (23)	24 (39)	Core
Disturbed sleep	22 (36)	13 (21)	Core

Distress	20 (33)	13 (21)	Core
Shortness of breath	3 (5)	37 (61)*	Core
Memory problems	8 (13)	30 (49)	Core
Lack of appetite	36 (59)*	6 (10)	Core
Feeling drowsy	32 (52)	3 (5)	Core
Dry mouth	33 (54)*	4 (7)	Core
Feeling sad	18 (30)	17 (28)	Core
Vomiting	11 (18)	41 (67)*	Core
Numbness/tingling	5 (8)	37 (61)*	Core
Mucus	31 (51)	4 (7)	H&N
Swallowing/chewing	37 (61)*	3 (5)	H&N
Choking/coughing	7 (11)	32 (52)	H&N
Voice/speech	17 (28)	8 (13)	H&N
Skin pain	17 (28)	16 (26)	H&N
Constipation	17 (28)	22 (36)	H&N
Taste	46 (77)*	3 (5)	H&N
Sore mouth/throat	35 (57)*	7 (11)	H&N
Teeth/gums	18 (30)	23 (38)	H&N

Table 3 number of participants reporting symptoms in week 4

Total Symptom Scores in Week 4

	Whole group scores n = 61 (%)
Range	4 – 160
Mean	78.26
0	0
1 – 20	4 (7)
21 – 40	6 (9)
41 – 60	9 (15)
61 – 80	17 (28)

81 – 100	10 (16)
101 – 120	8 (13)
121 – 140	3 (5)
141 – 160	4 (7)
161 – 220	0

Table 4 range of total symptom scores in week 4

Symptom Interference Scores week 4

Symptom Interference	Activity score n = 61	Afferent score n = 60
Mean score	11.8	11.4
Range	0 – 30	0 – 29
Number scoring 0	7 (12)	5 (8)
Number scoring 1 – 10 (%)	22 (36)	24 (40)
Number scoring 11 – 20 (%)	21 (34)	24 (40)
Number scoring 21 – 30 (%)	11 (18)	7 (12)

Table 5 symptom interference scores during week 4 of treatment

APPENDIX 9

Louise interviewed on 9/2/18

Louise became quite distressed and tearful at points during the interview.

I have highlighted in yellow all ideas and quotes of interest

Jane: So if you could start Louise by telling me how your taste has been affected during the treatment.

Louise: Oh, it's been totally affected, no taste at all. It went very quickly actually. I think it went, oh, right back in the first week. And it is changing throughout the time. I haven't been able to, first I could taste salty things and metallic things and um quite soapy really, um and the dry mouth has affected the taste as well. So I would say there is no taste there at all.

Jane: So there are no foods at the moment that you can taste?

Louise: No, nothing and I don't think there's been anything I can taste for a long time. So everything is just very bland or dry or tastes salty. Well the saltiness was at the beginning, that's sort of gone now umm, a bit metallic sometimes, um but no there's soapy, so if I taste something a bit different now it's soapy.

Jane: Soapy sounds quite unpleasant.

Louise: Yes, it's not nice, it's not nice.

Jane: And how are you managing that?

Louise: Um, um, yes it is difficult. All I eat now is porridge, which just goes down, and some cake and custard which just goes down um I can tolerate a yoghurt every now and again but it makes my mouth quite claggy and frothy afterwards and that's not nice and the same thing with the crème caramels and that sort of things, so I do have them sort of things. I try them and then I forget about them and then I think oh this is the reason I don't have them. Every other day I think oh let's have something different and then go back thinking oh that's why I don't have it.

Jane: So, it sounds like your persevering and going back and trying things.

Louise: Oh yes, I just think it is boredom really. We've always been quite a foody family and quite social and you know I haven't really been able to drink anything either, other than water. It's difficult, I miss hot drinks you know. It sort of breaks up the day really.

Jane: Yes, I think quite often our day is built around meal times.

Louise: Yes it is quite often I would see friends and we would go out for a coffee. Or we would meet up, do some shopping and then go for a coffee and a chat and that's it the day seems much longer because of that. So, although I was avoiding going out because my bloods were quite low because I didn't want to catch anything but also it's quite difficult because if people come to the house. You are always in the house or you go to them and they want to make tea or coffee and I can't really stand the smell of things. So it's not just the taste it's the smell of things too. You know if people have been cooking, I've got quite a heightened sense of smell.

