

New normal: a grounded theory study of  
reconciling change in appearance and function  
for men with head and neck cancer

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## Declaration

I declare the work in this thesis is my own, except where otherwise stated.

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## Abstract

HNC incidence and mortality is greater in men and is associated with high risk behaviours and social deprivation. HNC is frequently diagnosed at advanced stages requiring multi-modality treatment which can have a significant impact on appearance and function. Gender can influence health behaviours yet research into male experiences of cancer has primarily focussed on prostate cancer and HNC is an area which is under investigated.

The aim of this study was to explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis. Grounded theory methodology (GT) was chosen as the overall purpose of GT is the generation of theory from the data which has explanatory power and advances the understanding of social and psychological phenomena. Retrospective semi-structured interviews were performed with 12 men who were 12 to 24 months post-diagnosis. Key components of GT practice used were simultaneous data collection and analysis, constructing analytic categories from the data, constant comparison, memo-writing and theoretical sampling.

Three categories emerged from the data which were inter-related: normalising change; "*under siege*": getting through treatment; and reclaiming self. The core category was reconciling change; a new normal which reflects the social and psychological processes involved in accommodating and assimilating change in appearance and function for men with HNC. The substantive theory provides insight into how men with HNC prioritise function and actively distance themselves from concerns regarding appearance. Furthermore, it identifies men who are at risk of social anxiety and isolation due to multiple changes or body incompetence. This study builds on theories of masculinity, body image and disfigurement. The substantive theory developed provides health and social care professionals with new knowledge to support clinical practice and improve care provision.

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*“Perseverance, secret of all triumphs”*

Victor Hugo

## Contents

Chapter one: Introduction and overview of the thesis .....	8
1.1 Introduction.....	8
1.2 Policy context .....	12
1.3 Clinical background .....	16
1.4 Summary .....	18
1.5 Organisation of the thesis .....	19
Chapter two: Background literature.....	20
2.1 Introduction.....	20
2.2 Grounded theory and review of the literature.....	20
2.3 Search strategy .....	21
2.4 Masculinity.....	22
2.5 Masculinity and health behaviours.....	22
2.6 Masculinity and cancer .....	24
2.7 Body image.....	27
2.8 Models of body image and adaptation .....	28
2.9 Models of disfigurement and adaptation.....	29
2.10 Functioning .....	32
2.11 Quality of life in head and neck cancer.....	32
2.12 Appearance and functional change in HNC.....	36
2.13 Adjusting to change .....	41
2.14 Summary .....	44
Chapter three: Rationale for research methodology .....	45
3.1 Introduction.....	45
3.2 Research aim and questions .....	45
3.3 Qualitative research.....	46
3.4 Qualitative approaches .....	48
3.5 Grounded Theory .....	50
Chapter four: Research design and method .....	52
4.1 Patient involvement .....	52
4.2 Peer review.....	54
4.3 Ethical approval .....	55
4.4 Sampling.....	56

4.5	Sample .....	60
4.6	Recruitment process.....	61
4.7	Participant information.....	63
4.8	Patient and researcher considerations .....	63
4.9	Data collection .....	64
4.10	Field notes and memos .....	67
4.11	Data analysis .....	68
4.12	Quality .....	73
4.13	Data storage .....	76
Chapter five: Findings .....		77
5.1	Introduction.....	77
5.2	Normalising change .....	78
5.2.1	Appearance and function before diagnosis .....	78
5.2.2	Interpreting change .....	80
5.2.3	Cancer diagnosis .....	83
5.3	<i>“Being under siege”</i> : getting through treatment .....	84
5.3.1	Information provision.....	85
5.3.2	Cancer peers .....	87
5.3.3	Maintaining control.....	88
5.3.4	Maintaining normality .....	90
Section 5.5 Reclaiming self .....		96
5.5.1	Comparing against previous norm .....	97
5.5.2	Coping strategies .....	99
5.5.3	Not being understood.....	103
5.6	Core category: Reconciling change; a new normal .....	104
Chapter six: Discussion.....		110
6.1	Summary of research findings and new knowledge .....	110
6.1.1	Important appearance and functional issues for men with HNC ...	110
6.1.2	Appearance and functional change in the context of a HNC diagnosis.....	111
6.1.3	Appearance and functional issues during the care pathway .....	112
6.2	Masculinity and change to appearance and function in men with HNC	113
6.3	Body image and disfigurement in men with HNC .....	116
6.4	Adaptation to appearance and functional change in men with HNC ....	118

6.5 Study findings and the changing profile of HNC .....	120
6.6 Strengths, weaknesses and quality of the research study .....	122
6.7 Implications for clinical practice .....	124
6.8 Recommendations for future research.....	126
6.9 Conclusion.....	127
References.....	128
Appendix 1: Flow chart for participant identification and recruitment .....	156
Appendix 2: The grounded theory process .....	157
Appendix 3: Participant information sheet (V2-15 January 2011) .....	158
Appendix 4: Participant consent form V2 - 15 January 2011 .....	161
Appendix 5: Lead clinician letter .....	163
Appendix 6: University of Stirling Health Studies Research Ethics Committee .....	164
Appendix 7: NHS Research and Development department approval.....	165
Appendix 8: West of Scotland Managed Clinical Network HNC research sub-group.....	167
Appendix 9 - GP letter (V1-18 October 2010) .....	169
Appendix 10: Interview schedule (V1-18 October 2010).....	170
Appendix 11: Interview checklist .....	172
Appendix 12: Data collection sheet (V1- 20 August 2010) .....	174
Appendix 13: Field notes.....	175
Appendix 14: Memoing .....	177
Appendix 15: Memo showing comparative analysis/theory development .....	180
Appendix 16: Participant progress report .....	181
Appendix 17: Participant consent form (V1 - 18 October 2010) .....	182
Appendix 18: In-vivo code " <i>being under siege</i> " .....	183
Appendix 19: Transcript participant 12.....	184
Appendix 20: Final summary report (ref: 10/S1001/72).....	207
Appendix 21: Participant letter (P5).....	213
Appendix 22: CNS feedback .....	214
Appendix 23: Draft article for publication.....	216

## Chapter one: Introduction and overview of the thesis

The aim of my research was to explore how men with head and neck cancer (HNC) experience appearance and functional change in the first 12 months following diagnosis. Despite the fact that HNC is the fourth most common cancer in men, research around male experience has primarily focused on prostate cancer. Therefore my research questions were:

1. What appearance and functional issues are important for men diagnosed with HNC?
2. How are appearance and functional issues experienced within the context of a life-threatening diagnosis of HNC?
3. At what point in the care pathway are appearance and functional issues important?

HNC incidence, risk factors, mortality rates and management are discussed in this chapter. The purpose of presenting this information is to provide the context and rationale for my study as there is a higher incidence of HNC in men and both HNC and its treatments have a significant impact on appearance and function. Following on from this, the policy context and the clinical background to the development of my research aim and questions are explored. Finally, the organisation of the thesis is presented.

### 1.1 Introduction

HNC is a term used to describe cancers that arise from the surface mucosa of the upper aerodigestive tract and involves over 30 specific sub-sites in the head and neck region (NICE, 2004). The main tumour sub-sites are the oropharynx (27%), oral cavity (27%), and larynx (24%) and the majority of cancers are squamous cell cancers (West of Scotland Cancer Network [WoSCAN], 2013).



Incidence and mortality rates for HNC within the West of Scotland (WoS), where my study was conducted, are presented to highlight the importance of this issue. HNC is the fifth most common cancer in WoS with 596 new diagnoses each year and this accounts for half of all HNC diagnosed in Scotland (WoSCAN, 2013). There is a marked gender difference, with HNC occurring more often in males, where it is the fourth most common cancer with 408 cases per year. By comparison, it is the eighth most common cancer in females with approximately 188 cases per year (WoSCAN, 2013). The incidence rate over the last 10 year period has increased in men by 7% and in women by around 16% (WoSCAN, 2013). The increase in incidence is due to the prevalence of risk factors such as alcohol consumption, tobacco use (smoking and smokeless) and human papilloma virus (HPV) infection (WoSCAN, 2013; Audit Scotland, 2012). Tobacco and alcohol remain the major risk factors for HNC which together account for approximately 75% of cases (SIGN, 2006; NICE, 2004; Cruz et al, 2002; Bagnardi et al, 2001; Corrao et al, 1999). High levels of alcohol consumption and smoking have synergistic or multiplicative effects on the risk of head and neck cancer (SIGN, 2006). For heavy drinkers who are also heavy smokers, the risk of oral cancer is over 35 times that of those who neither smoke nor drink, and a similar pattern is found with cancer of the larynx (Blot et al, 1988). Furthermore, three quarters of cases diagnosed occur in the over 60 age group and 63% are from the most disadvantaged socio-economic groups (WoSCAN, 2013; SIGN, 2006). However, HPV related oropharyngeal cancer is increasing in younger, more affluent individuals without other risk factors (Herrero et al, 2003). Furthermore, over 20% of patients diagnosed with HNC will develop a second or third tumour, most often in the oral cavity, due to the susceptibility of the mucosa to carcinomatous change (Eakin, 2001).