Jane: Has that been quite difficult for you to manage?

Louise: Yes, so if I go out and about and there's smokers or food cooking or um and January all that's on the telly is food and it's all just social media is all food, everything. I just can't believe how much it's all geared to food.

Jane: It is difficult isn't it?

Louise: Yes, and January everyone is dieting.

Jane: It is all talk about food isn't it?

Louise: Everything, all the time, all the television programmes are about food. So apart from having a long day, all the food programmes are on as well. We've always cut down and dieted you know and then now everyone is saying you got to eat, you got to eat. And I think oh well I'd like to drop 2 stone that would be lovely. It would suit me you know but you know that's everything you go against isn't it really (laughing)

Jane: Yes, you mentioned you know that normally you are quite a foody. What sort of things would you normally like to eat?

Louise: Oh yes, everything and food in work you know, we would go out for lunch, not all the time. I miss work a lot and you miss the work and I work with a good gang of people you know yeah.

Jane: Has that been quite hard for you then?

Louise: yes, they've all been in contact and that and like Steve and I have never had so much time off and you know he's been wonderful. I just think that when you don't put food in that social role it's really difficult.

Jane: Do you still eat as a family?

Louise: No, I eat and because I eat slower I find I can't sit at the table to eat cos it affects my neck a little bit. Yeah I find I'm better off sitting on the sofa to eat. But I don't actually like the smells of all the food and there's nothing worse than somebody sitting by you and sort of pulling a face while you are eating. So for them it's not very nice, so they eat and then I eat in the living room then.

Jane: So has that been quite isolating for you?

Lyndsay: Ah it's not bad. I just removed the food issue really. I just try not to think about it.

Jane: Is that a working around it strategy then do you think? Something that works for you and the family.

Louise: Yeah, well I can't stand the smell. They can't sit there with me sort of breathing in to my scarf so and yeah, that's what happens really. Jane: Okay. Louise: It's not for ever.

Jane: And has that caused any problems in the family?

Louise: No they're not having any, they just know. Jane: They know that's the best way?

Louise: Yes, it is.

Jane: I think you've talked a little bit about this but it sounds like your altered taste has stopped you doing things?

Louise: Yes but I just think that its 6 weeks out or 8 weeks out and then hopefully my blood will be back and then I can start moving on a little bit really.

Jane: Definitely, that sounds good. Have you found the **texture of foods off putting?**

Lyndsay: **Awful, yes.**

Jane: Anything in particular?

Lyndsay: Long pause um just the texture of the food has been awful, like yoghurt is awful and everything is really. I just have to you know, even eating porridge isn't nice aw it's just necessity.

Jane: It's just got to be done?

Louise: **I think oh well, I don't want a feeding tube and we've come so far and I just think just another week now and just do it another day, yeah.**

Jane: Is that how you would normally deals with problems, deal with them a step at a time?

Louise: Yes, I'm just quite a black and white person. **I think you got to do what you got to do and just get on with it.**

Jane: Yes, Lyndsay: Yes. Jane: and do you look forward at all?

Lyndsay: Yeah! Yes we count down the days and for me that's you know it.

Jane: You see yourself getting towards the end of it?

Lyndsay: Yes, yes. I do yes.

Jane: There was something you had written on your questionnaire

Lyndsay: who knows when I wrote that, I was very up and down laughs.

Jane: Well, with the question what advice were you given that might help you cope with taste changes

Lyndsay: oh yeah, yeah.

Jane: **You said that food was medicine not enjoyment.**

Louise: I find taking tablets difficult. Cause you get quite an after taste on them and they really upset your stomach, but it's not your stomach, I think it's in your head so I feel like I have to span things out like, so they don't make me feel sick. You know like, as a family like were not like that. If we got it in our head we don't like it, we don't like it. **You have to get your head round it. Sometimes I might have to spend a couple of days thinking about it then trying it.**

Jane: So, it sounds like you have that sort of strategy then. Think, right I'm going to do this, then you do it,

Louise: Yes, yes and I think we're a bit prone to be like that if it's a bit strange, you know we need to think about it a little bit and then ah well, what's the worst that's going to happen? Then you carry on with it.