In HNC, 60% of patients present with advanced stage disease (WoSCAN, 2013; SIGN, 2006). This is due to a long delay from onset of initial symptoms to the individual presenting to a healthcare professional as initial symptoms are perceived as innocuous (Rogers et al, 2011; Scott et al, 2006; McGurk et al, 2005; Hollows et al, 2000). Forty per cent of patients with oral and oropharyngeal cancers take more than three months to present to a healthcare

professional with symptoms (Rogers et al, 2011). The proportion of patients presenting with delays has not changed in 40 years despite public education and it is suggested that some tumours are silent and that initial symptoms may not reliably predict early disease (McGurk et al, 2005). Deprivation has not been found to significantly lengthen presentation however it may be that deprivation is associated with more rapidly growing tumours (Rogers et al, 2011).

Delays in diagnosis affect treatment choice which takes into consideration: the location and stage of disease; organ and function preservation; previous treatment; the general medical condition of the patient as well as the patient's wishes (SIGN, 2006). Patients who present early with localized disease can be treated with either surgery or radiotherapy, whereas combined treatment is usually necessary for more advanced disease (SIGN, 2006). In the most recent WoS audit, 41% of patients had surgery and 53% had radiotherapy, either as a sole modality or in combination with surgery and/or chemotherapy (WoSCAN, 2013). Chemotherapy is increasingly being administered at the same time as radiotherapy (to individuals under 70 years of age) as it has been shown to provide an absolute overall survival benefit at 5 years of 8% (SIGN, 2006). However, while multi-modality treatment improves outcomes, it can have a significant impact on both appearance and function.

The aesthetic and functional impact of major cancer surgery in the head and neck region can be devastating and to rehabilitate the patient, it is essential to reconstruct anatomical defects in an attempt to restore form and function (Carew et al, 2003). The use of microvascular reconstruction has increased over the last few decades and free tissue flaps and skin grafts are routinely used to repair deficits which arise from the loss of resected soft tissue and/or bone. There has also been a lot of progress in products available to improve speech and optimise breathing following laryngectomy and tracheostomy procedures. These developments have resulted in better functional and aesthetic outcomes (SIGN, 2006). However, despite advances, surgery can result in scarring, facial paralysis, drooling and/or difficulties with speech and eating, which can all have a significant on an individual's life.

Radiotherapy may be used as primary treatment or following surgery where there are features associated with a high risk of recurrence (advanced tumour stage; close or positive margins; more than one positive lymph node; lymphovascular; or perineural invasion). There has been a substantial increase in radiotherapy use over the last decade and development of new techniques including Intensity Modulated Radiotherapy (IMRT) have been incorporated into standard practice. The majority of radiotherapy regimes involve treatment five days a week over a six week period either alone or in combination with chemotherapy. This treatment results in many acute side-effects including: pain; skin breakdown; mucositis (ulceration); xerostomia (dry mouth); altered/loss of taste; weight loss and fatigue. Acute side effects often become chronic and late side-effects can appear many months or years after treatment. Chemotherapy given at the same time as radiotherapy (concomitant chemotherapy) also brings the risk of additional side-effects such as nausea, vomiting and neutropenia (low white cell count) and generally intensifies the overall impact on an individual's life. To treat and support appearance and functional change in individuals with HNC a wide range of specialties and professionals are required and the multi-disciplinary team should include a clinical nurse specialist, dietitian and speech and language therapist (WoSCAN, 2013).

While cancer mortality rates in Scotland have reduced by 15% in males and 6% in females, HNC mortality has increased in both males (2%) and females (18%) (ISD, 2014). Five year relative survival is marginally higher in females than males at 60% and 55% respectively (ISD, 2014). HPV related oropharyngeal cancers have more favourable prognosis than non-HPV related oropharyngeal cancers, particularly in non-smokers (Mehanna et al, 2010). Deprivation continues to be a key factor in both cancer incidence and cancer mortality (The Scottish Government, 2008a). The WoS encompasses some of the worst areas of socio-economic deprivation in Scotland and the overall life expectancy for specific postcode areas is lower than that of any other area in the United Kingdom (Audit Scotland, 2012). Additionally, the high index of deprivation is

coupled with above average levels of smoking and alcohol use (Audit Scotland, 2012). It has been suggested that there is a “*Glasgow effect*” as despite having similar levels and patterns of deprivation as Liverpool and Manchester, Glasgow has a profoundly different mortality profile (Walsh et al, 2010). While higher levels of mortality are seen across the entire population of Glasgow, premature mortality is greater in the more deprived areas particularly amongst males with half of excess deaths directly related to alcohol and drugs (Walsh et al, 2010).

In summary, HNC is increasing in incidence and there is higher incidence and mortality in males. While multi-modality treatment increases survival, it has a significant impact on appearance and function. Therefore, understanding how men experience changes in appearance and function and manage these changes is essential if health and social care professionals are to provide appropriate support and care. Having considered incidence, mortality and management of HNC, policy context and clinical background to my study will now be explored.

## 1.2 Policy context

As health is a devolved issue and this study was conducted in Scotland, cancer policy represented an important context for my study. In particular, policy relevant to my study exploring how men with HNC experience appearance and functional change in the first 12 months following diagnosis is considered. The number of people diagnosed with cancer and surviving cancer is rising as a result of the ageing population, earlier diagnosis and new and different treatments, particularly combination cancer treatments (NCSI, 2013; MacMillan Cancer Support, 2013; The Scottish Government, 2008a). Cancer is increasingly being considered as a chronic disease (NCSI, 2013; Macmillan Cancer Support, 2013). Over the last decade, cancer has become one of the national health priorities within Scotland, bringing an associated increase in financial investment (The Scottish Government, 2008b). Better Cancer Care:

An Action Plan was introduced in Scotland in 2008 and focusses on prevention; early detection; ensuring better treatment; living with and beyond cancer; and improving service delivery and quality of care for patients. The Scottish Cancer Taskforce has overseen the delivery of actions set out within Better Cancer Care working with NHS Boards, Regional Cancer Networks, patients and voluntary sector colleagues. A wide-ranging approach to quality improvement was indicated to ensure that services provided are patient-centred, safe, effective, efficient, equitable and timely (The Scottish Government, 2008a). This policy focus is important in HNC due to the risk factors associated with the disease, advanced presentation and the specific impact of treatment on appearance and function.

Better Together, the Scottish Patient Experience Programme, was introduced to prioritise action to improve cancer services on the basis of feedback from patients, putting patients at the centre of care (The Scottish Government, 2008b). Key areas where patient experiences are expected to have an impact and are related to my research include: at the transition point when an intense treatment phase is completed; getting “*back to normal*”, including rehabilitation and adjusting to life after treatment; and in the detection and management of treatment related side-effects including “*late effects*”. While the Better Together programme has attempted to reach difficult to reach groups (for example, older or younger people, and ethnic minority groups), it is important to recognise that much of the focus has been on patients with cancer of the breast, lung, prostate or large bowel. As a result policy and practice are predominantly informed by people who are neither living with nor beyond HNC.

More recently, the Quality Strategy has provided the blueprint for improving the quality of care that patients and carers receive from the NHS across Scotland (The Scottish Government, 2010). The Quality Strategy was informed by the people of Scotland who want the following from their healthcare system: care; compassion; communication; collaboration; clean environment; continuity of care; and clinical excellence. The three quality ambitions of safe, person-centred and effective care were thus developed and all healthcare policy is now being aligned to deliver these ambitions. The Quality Strategy builds on the

significant progress made in healthcare over the last few years and centres on health and social care integration (The Scottish Government, 2010). As previously noted (section 1.1) there is a strong association between HNC and social deprivation and therefore health and social care integration is essential to reduce inequalities and improve outcomes.