Jane: and do you feel you have had time to think about things?

Louise: yes, yes I have.

Jane: because I'm aware we give lots of advice, try this or try that

Louise: I do it in order of what I think is important, you know and what I think, um um, what I think I need to do next for the best. I can't do everything and then you know I just try it then. And sometimes it's not until a week later, you know try it then. Jane: yes?

Louise: oh I know sometimes I think I don't quite need that just yet. But I think things have been handy and I've tried them and some have worked and some haven't worked.

Jane: We know some things suit some people better than others, so hopefully we are giving you enough information so that you can find a way that works for you.

Louise: yes and I do find it difficult because it is all so unknown, because everybody is so different that you wait for the worst case scenario and then sometimes you think, maybe it won't get there. So, it's shifting those boundaries then as well, that's quite difficult.

Jane: and you have said "food is medicine" Louise: Yes. Jane: does that I think suggest that you don't get any enjoyment from food?

Louise: Oh no, I've got no appetite either, for the first time in my life I can leave it and You think, I didn't ever think I could leave food but I've got to eat it, It's just part of the day.

Jane: Has that been a helpful way to think about food for you or do you think it's made it more difficult?

Louise: No I just think that's helpful. You have to do what you have to do really, that's what I think.

Jane: So, it sound like you have a good understanding of why you need the nourishment to get you through treatment.

Louise: Yes, yeah.

Jane: Somebody said to me that it would be easy to go all day without eating.

Louise: Oh yes, quite easy, I wouldn't miss it and I don't think that would be me before. Food is a part of this treatment sand I see it like a medicine to get you through really. I never took tablets before and I never realised that they would upset you so much. But, it's oh I don't know.

Jane: It's okay, take your time.

Louise: Long pause, but I think um, there's things you learn because, like being a nurse but then there are things I never realised But I do think it makes you better for the future.....

Jane: I think definitely it does, I think there are some things you can't know until you have been through it.

Louise: Yes, crying.....oh yes, oh definitely

Jane: You know you have an empathy and a certain understanding, but you never really know until you have done it.

Louise: No, just the simple thing of taking tablets is sometimes so big, yes, I think more than the food actually it's weird isn't it, because you give them out so often yes, yes

Jane: weird and yet not weird I think,

Louise: It must be weird I'm sure

Jane: I hear lots of people say, oh I don't believe in tablets and this and that

Louise: Its funny, it's really funny. You give things out and people take them you know, some people like taking tablets. You know I've got family members that like taking tablets and swap tablets and oh you just think God why do you do that? Yeah, I've never taken tablets and then cor they make you shudder, phew, they're not easy. It's this after taste, I never, I never I've never known people say that, it might just be me it might be but....

Jane: I think quite often and it maybe possibly part of your taste being altered so with the treatment as well, a lot of people say they don't like the taste of them and whether that's a psychological thing because it's something you don't want to take so you are imagining that it's not nice or Louise: yeah, yeah. Jane: or whether it is all part of the taste change thing.

Louise: Well I would be quite happy not to take them I've got to say.

Jane: So, are you managing to have meals at the moment or?

Louise: Yeah I have 2 a day and then I try to have something else as well but in between everything else I can't take no more and I think well, that's as good as its going to get.

Jane: I think a lot of that is you know doing the best you can to get yourself through.

Louise: yes it is and I think I'm going to try because my throat doesn't seem quite so bad the sore bit in my throat so that may be from the steroids or something its healed that bit up. I might try some soup again the weekend. Because that seemed to go down okay. I know it's not that calorific but it's just something that bit different.

Jane: Have you found that you get almost like a taste fatigue for things and you think oh no not that again Louise: yes. Jane : quite often patients are reduced to quite a small number of foods that they can tolerate

Louise: sorry, tearfully I don't think I will ever eat porridge again, I used to eat it every day you know, just something, but oh god if I see that by there

Jane: so are you finding things that are blander easier to eat?

Louise: Milkier things are easier I think because anything else is acidic is the only thing I can think of, in my throat, quite acidic and so it would burn. Steve made soup and there was no salt, nothing and it just hit it and it just sent this pain all around the side of my neck and in my ear and I think it's quite hard on people they don't know what to say or to bring because you have one mouthful and you and you can't and not only that it puts you off trying anything for a couple of hours. So you sort of think I'll stick to the same things because I know I can eat it.