The National Cancer Survivorship Initiative (NCSI) was launched in 2007 and the main aim of the NCSI was to develop services to support and enable cancer survivors to have as good a quality of life for as long as possible. This initiative included all countries comprising the United Kingdom and hence, influenced Scotland's direction of travel. The NCSI report "*Living With and Beyond Cancer*" (2013) sets out a vision identifying major shifts required to improve care and support for cancer survivors. These shifts are focussed on five key survivorship stages including: support from the point of diagnosis; promoting recovery; sustaining recovery; managing the consequences of treatment; and supporting people with active and advanced diseases. Key areas of survivorship work which have been prioritised include: the recovery package; stratified pathways of care; physical activity; the consequences of cancer and its treatment; and patient reported outcome measures.

While many cancer patients will complete their primary treatment and return to similar levels of health and well-being, a significant proportion will experience a wide range of distressing physical, social, financial and emotional long-term problems (NCSI, 2013; Macmillan Cancer Support, 2013; Department of Health et al, 2011). The emotional aspects of cancer can be the most difficult to cope with and these needs are often unrecognised and do not receive the same level of support as physical needs (Macmillan Cancer Support, 2006; NICE, 2004; Zabora et al, 2001). It is recognised that while cancer may be regarded as a long-term condition, many issues can be improved by tailored support within the survival phase (NCSI, 2013; Lang et al, 2013; Armes et al, 2009). Implementing the recovery package has been identified as the most important step to improving the lives of those affected by the consequences of cancer and its treatment (NCSI, 2013). As part of the recovery package, it is suggested that holistic needs assessment (HNA) should be carried out around the point of

diagnosis, at the end of treatment and at any other time the patient's needs change (NCSI, 2013). The HNA should use a standardised assessment tool and result in a written care plan outlining the actions to be taken to address identified needs. In addition, a health and well-being clinic, to help prepare the patient and their carers for supported self-management, is recommended (NCSI, 2013). There is increasing evidence to suggest that people who are engaged and informed about how to manage their own health needs may achieve the best health and quality of life (Macmillan Cancer Support, 2013; The Scottish Government, 2008a, The Scottish Government, 2008b). Self-management is important and entails an active partnership between healthcare professionals and patients, combining professional expertise and lay experiential knowledge (The Scottish Government, 2008a; The Scottish Government, 2008b; Von Korff et al, 2002). In this collaborative approach, the health professional's principal role is to encourage, facilitate and support the patient in their self-management activities (The Scottish Government, 2008a; The Scottish Government, 2008b; Coulter and Ellins, 2006). Currently there is irregular implementation of HNA and health and well-being clinics. Also it is not known if men, particularly those from lower social-economic classes, will attend a health and well-being clinic.

In June 2013, the Transforming Care After Treatment (TCAT) programme was launched within the WoS. TCAT is a partnership between the Scottish Government, Macmillan Cancer Support, NHS Scotland and local authorities to support a redesign of care following active treatment of cancer. Macmillan Cancer Support is providing £5 million over five years to test and facilitate the development and implementation of models of care that enable people affected by cancer to play a more active role in managing their own care; provide services which are more tailored to the needs and preferences of people affected by cancer; give people affected by cancer more support in dealing with the physical, emotional and financial consequences of cancer treatment; and improve integration between different service providers and provide more care locally. However, the first phase of bids received through TCAT both within the WoS and Scotland have mainly focussed on breast, lung and prostate cancer.

In summary, a number of policy documents and strategic frameworks have identified the major shifts required to improve care and support. These shifts focus on identification of patient needs and tailored support provision during treatment and beyond to facilitate self-management and recovery. There is recognition that the NHS should put patients at the centre of care and that cancer services should be developed based on the feedback of patients. Nevertheless, HNC patients' views are currently underrepresented. To provide quality care for men with HNC who experience appearance and functional changes further research is required. Having considered the policy context, the clinical background to my thesis must now be considered.

### 1.3 Clinical background

I worked in NHS Ayrshire and Arran as a HNC Clinical Nurse Specialist (CNS) for 11 years before being appointed as the Macmillan Cancer Nurse Consultant in 2015. The CNS role involves various components, with the main focus on support provision for patients and their families throughout the care pathway. Essential aspects of this support include care coordination, information provision, symptom management and psychosocial care provision. Where possible, supportive care is based on research evidence nevertheless in a number of areas of HNC there are gaps in the literature.

The University of Washington Quality of Life questionnaire (UWQOL) is recognised as an appropriate screening tool for the identification of patient concerns to stimulate discussion within clinical practice (Laraway and Rogers, 2012; Rogers et al, 2002). Two national bodies, the British Association of Head and Neck Oncologists and the British Association of Otorhinolaryngologists Head Neck Surgeons, both recommend longitudinal use of the UWQOL. Version four of the UWQOL covers 12 domains including pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder function, taste, saliva, mood and anxiety. Thus appearance and function are recognised as key



domains. Each question is scaled from 0 (worst) to 100 (best) according to the hierarchy of response. In addition, there are three global questions, one as a five-point Likert scale asking about health-related quality of life compared to the month before the cancer, and the other two as a six-point Likert scale, one asking about health-related and the other asking about overall quality of life during the previous seven days. Furthermore, there is a question asking about the importance of domains and an option for free-text comment.

Between 2004 and 2007 I administered the UWQOL tool within clinical practice with patients around the point of diagnosis and at six months and one year following diagnosis. Results at one year are felt to indicate long-term outcomes (Millsopp et al, 2006). I used the UWQOL tool to facilitate discussion which focussed on the domains which individuals prioritised as important. I found that across time points, appearance was one of the most important issues in HNC after swallowing, speech, chewing and saliva and was frequently an issue in combination with other domains. My findings have since been reflected in a study by Katre et al in 2008. However, I felt that men on my clinical caseload downplayed appearance issues, rationalised change and preferred to concentrate on functional issues. Additionally, although priorities were identified, overall quality of life was high at one year post-diagnosis. After 2008, I stopped using the UWQOL and started using a HNA tool, the Distress Thermometer, within clinical practice at the end of treatment and at other time points as indicated. The Distress Thermometer asks individuals to rate their distress over the last week, identify physical, social or psychological issues and prioritise their top three concerns. Of particular interest I noted that patients rarely indicated that appearance was an issue at the end of treatment yet discussed change in appearance and weight loss in relation to swallowing issues, diet and fatigue. Indeed, Millsopp et al (2006) suggests that patients may not express their specific concerns with regard to appearance within clinical practice and that often this issue may not be addressed due to other treatment priorities.

Furthermore, in 2008 I led a project for Macmillan Cancer Support on body image and cancer. The aim of the project was to increase knowledge and

understanding of body image and cancer issues and develop resources for individuals with cancer and healthcare professionals both locally and nationally. As part of the project, I conducted focus groups with men and women with a variety of cancers including HNC (n=32; 22 women - 2 HCN)/10 men - 1 HNC). A further five patients views were elicited by individual interview or telephone/email discussion as they were unable to participate in the focus groups or did not wish to participate within a group setting (3 women/2 men). Themes were identified relating to the experience of body image and supportive care including context; loss of self; and adapting to a “*new self*”; communication; sign-posting; peer support and social networks. It was challenging to recruit men and I found that discussion within the male focus group was superficial and focussed on functional change and being able to fulfil role expectations, with little discussion about appearance or emotional disclosure (Hood, 2010). Furness et al (2006) also found that focus group discussion around appearance change following disfigurement was more superficial than individual interviews. I therefore felt that further research was required to explore appearance and functional change in men and focussed on HNC which is my clinical speciality. Having considered how my clinical and project experience has influenced my research study, a summary of the rationale for my study is now presented.

#### 1.4 Summary

To summarise, HNC is increasing and there is a higher incidence and mortality in men. The majority of HNC patients present with advanced disease and require multi-modality treatment which can have a significant impact on appearance and function. Policy and strategic frameworks have aligned to focus on health and social care integration and the provision of safe, effective, person-centred care for those living with and beyond cancer. Patient experience work and testing of new models of care have primarily involved individuals with cancer of the breast, lung, prostate or large bowel. HNC patients’ experiences are under-represented and yet they face specific

challenges due to high levels of social deprivation, engagement with risk behaviours and short and long term effects on appearance and functioning. My clinical experience suggests that men with HNC experience appearance in combination with functional difficulties yet appearance change does not appear to be a priority. My research study was developed to improve our understanding of men's experiences of appearance and functional change in the first 12 months following a HNC diagnosis. Having considered the background to my study, the organisation of the thesis is now explained.

## 1.5 Organisation of the thesis

In chapter two, grounded theory methodology (GT) and its influence on review of the literature is discussed. Following on from this, background literature is presented focussing on masculinity; body image; models of body image, disfigurement and adaptation; appearance and functional change in HNC; and adjusting to change. In Chapters three and four, the rationale for GT methodology and the application of GT within my study is explored. Chapter five presents the findings of my study, focussing on the categories and substantive theory. Finally, in Chapter six my substantive theory is discussed in relation to other theories and research evidence and implications for clinical practice and future research are considered.

## **Chapter two: Background literature**

### 2.1 Introduction

In the following chapter, grounded theory methodology (GT) is discussed in relation to its influence on review of the research literature. The search strategy utilised is then presented. Following on from this, the research literature is critiqued and synthesised, highlighting gaps and supporting the need for the proposed research study.

### 2.2 Grounded theory and review of the literature

According to Glaser (1992), when performing GT, the researcher should not review the literature in the substantive area under study as it may contaminate, stifle or otherwise impede the generation of categories. However, Corbin and Strauss (2008) note that researchers bring to the enquiry their considerable background in professional and disciplinary literature and therefore this is often impossible. Ultimately, researchers need to be pragmatic to present their rationale for studying the chosen phenomenon and justification for the methodology (Bluff, 2005).

It is also impossible to know what relevant concepts will be derived from the data a priori (Corbin and Strauss, 2008). Once analysis has commenced and theory has been sufficiently developed, Glaser suggests that researchers then need to review the literature in the substantive area and relate this to their own work. Charmaz (2006) argues that guiding interests, sensitizing concepts, and disciplinary perspectives often provide researchers with points for departure for developing rather than limiting ideas.

## 2.3 Search strategy

An initial literature review was undertaken as part of the research proposal for the clinical doctorate programme to support the need for the study, to develop the research proposal and to gain research and ethics approval. Literature was reviewed using a combination of the following search terms: head and neck; cancer; neoplasm; tumour; men; masculinity; body image; appearance; disfigurement; function; dysphagia; speech and quality of life. Further literature was accessed as data from participants was analysed to explore the emerging concepts and categories by adding the following search terms: adaptation, coping and new normal. A database search of the Cochrane Database of Systematic Reviews, British Nursing Index, CINAHL, Embase, Medline and Psycinfo was performed. Searches were undertaken periodically between 2007 and 2016 and were restricted to English language published research between 1985 and 2016.

Within my study I used the literature as suggested by Corbin and Strauss (2008, p37) as a source for making comparisons; to enhance sensitivity; to provide a cache of descriptive data with very little interpretation; to provide questions for initial observations and interviews; to stimulate questions during analysis; to suggest areas for theoretical sampling; and to confirm findings or illustrate where the literature is incorrect, simplistic or only partially explains a phenomenon.

Where possible, a focus on HNC was maintained due to its association with visible change to appearance and function, social deprivation and high risk behaviours (including excessive alcohol intake) which can affect social support, coping and adaptation.

## 2.4 Masculinity

Masculinity provides a broad context for understanding the ways in which men experience their appearance and functioning and hence is an important construction for my study. Kimmel (1995) suggests that gender is constructed from cultural and subjective meanings that constantly shift and vary, depending on the time and place. People are encouraged to conform to stereotypic beliefs and behaviours and therefore commonly adopt dominant forms of femininity and masculinity (Eagly, 1983). While it has been argued within the literature that there are multiple masculinities, there is general consensus that the predominant form of masculinity is hegemonic masculinity (Connell, 2010; Courtenay, 2000; Kiss and Meryn, 2001; Kimmel, 1995). Social constructivists describe a hierarchy of masculinities, in which hegemonic ideals prevail at the top of the gender order (Connell, 2010). Within the overall framework there are specific gender relations of dominance and subordination between groups of men (Connell, 2010). Hegemonic masculinity includes the following characteristics: restricted experience and expression of emotion; no emotional sensitivity; toughness and violence; powerful and successful; self-sufficient (no needs); stoicism; 'being a stud' (heterosexism) and misogyny (Kiss and Meryn, 2001; Kimmel, 1995). Men's narratives focus on themes such as heroism, conflict and achievement and emotional expression and self-disclosure are largely absent (Coates, 2003). Hegemonic masculinity therefore leads men to present themselves as independent, unrestrained and strong. While many men do not actually meet the normative standards of hegemonic masculinity in its entirety, benefit is generally gained from overall subordination of women (Connell, 2010).

## 2.5 Masculinity and health behaviours

Men of all ages are more likely to engage in behaviours that increase the risk of disease, injury and death and make far fewer health care visits than women (Courtenay, 2000). Healthcare is primarily viewed as a female domain, with the

female in the family often managing the health needs of their partner (Stapleton and Pattison, 2015; Cahonas Scotland, 2011; Courtenay 2000). Men generally show widespread reluctance to seek help or support and go to great lengths to manage issues independently (Nobis et al, 2007; Chapple and Ziebland, 2002; Gray et al, 2002; Gray et al, 2000a). It is therefore important to consider how men with HNC seek help or support if they experience a change in their appearance or function.

Young men, in particular, tend to delay or avoid presenting with “*trivial*” or “*minor*” symptoms and only access health care when symptoms are perceived to be ‘serious’ (O’Brien et al, 2005). However, serious symptoms such as a significant physical change or change in ability to function may also be trivialised or even overlooked to allow men to avoid challenges to their masculinity or to test their masculinity by withstanding severe symptoms that warrant attention (O’Brien et al, 2005). Where health issues are not visible or if it is not obvious that symptoms are serious, men may need validation and encouragement from someone, commonly their wife or partner, to seek support (O’Brien et al, 2005). Moreover, men from more deprived areas have been found to normalize more severe symptoms and illness behaviour is shaped by social and cultural factors in addition to gender (Richards et al, 2002). This may be particularly important to both the experience of appearance and function concerns and help seeking behaviours as there is a strong link between HNC and social deprivation.

Physical symptoms are usually the determining factor for help seeking by men because emotional expression and vulnerability is associated with femininity (O’Brien et al, 2005; Moller-Leimkuhler, 2002). Additionally men perceive others, including healthcare professionals, as being less prepared to assist with psychological difficulties which can contribute to the hidden nature of depression (O’Brien et al, 2005; Courtenay, 2000). When men state that they have not been at a doctor in years, they are simultaneously describing a health practice and demonstrating dominant norms of masculinity such as strength and independence (Courtenay, 1999). O’Brien et al (2005) found that help seeking is more quickly embraced when it is perceived as a means to preserve

or restore another more valued enactment of masculinity such as working or maintaining sexual function. The constitution of masculinity through bodily performance means that gender identity is vulnerable when performance cannot be sustained (Connell, 2010). Men generally aim for more muscular bodies and motivating factors include concern regarding physical appearance, popularity and attractiveness to the opposite sex (Corson and Anderson, 2004). Physical illness can afford men the opportunity to examine and reconstruct their masculine identities (Charmaz, 1994). Indeed, masculinities can be negotiated and renegotiated in accordance with the limitations which can be placed on men by their own and others understanding of the personal and social consequences of the disease (O'Brien et al, 2007). However, this may be challenging where the consequences of disease are not understood.

## 2.6 Masculinity and cancer

Overall, when looking at men's health, what is striking is the absence of knowledge grounded in the everyday experiences of men themselves (Watson, 2000). Studies within cancer have primarily focussed on men's experiences of prostate cancer due to the impact of disease and treatment on continence and sexual function. Generally, men with prostate cancer appear to relate to the body in terms of its function rather than appearance although the interconnectedness of function and appearance is recognised (Cecil et al, 2009; Gray et al, 2002). O'Brien et al (2007) found that men with prostate cancer felt they had changed as men because essential aspects of male identity (for example libido and sexual function) as opposed to aspects of gender identity (for example work) were disrupted. While the ability to have an erection may be an important part of male identity, men who have only experienced changes in sexual function, may reframe this as a small price to pay (Chapple and Ziebland, 2002). Indeed, some older prostate cancer patients suggest that sexual dysfunction was no longer a problem but it would be to a younger man (Chapple and Ziebland, 2002). Although strength and physical ability is integral to masculinity, expectations regarding what was important and could be



achieved during the disease trajectory are often modified (Stapleton and Pattison, 2015). Body changes which are not associated with sexual ability and functioning may also present challenges to masculinity and male identity in cancer patients (Cecil et al, 2009). Cecil et al (2009) found that younger men consider the aesthetics of body changes more and therefore age may alter the experience of both functional and appearance change. Consideration of aesthetics as well as function may represent a shift in attitudes towards the male body over the last 20 to 30 years (Grogan and Richards, 2002). While appearance may not be considered to be important during ill health, it becomes increasingly important following resolution of treatment side effects (Stapleton and Pattison, 2015).