Jane: and that's how a lot of people manage, knowing these things work for me so I'm just going to have those.

Louise: It's quite frustrating for others and when they are so good and they've cooked something and then you can't even look at it or can't even.....

Jane: and your family and loved ones they want to nourish you

Louise: yes they do yeah. And they say oh well try it then and it's like don't pressure me now.

Jane: and how do you feel when that happens, if someone has made you something and you can't eat it?

Louise: oh well we've stopped all that now because it's you know not fair on them and it's just oh look let me do my own. If I have something and I have a little bite and then see you know.

Jane: save it for when you are feeling better.

Louise: yeah, I think oh well I can't taste it anyway so yeah and I think the dry mouth sometimes you can't because of that you know.

Jane: is that because they just won't work in your mouth?

Louise: Yes, they just won't go, yes they won't go and that went quite early you know the first week or 2 weeks really. It would just be stuck in your mouth and your mouth would be very dry. So you would start eating things and then you couldn't so it wasn't about the swallowing it was about the dry mouth. But then the swallow does go a little bit, it's still there, I can manage water and the things that I eat. I think things have changed weekly as well. So what you can do one week you don't do another week and you can't really think about it then you know.

Jane: is there any advice you've been given that you have found helpful particularly, I know we give you lots of advice?

Louise: yes lots of things, I think to try things and I tried that raspberry stuff and uh but I think I had hopes that it would help the sore as opposed to the swallow because my swallow is fine um but it didn't um I think you have just got to give everything a go really and see what suits you and just take on as much as you can really. I think you've got to know a little bit about yourself too really.

Jane: and have you learned stuff about yourself?

Louise: oh yeah (sounding quite reflective).I know I'm strong (tearful)yeah, funny isn't it.....yeah. My brother had leukaemia 6 years ago. Jane: did he? Louise: he's really well and he had 18 months of treatment, about 18 months Jane: that's a long time isn't it. Louise: Oh yes, but it was very different to mine as well. Oh yes, but he has been, he was really strong, he was really good in his treatment but really strong and I wouldn't have said before he was strong, he is the baby of our family. But he's been really quite upset because he was rushed in, he was unwell, he was rushed in he didn't see all the emotions of other people (sniff) and he's had to deal with that and he's found that quite difficult.

FEELINGS OF GUILT

Jane: yes, I suppose

Louise: because he was so unwell in the beginning, unwell and then virtually collapsed he went in and they sort of diagnosed it and treated it immediately and that's how it was and through his treatment he got better you know but was really oblivious to the support and knew everyone was upset but was quite oblivious to all the emotional stuff, so he's found that quite difficult. It's funny how it upsets other people whereas I know I can deal with it, it's upsetting other people. **GUILT**

Jane; we often see that, that relatives and loved ones are more upset than the person going through the treatment.

Louise: oh yes, I think it is easier to do it yourself. Although it's not easy but you just get on and do it.

Jane: you've just got to focus on yourself but for others wanting to do things to help.

Louise: like my parents you know it's hard, oh it's hard.

Jane: do they live nearby?

Louise: **yes, they are good but they are in their 80's you know and it's hard for them to go through it again (tearful sniff)**

Jane: sounds like you have a good family.

Louise: yes we are a close family.

Jane: is there anything else you would like to say about your taste?

Louise: **No, I just hope it comes back soon, although I know it will probably take a while.**

Jane: it is usually about 2 or 3 weeks after the treatments finished that it starts to get better. It will improve from how it is now.

Louise: and I just think if the RT is not working, you know, I know it works continuously afterwards for a while and um yeah I think it will just be a bit of pressure off from coming every day you know.

Jane: do you find it hard to fit everything in during the day?

Louise: **No, they are long old days. We never have enough hours in the day and now I've got ugh twice as many as I need.**

Jane: OK, so are you planning on going back to work once you are feeling better.

Louise: Yes, I'm not going to rush back because I'm in a really busy job and I'm just going to take some time to think about things and yeah I'm not in a rush. They know too, it is what it is.