Wenger and Oliffe (2014) found that cancer significantly challenges men's ability to manage their lives and themselves in ways they value. The ability to work appears to be a key aspect of male self-identity (Coates, 2003; Watson, 2000; Moynihan, 1998). Ambition is also integral to masculinity and can be thwarted by a cancer diagnosis and treatment which impacts on all aspects of men's lives (Stapleton and Pattison, 2015). Illness, including cancer, has been shown to reduce a man's status in masculine hierarchies, shift his power relations with women and raise self-doubts about his masculinity (Stapleton and Pattison, 2015; Charmaz, 1995). Where men are unable to return to valued activities, new ways of affirming their masculinity are required (O'Brien et al, 2007; White, 1999; Moynihan, 1998; Charmaz, 1987). The extent of the challenge an illness presents to masculinity therefore appears to depend on the nature of the loss experienced as well as the interpretation of that loss. Physical side-effects and reconstructed futures form a significant part of men's prostate cancer narratives (Cayless et al, 2010).

Men often feel uncomfortable with talking about feelings or their cancer experience (Cecil et al, 2009; Gray et al, 2000b). When confronted by their own vulnerability, men usually limit discussions until they have sufficient detail within which to frame their situation (Oliffe et al, 2009; Hilton et al, 2007; Gray et al, 2000a). Men frequently access information and develop their knowledge about their disease/illness to try and facilitate self-management, maintain a

degree of control and regain power (Wenger and Oliffe, 2014; O'Brien et al, 2007; Emslie et al, 2006). Gray et al (2002) suggest that accessing information and developing knowledge reflects hegemonic masculinity valuing science, reason and action more than relationships, emotion and sharing. One study which involved men with HNC found that the men went into survival mode, focussing on the present, compartmentalising their illness and attempting to present themselves as unchanged (Wenger and Oliffe, 2014). It appears to be crucial for men to be controlled and silent about their emotional life, representing the traditional masculine stereotype and loved ones may use a strategy called protective buffering where they mirror this silence (Boehmer and Clark, 2001; Moynihan, 1998). Although many men value support provided by partners or friends, the intensity of their experience can exceed normal boundaries of the relationship (Wenger and Oliffe, 2014). Men found sharing experiences with others who had cancer helpful as these individuals normalised what the men were feeling, thus reducing feelings of isolation (Wegner and Oliffe, 2014).

In summary, hegemonic masculinity suggests that men should be independent, strong and stoic. Men therefore commonly trivialise symptoms, including changes in physical appearance and ability to function, and show a general reluctance in seeking help. Research into masculinity and cancer has focussed on men with prostate cancer who relate to the body more in terms of function than appearance. A relatively neglected subject is the experience of men with HNC who experience of appearance and functional change. Men frequently limit emotional disclosure and may present themselves to others as unchanged. Information and knowledge can be used to frame the experience, support self-management, maintain control and regain power. Having considered the impact of masculinity of men's experience of cancer, in the following sections body image and models of body image, disfigurement and adaptation are considered.

## 2.7 Body image

Cancer and cancer treatments can significantly change appearance, function, body integrity and sensation (White, 2000; Carver et al, 1998). While most individuals are primarily concerned with the diagnosis of a potentially life-threatening illness, some experience significant distress about changes to their body (Harcourt and Rumsey, 2006). The classic definition of body image was provided by Schilder (1935, p17) who defined body image as *“the picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves”*. Schilder (1935) states that body image is dynamic, changing both during the life cycle and in response to short term alterations. Body image is in a state of continuous construction, destruction and reconstruction by virtue of its reciprocal interaction with the body images of those with whom we come into contact (Schilder 1935, p241). Part of this reciprocity involves the imitation of others, whose body images come to be incorporated within our own, either through integration within or in addition to our previous views of ourselves. Schilder (1935) moved the study of body image beyond the exclusive domain of neuropsychology, emphasising the relatedness of the somatic, psychological and interactional aspects of body image, thus giving an early bio-psycho-social account of the phenomenon. Although related, it is generally accepted that body image is separate from self-image, self-esteem and self-concept (Dewing, 1989).

White (2000, p189) defines a clinically significant body image problem as *“the existence of a marked discrepancy between the actual or perceived appearance or function of a discrete bodily attribute(s), and an individual’s expressed ideal regarding the bodily attribute(s). This discrepancy, by virtue of significant personal investment and association with dysfunctional assumptions about appearance mediates negative emotional and behavioural consequences, which interfere significantly with normal routine, occupational functioning, social functioning or relationship quality.”* White (2000) suggests that a significant body image problem is more evident in patients who place greater importance on their appearance or whose cancer is affecting a body

part which is particularly valued part of the body. However, the intensity of personal investment in appearance or function is likely to change as a function of time, status of cancer, emotional functioning, and social network and relationship quality (White, 2000).

## 2.8 Models of body image and adaptation

A number of models of body image and adaptation to body image disruption cited in the literature have built on Schilder's initial work (Rhoten et al, 2014; White, 2000; Newell, 1999; 1991; Price, 1990; Dropkin, 1989). In nursing, the most commonly cited and comprehensive account of body image comes from Price (1990). Price (1990) suggests that body image consists of three related components: body reality, body ideal and body presentation. Body reality refers to the body as it is constructed, and includes both external elements (such as height) and internal elements (such as organs of the body and functions). Body reality can therefore change as a result of insults to the body through disease or trauma or through life due to the ageing process. The defining characteristic of body reality is that it consists solely of the physical attributes of the body and is not related to our attitudes to the body. In contrast, body ideal is attitudinal, and represents how we would like the body to be. Like Schilder (1935), Price sees this ideal as being gained through a process of identification with the body ideals of others and through our interactions with the rest of society. Our body ideal thus reflects a set of internalised societal norms of how society as a whole thinks we should look and the way in which it thinks our bodies should function. While body ideal is primarily a learnt phenomenon, it may be influenced by changes in body reality, but is not necessarily matched to this reality. Indeed, according to both Price's and White's model, a mismatch between the reality and the ideal may result in significant psychosocial distress (White, 2000; Price; 1990). Finally, body presentation refers to how we present all aspects of our bodily appearance, including dress, grooming and behaviour. Body presentation is mainly under the conscious control of the individual, who can alter the presentation of the body reality to conform to the ideal.

The three elements of the model exist in a state of tension or balance and can combine to support a satisfactory body image which individuals strive to maintain (Price, 1990). Price (1990) also identifies coping strategies and social support as contributing components. While Price provides numerous clinical examples of disturbance in body image and its effect in relation to body ideal, body reality and body presentation, his model of body image remains a set of untested assumptions and is purely speculative (Newell, 1999). Similarly, a more recent theoretical model of body image has been proposed by Rhoten et al (2014) based on the HNC literature. This model recognised the moderating effects of personal, social and environmental factors on the effect of dysfunction and disfigurement in both a positive and negative direction. Over time, some patients may accept changes in physical appearance and function leading to reintegration while others may not and therefore it is suggested that body image is an evolving phenomenon (Rhoten et al, 2014).

## 2.9 Models of disfigurement and adaptation

A further important account of disfigurement and adaptation from the nursing literature is suggested by Dropkin (1989) who draws considerably on Lazarus's formulations of stress and coping (Lazarus, 1966). According to coping theory, coping is the process of managing internal and external demands which are appraised as taxing or exceeding the resources of the individual (Lazarus and Folkman, 1984). It is the interaction between the individual and the environment in which each affects each other (Lazarus and Folkman, 1984).

Dropkin's model is widely cited and was developed principally in the context of post-operative recovery following surgery for HNC. Using Lazarus's model, the surgical procedure for removal of cancer is portrayed by Dropkin as the stressor to which adaptation is required. The person's cognitive appraisal of this threat leads to a series of affective and physiological responses which interact with behavioural responses. These behavioural responses are seen as indicative

of adaptation or body image reintegration, which involves confrontation, compliance and redefinition. The redefinition element involves the individual changing their value system following disfiguring surgery towards an appreciation that change in appearance or function does not change the nature of the person. Self-care, grooming and socialisation are viewed as key elements of the process of adaptation and reintegration during the first eight post-operative days.

Additionally, Newell (1999) suggested a fear avoidance model of social anxiety among people with a visible difference. Newell's model proposes a continuum of confrontational and avoidant responses, with confrontation presumed to be more adaptive. Avoidance is prompted by fear and anticipation of a negative outcome (for example intrusions such as staring, comments and questions) and leads the individual to engaging in a reducing range of activities as more situations are determined as threatening. Fear and avoidance are therefore conceptualised as potential mediators for adjustment and distress. However, Newell (1999) does not suggest if there is a time frame when avoidance may be a useful coping strategy.

There are three main issues identified in relation to Dropkin's model. First, Dropkin's investigations are mainly in the field of cancer surgery, where the patient may have to adapt to other stressors in addition to disfigurement. Second, although the role of self-care tasks and socialisation are explained in terms of Lazarus's model, the precise process by which such tasks lead to adaptation is not described. More importantly, the role of the nurse in facilitating these behaviours and attitudinal changes is not described in any detail (Dropkin 1989). Third, Dropkin is concerned primarily with short-term adjustment during the post-operative period. While initial adjustment is important, it is not the sole focus of my study which is concerned with the experience of appearance and functional change over time. It should be noted that treatment in HNC has changed significantly since the 1980s with advances in surgical procedures and reconstruction and increasing use of multi-modality treatment.

Furness et al (2006) performed a robust GT study of the predictors and processes of adaptation to facial surgery survivors including cancer patients. Sixty-five per cent of participants were female and time from surgery ranged from three months to 22 years. A model of adaptation was developed which reflected the inter-relationship between the four categories generated: demands; resources; responding and management; and consequences. Demands were situational factors eliciting responses and necessitating adjustment. Primary demands were direct consequences of the condition or surgery (such as altered appearance, functional change and unpredictability) and secondary demands were indirect effects upon social roles and experiences (such as work, finance, social reactions). Influences and resources were internal and external factors which were perceived to alleviate or exacerbate situational demands. Responding and managing was identified as the core category, comprising of participants' affective, cognitive and behavioural responses to demands. Of interest, when type of surgery was grouped into cancer and non-cancer related, individuals with cancer rated their appearance as less altered. However most of the participants had oral and jaw cancers, and the few with highly visible ocular cancers rated their appearance as considerably altered. Additionally, the majority of individuals with cancer participated in focus groups where there was more superficial discussion and expression of minority opinion was limited.

In summary, while different theoretical models of body image, disfigurement and adaptation have been proposed within the literature there are considerable similarities between those models. Body image relates to how an individual's body looks and functions as well as how an individual would like their body to look and function. The role of self-care, socialisation, social and personal resources is recognised however some of these models are theoretical and have not been tested. Additionally, within the studies discussed, the experience of men with HNC is under-represented. Having considered theoretical models of body image, disfigurement and adaptation, function is now explored.

## 2.10 Functioning

The World Health Organisation (WHO) adopted the International Classification of Functioning, Disability and Health (ICF) to assess functioning and disability in a standard and internationally recognised language (WHO, 2001). The ICF defines functioning from the perspective of the body, the individual and society in two parts: functioning and disability; and contextual factors. Functioning and disability is comprised of body functions and structures, as well as activities and participation. Contextual factors include environmental factors which consist of physical, social, and attitudinal environment, as well as personal factors, which refer to the background of an individual's life and living (Nund et al, 2014). Each of the components mentioned above consist of several domains and within these domains are categories which can be used to describe an individual's health and health-related state using specific category codes. The ICF contains over 1400 categories which make it a highly comprehensive tool however this also limits its practicality and usability. To address this, Tschiesner et al (2010; 2007) developed an ICF core set for HNC which has over 100 category codes, reflecting the widespread, complex and multifaceted nature of functioning and disability for HNC. This core set includes categories which capture change in appearance and function and impact on social activity. The ICF has been suggested as a framework which can be used to guide the evaluation of outcomes following HNC treatment and direct management due to its broad psycho-social approach (Tschiesner, 2011; Tschiesner et al, 2009a; Tschiesner et al, 2009b). Rogers et al (2010) suggest that as the brief ICF core set sits within the WHO classification of functioning, disability and health, it has the potential for international development and universal adoption. However, the research literature is still dominated by the concept of quality of life in head and neck cancer, which will now be considered.

## 2.11 Quality of life in head and neck cancer

HNC has a large impact on health related quality of life both as a result of disease and its treatment as key functions for social interaction are affected



such as appearance, chewing, saliva speech and swallowing (de Graeff et al, 2000). Quality of life has increasingly been recognised as an important outcome parameter in HNC in addition to recurrence rates and survival (Rogers et al, 2007). The WHO defines health-related quality of life (HRQoL) as a construct affected by patients' physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment (WHO, 1987). HRQoL has been incorporated into cancer research to reflect patients' experiences of their illness and treatment (Au et al, 2010). Validated questionnaires have been developed and the most commonly used HNC specific instruments in published reports include: the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30 and HN-35 module), University of Washington Quality of Life Questionnaire (UWQOL), and Functional Assessment of Cancer Therapy Head and Neck Cancer questionnaire (FACT-H&N) (Klein et al, 2014). Quality of life research has most frequently supported: understanding of treatment benefit; comparing treatments for quality of life effect; and advancing quality of life research methodology (Rathod et al, 2015). While there has been an increase in the number of articles reporting quality of life outcomes, discrepancies in measurement, reporting and presentation pose challenges to applying these findings to patient care (Rathod et al, 2015; Brundage et al, 2008).

Generally, a drop in QOL scores is seen at three and six months following surgery and scores at 12 months give a good indication of longer term outcomes (Rogers et al, 1999c). In a large study, Rogers et al (2007) described six groups of oral and oropharyngeal cancer patients' QOL at two years. Overall findings indicate that patients who do best are those with the smallest oral cancer tumours, having simple surgery (laser or primary closure) without radiotherapy. Those doing least well in respect of functional aspects of swallowing, chewing, speech, taste and saliva were those who had adjuvant radiotherapy and most of the oropharyngeal group. Of significance, appearance was identified as one of the most important issues by patients with early cancer who underwent simple surgery. In a study to describe appearance issues in oral and oro-pharyngeal cancer patients, Fingeret et al (2010) found

that patients who report a problem with appearance are more likely to have appearance as a major issue in combination with a set of other domains. Around a quarter of patients had either notable issues regarding their appearance or were bothered by it and younger patients (under 65 years of age) were more concerned about their appearance. Predictors for decreased QOL included greater body image dissatisfaction, greater number of body image concerns and time since surgery. However, due to the cross-sectional design changes over time were not explored.

In a study of laryngectomy patients at two years post diagnosis, the majority of patients reported a good to excellent overall QOL and most patients reported that their general health was the same or better that it was before the diagnosis of cancer. While loss of speech is disabling and laryngectomy is disfiguring, only a minority of patients reported speech or appearance as being more than “*somewhat important*” to their overall quality of life (Deleyiannis et al, 1999). Metreau et al (2014) compared long-term functional and QOL results between laryngectomy patients versus organ preservation strategies (chemo-radiotherapy) for advanced pharyngolaryngeal cancer. Both total laryngectomy and concurrent chemo-radiotherapy led to similar high rate of dysphagia-related morbidity and QOL alteration nevertheless there were differences in several specific sectors of QOL. Surgery patients reported significantly greater difficulties with sensory disturbances such as smell and taste. Only 72% of chemo-radiotherapy patients had a functional larynx at two years and they reported significantly worse scores in the “*dry mouth*” and “*weight loss*” items. Average weight loss after chemo-radiotherapy ranges from 7% to 12% (Nguyen et al, 2004; Newman et al, 1998; Lazarus, 1993). Almost 20% of the patients were still feeding-tube dependent after one year of treatment completion either after total laryngectomy or chemo-radiotherapy. In the chemo-radiotherapy group, the median duration of feeding-tube dependence was six months. After total laryngectomy, feeding-tube dependence is known to be secondary to pharyngeal stenosis, which occurred in 7.7% of patients in this series. Postoperative radiotherapy and chemo-radiotherapy can also be responsible for

dysphagia via xerostomia and muscular sclerosis with significant alteration of the first phase of the swallowing process (Maclean et al, 2009).