Jane: That's right

Louise: and I think because of my dry mouth like, **I talk all day and I don't know how that's going to be you know and I don't know if I want to go back and do what I want to do. You know I love my job and I love the people I don't know. I don't know I'm going to turn back**

around and go back to such a busy job. Sometimes you work really hard and sometimes you are just paddling nowhere aren't you? I just think it gives you an opportunity to think

Jane: it's a bit of a stock take moment, isn't it? Time to think what do you really want?

Louise: yes, yes

Jane: Its given you that space to do that

Louise: so no I'm not in a rush

Jane: I think I've covered all the questions I've had. So that's been really helpful actually. I hope it's been okay for you?

Louise: yeah its funny I don't know why things trigger things off

Jane: I think that's just the way things happen. You are feeling quite emotional going through the treatment anyway.

Louise: Yeah

Jane: and it's obviously been a huge change for you, not doing the things you normally do.

Louise: yes and quite unexpected really, I think that's the thing you know. I said to the consultant when I saw him I'm too well to be ill. You know, that was wrong that's how it worked out.

Jane: For me that's one of the things with RT people start off feeling quite ok and as it goes on feel worse. When you have an operation you feel awful but quite quickly start to feel better. RT is like an operation in reverse.

Louise: yes and I think it's the unknown then isn't it? There's so many variables and you just hope that you will be this one person who will be quite well and skip through it then you think well I didn't think I was the sort of person who would have had this in the beginning.

Jane: Has it been worse than you thought it would be?

Louise: um..... I don't know, I don't know. I'm just glad that I haven't lost my swallow. That's the thing really. I just got to keep going next week. I think that's the thing.

Jane: It's usually about 10 days after you finish that things start to get better.

Louise: yes, so just having finished the RT is just one stepping stone isn't it and then I can do the next bit then Jane: and things will start to get better then. Louise: yes that's the thing and then I think I'll feel it's just the next step then isn't it.

Interview Analysis Example: 6 Louise (Pseudonym)

NG tube placed after 28/30# RT

Text	Comment
Totally affected, no taste at all. It went quite quickly, changing all the time. Quite a soapy taste now, dry mouth doesn't help. No foods I can taste now. Everything was salty but that has gone now and everything is soapy.	Taste
It's difficult – porridge just goes down, custard just goes down. No chewing required.	Difficulty to make yourself swallow – managing taste
Yoghurt makes my mouth claggy and frothy, - not nice	Claggy mouth
I keep trying things and then remembering why I don't have them anymore.	taste
Boredom, we are a foody family. I miss coffee with friends. I miss the social side, it's a long old day.	Boredom and isolation
I can't stand the smell of things so I eat away from the family. It's not fair on them to have me pulling faces and gagging.	Smell isolation
Everything is geared to food, TV, social media	Taste/food
I try to remove the food issue, try not to think about it.	food
It's not forever, hope for better in the future, return to normal	Hope and making sense of the situation
Texture is awful	Texture
Eating isn't pleasant. It's a necessity. Just do it, one day at a time. "do what you've got to do" No appetite, no enjoyment in food. It's a necessity Food is medicine now not enjoyment	Necessity to eat No appetite Motivation
Difficulty with taking tablets/medicines	tablets
I do things in the order that I think is important. If I think "I don't need that yet" I won't do it	Control Coping strategy
Food and nutrition are part of the treatment	food
Makes you stronger for the future	Making sense of the experience. Resilience
I do what I can. 2 small meals and try to have something else. That is as good as it gets.	Do what you can/control
Boredom, eating the same things. Milky things are easier, stick with what you know you can eat.	Boredom Managing taste changes
It's difficult for carers, hey try their best but they don't know what to say or to make for you. They make you something nice and you can't even look at it. I've stopped people bringing things now.	Guilt and frustration. Coping strategy
Dry mouth makes it worse, food sticks in your mouth.	Dry mouth/ saliva
Try things and see what suits you	try
Guilt and burden to others, causing worry for elderly parents	guilt
Hope for better in the future. Hope you will be the person who does well	Making sense of the situation
Days are long. I've twice as many hours in the day as I need	boredom

Motivated to keep my swallow	Motivated to keep swallowing
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Colours have been used to highlight the sections of transcription cut out and placed under themes identified and then placed in poly pockets.