Advanced RT techniques like intensity modulated radiotherapy (IMRT) were developed with the intent to reduce dose to normal tissues compared with 3D conformal radiotherapy (3D-CRT) while still delivering ablative doses to cancer (Parliament et al, 2004). In a comparative, non-randomized study, Vergeer et al (2009) demonstrated statistically significant reductions in patient-reported xerostomia with IMRT compared with 3D-CRT. At six months post-treatment, 67% of patients treated with 3D-CRT reported moderate or severe xerostomia compared with 41% of patients treated with IMRT. Xerostomia is a persistent cause of diminished HRQoL in HNC patients and for which a dose-response relationship has been demonstrated (Jellema et al, 2007; Parliament et al, 2004; Jellema et al, 2005). HRQOL scores reported by IMRT patients were significantly better than the 3D-CRT group in the global, cognitive and social domains as well as the symptom-specific metrics of pain, swallowing, and social eating. Wells et al (2014) identified that younger age, lower socio-economic status, employment, and self-reported comorbidity are independent predictors of reduced cancer specific and generic quality of life in HNC survivors. Additionally, having a diagnosis of oral cavity cancer and ever having had a feeding tube fitted were also independent predictors of reduced cancer-specific QOL (Wells et al, 2016).

A point for consideration is that those patients whose QOL is poorest are least likely to respond to questionnaires or return to follow up which will inject bias in the data (Weymuller et al, 2000). It has also been noted that total QOL score (sum of the domain scores) is a relatively insensitive measure because patients tend to adjust to their disabilities (Weymuller et al, 2000). De Graeff et al (2000) concluded that the impact of the disease in long term survivors seems less severe than is often assumed. While successful treatment and recovery from acute toxicity certainly accounts for some improvement in HRQOL over time, coping mechanisms like “*response shift*” may also contribute. In this phenomenon, patients adjust their perception of pre-treatment HRQOL and

their judgment of “*acceptable*” HRQOL as a result of their disease and treatment experience (Ring et al, 2005).

In summary, QoL generally reduces in the first three months following diagnosis with recovery evident over the first year. Younger age, lower socio-economic status, employment, self-reported comorbidity, oral cancer and feeding tubes are associated with poorer QoL. However limitations such as patient response and coping mechanisms should be considered. In the following section, appearance and functional change in HNC will be discussed with a focus on qualitative research.

## 2.12 Appearance and functional change in HNC

The face is a visually prominent area and its fine muscle movement allows the expression of a range of moods, emotions and cognitions which facilitate social interaction (Cole, 1998). Hammerlid et al (1999) identified that a third of newly diagnosed patients with HNC can be classified as possible/probable cases of major mood disorder using the Hospital Anxiety and Depression scale. HNC and its treatment can cause significant changes to appearance which in turn, can cause fundamental emotional issues for patients.

Rumsey et al (2004) performed the largest cross-sectional study to date (n=458) to establish the extent and type of psychosocial needs of outpatients with a wide range of disfiguring conditions including HNC. Disfigurement is defined as “*the spoiling of appearance of something or someone*” (Oxford Dictionary of English, 2010). Standardised measures of anxiety and depression, social anxiety and avoidance and quality of life and a semi-structured interview were used to generate quantitative and qualitative data. A higher level of psychological distress was identified in the sample in comparison with normative values, however, the variability of responses within the sample was striking (Rumsey et al, 2004). Rumsey et al (2004) also found that women experienced more distress than men but there was no discussion why this may

be the case. Difficulties primarily related to social encounters, particularly with strangers, where individuals experienced feelings of anxiety and embarrassment supporting Newell's fear avoidance model (Newell, 1999). Comments and questions relating to the condition were experienced and many reported frequent misunderstandings about the nature of their conditions. However, due to the cross sectional nature of the data collection in this study, it was difficult to identify points in treatment at which people may be particularly vulnerable. Some condition-specific effects were apparent and HNC patients were found to have less appearance related concerns than patients with non-cancer related disfigurement and these findings support previous findings (Furness et al, 2006; Katz et al, 2003; Newell, 1999).

Katre et al (2008) suggest that the characteristics of HNC patients (lower social income; lower levels of self-care; higher consumption of alcohol and nicotine) may mean that self-image is less important pre-treatment in comparison to published norms. Other research has suggested that HNC patients view appearance change as the "*price to pay*" for survival (Semple et al, 2008; Larsson et al, 2007). Younger HNC patients (under 55 years of age) have however been found to display significantly higher levels of dissatisfaction with appearance (Fingeret et al, 2012; Katre et al, 2008; Katz et al, 2003). Studies have shown that perception of social support was associated with more favourable adjustment (Rumsey et al, 2004; Kleve et al, 2002). The more supported the individual felt, the less noticeable they thought their condition was to others, the less they worried about appearance, the less they felt it affected their lifestyle and the more they felt they could cope (Rumsey et al, 2004; Kleve et al, 2002).

The most striking conclusion from the literature is that there is no demonstrable relationship between size, severity and visibility of appearance change and psychological distress (Katz et al, 2003; Thompson and Kent, 2001; White, 2000). The biomedical bias towards the assumption that people who are most severely affected are also those at most psychological risk implies that people with "*minor*" problems may be overlooked (Rumsey et al, 2004). The issue of appearance can be important to a significant number of patients who have

undergone surgery for HNC however the issue is under-reported and is poorly recognised in routine clinical practice (Millsopp et al, 2006). Patients may not express their specific concerns with regard to appearance and often appearance issues may not be addressed due to other treatment priorities (Konradsen et al, 2009; Millsopp et al, 2006). Issues with appearance commonly occur in HNC in conjunction with other issues and the number of issues experienced has been shown to be a significant predictor of emotional and behavioural difficulties (Fingeret et al, 2012; Katre et al, 2008; Rogers et al, 2007). A Canadian study found that patients who had surgery to remove their larynx faced particular challenges as they transition and accommodate to changes in both appearance and function (Dooks et al, 2012). These patients received limited support from community healthcare professionals who were unfamiliar with this rare surgery. Nurses are in a unique position to support patients who experience appearance change but they often feel they lack the appropriate knowledge and education (Rumsey et al, 2004; Clarke and Cooper, 2001). However, Konradsen et al (2009) found that even within a surgical unit, nurses did not actively raise the issue of disfigurement and this in turn influences what patients felt they could talk about. While information can help patients adapt to change and engage in self-management, HNC patients have been found to feel dissatisfied with information related to body image and unprepared for long-term lifestyle changes (Fingeret et al, 2012; Newell et al, 2004). The desire for clinic-based support for appearance concerns in HNC has been recognised (Rumsey et al, 2004).

As discussed in section 1.1, most patients require multi-modality treatments. During radiotherapy treatment, taste changes, vocal changes, oral pain, dryness and narrowness result in losses and threats on different levels within daily life (Larsson et al, 2007; Roing et al, 2007; Larsson et al, 2003). The impact of cancer treatment is frequently unexpected and as symptoms increase, normal function becomes difficult and habits that were once pleasurable and routines that were taken for granted acquire new meanings (McQuestion et al, 2011; Roing et al, 2007; Larsson et al, 2003). Roing et al (2007) suggest that during radiotherapy there is no escape from a wounded mouth and that at the end of treatment the mouth is disabled. Eating in

particular is affected and subsequently meal times are no longer a social occasion to be enjoyed (Roing et al, 2007; Larsson et al, 2007; Larsson et al, 2003).

Patients undergoing radiotherapy or chemo-radiotherapy treatment frequently require nasogastric feeding as a result of inadequate oral intake and the mean length of use is 72 days (Sheth et al, 2013). Earlier independence from nasogastric tube feeding compared with gastrostomy feeding has been reported in several studies (Corry et al, 2009; Al-Othman et al, 2003; Mekhail et al, 2001; Lees, 1997). Bjorklund et al (2010) found that daily life becomes focussed on enduring suffering and surviving and living with HNC has been expressed as living in captivity due to the profound disruption to life. Strategies used to cope with the functional changes experienced commonly include; active planning; fighting spirit; positive thinking; comparing oneself with others; trial and error; problem-solving; developing self-reliance; modifying their lifestyle (Hu et al, 2009; Semple et al, 2008; Larsson et al, 2007; Wells, 1998). Due to the length of treatment, patients undergoing radiotherapy can lose contact with normal life making them feel lonely and vulnerable (Egestad, 2013). Meeting other patients with experience of HNC allows sharing of information about radiotherapy and side-effects and is considered to be of particular value (Egestad, 2013). Gaining insight into fellow patients' thoughts and feelings allow HNC patients to view their own experiences as normal reactions and their sense of being different was reduced (Egestad, 2013).

The treatment period is generally seen as safe and secure due to daily contact with healthcare professionals and the perception that the cancer was being actively fought (Bjorklund et al, 2010; Wells, 1998). Severity of side-effects can fluctuate and can be difficult to tolerate if they continue for longer than expected and individuals can vacillate between hope and despair as they struggle to maintain power and control over everyday life (Bjorklund et al, 2010). The hope for change can be measured on a daily basis and there may be fear about the long term impact of some of the changes and how much of the transformation may permanent (McQuestion et al, 2011). Feelings of abandonment are particularly evident after treatment when access to healthcare professionals

with specialist knowledge is limited (Bjorklund et al, 2010; Semple et al, 2008; Larsson et al, 2007; Wells, 1998). Larsson et al (2007) suggest that HNC patients need continuous contact with a healthcare professional, who is both competent and knowledgeable and can guide the individual through the different phases involved in the treatment trajectory.

A recent systematic review and meta-synthesis of the psychological experience of living with HNC identified six core concepts including: uncertainty and waiting; disruption to daily life; the diminished self; making sense of the experience; sharing the burden and finding a path (Lang et al, 2013). Patients' struggles between the daily disruption and uncertainty caused by cancer and its treatment were evident, in addition to attempts made to regain control and a sense of self. Disruption was felt in all aspects of life and the experience was characterised for some by a sense of the self being diminished (Lang et al, 2013). However, people who were successful in developing coping and self-management strategies viewed their future as changed or enhanced (Lang et al, 2013). Patients have noted benefits including a change in life priorities, a greater closeness to family and friends, a greater awareness of self, an increase in self-confidence and empowerment, and a greater awareness of faith and spirituality (Thambyrajah et al, 2010).

In summary, there is consensus within the literature that there is no demonstrable relationship between size, severity and visibility of appearance change and psychological distress. Appearance concerns often occur in conjunction with functional concerns and are frequently under-reported and not addressed within clinical practice. Chemo-radiotherapy causes profound changes in function which can be difficult to endure and patients can oscillate between hope and despair. While the challenges during treatment are recognised, there is little published work which explores the experience of appearance and functional change for men particularly during the recovery phase. Having considered appearance and functional change in HNC, adjusting to change is now explored.



## 2.13 Adjusting to change

Since the 1960's, there has been growing recognition that while stress is an inevitable aspect of human condition, it is coping that makes a difference in adaptational outcome (Lazarus and Folkman, 1984). Psychological stress is a relationship between the person and the environment that is appraised by the person as taxing their resources and endangering their well-being (Lazarus and Folkman, 1984). Pioneering work by Lazarus and Folkman (1984) suggested that judgement of situations hinges on primary and secondary cognitive appraisal. Primary appraisal involves considering: harm and loss which has been sustained; harm and loss which is anticipated (threat); and challenge which also includes the potential for gain or growth. Secondary appraisal is a complex evaluative process which takes into account: coping options available; the likelihood that the coping option will accomplish what it is supposed to; that one can apply a particular set of strategy or set of strategies effectively. Reappraisal refers to a changed appraisal on the basis of new information from the environment (Lazarus and Folkman, 1984). Personal factors (for example commitment and belief regarding control) influence the way a person appraises a situation and strongly influences the coping process and how the person reacts emotionally. Coping is therefore defined as "*constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resource of the person*" (Lazarus and Folkman, 1984, p141).

Similarly, Leventhal's Self-Regulatory Model (Leventhal and Cameron, 1987 p127) describes how an individual interprets and manages illness and is composed of three stages:

1. The cognitive representation of the health threat which includes such dimensions such as perceived identity (the symptoms and label which identify the threat), potential cause(s), possible consequences, and perceptions of how the health threat manifests itself over time.
2. The action plan or coping stage.

3. The appraisal stage, in which the individual utilises specific criteria to gauge success of one's coping actions, with perceptions of insufficient progress leading to modifications of representation and/or coping plans.

Furthermore, emotional reactions may occur at any of the three stages and additional coping plans and appraisals may be generated to control them. The processes involved in coping with emotional reactions are independent of cognitive processes involved in the representation and coping with the health threat, although the two may interact (Leventhal and Cameron, 1987).

In the previous sections within this chapter, key aspects of adjusting to change in appearance and function in HNC have been explored. Most of the research on adjustment has focussed on chronic illness and as cancer is increasingly being viewed as a chronic illness, this literature was considered to be relevant. Bury (1989) proposes that chronic illness is a "*biographical disruption*" as the structure of everyday, forms of knowledge that underpin them, and future expectations are disrupted. Chronic illness involves recognition of the worlds of pain and suffering, possibly even death, which are normally only seen as distant possibilities or the plight of others (Bury, 1982). In a society which emphasizes doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life (Charmaz, 1983). Maintaining a normal life or returning to one subsequently becomes the symbol of a valued self (Bury, 1991; Bury, 1982; Charmaz, 1983). Chronic illness affects relationships between individuals, families and social networks due to changes in dependency and roles.

Charmaz (1989) identified that chronic illness is experienced by individuals in three ways: as an interruption of their lives, as an intrusion, and as an immersion in illness. Others generally view the chronically ill through the framework of acute care with its assumption that illness causes temporary disruptions of self rather than causing continued losses of self (Charmaz, 1989). Restrictions can result in an all-consuming retreat into illness as the illness structures the individuals' worlds and shapes their self-concepts (Charmaz, 1983). Chronically ill people frequently experience a crumbling

away of their former self-images without simultaneous development of equally valued new ones (Charmaz 1983). Charmaz (1983) notes that the greater the loss of control and the amount of potential embarrassment from the illness, the more likely it is that the individual's self-concept will be affected. However individuals can undergo "*biographical repair*" as they regain identity or develop a new self (Bury, 2001; Charmaz, 1995). For some people who experience periods of lengthy illness then recover, illness can become a tool of self-discovery and a fundamental source of self-development (Charmaz, 1983).

Within cancer, Brennan (2001) proposes a social cognitive transition (SCT) model of normal adjustment and suggests that adjustment is the process of change occurring within the individual and not merely an end-point of coping (Brennan, 2001). Adjustment refers to the psychological processes that occur over time as the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by their illness and its treatment (Brennan, 2001). The burden of many months of treatment often reduces opportunities for people to engage in work and other social roles which formerly provided feedback about their competence and value in the world (Brennan, 2001). Studies consistently indicate that for people with cancer, work is central to maintaining normality, self-identity and self-esteem (Lang et al, 2013; Spelten et al, 2002; Peteet, 2000).

In a recent study of breast, lung and prostate cancer patients, Baker et al (2014) found that some participants, particularly those who had just been diagnosed, maintained continuity with their past identity by upholding previous routines, emphasising resilience and by minimising the disruption caused by cancer. Other participants spoke of a new normality, which was discontinuous with their past, due to changes or constraints caused by cancer. However, most accounts evidenced both continuity and discontinuity with their past, often in contradictory ways. Baker et al (2014) suggest that holding contradictory perspectives is indicative of an intermediate stage of adjustment for some patients between reliance on continuity with the past following diagnosis and later a sense of being a new person who has been changed by cancer. Furthermore, in a study of rehabilitation in gastrointestinal and gynaecological

cancer, new normal has been associated with adjustment to the individual's physical and social limitations, the psychological consequences and an alteration of expectations related to survivorship following treatment for cancer (Sandsund et al, 2012).

In summary, patients frequently try to continue with their normal life or return to normal life to try and maintain their identity and minimise disruption caused by cancer. As individuals begin to acknowledge and adjust to changes experienced they can develop a new self-identity.

## 2.14 Summary

Masculinity provides an important context for understanding men's experiences of cancer. While there are a number of theoretical models of body image and cancer, where studies have been performed within HNC, they have focussed on the initial post-operative period or men have been under-represented. Quantitative studies have identified issues which influence quality of life however they are mainly cross-sectional and do not identify how patients adapt over time. Qualitative studies on HNC have concentrated on particular cancer type), specific periods in the care pathway or specific issues. As highlighted in Chapter one, all treatment modalities have developed over the last decade with the majority of HNC patients receiving multiple treatment modalities. There is therefore the need for a robust study focussing on the experience of appearance and functional change in men with HNC. Due to the increasing strategic and clinical focus on survivorship, it was felt that the study should go beyond the treatment period and review the experience within the first 12 months following diagnosis. This focus supports the study of appearance and functional priorities for men with HNC, the impact of a cancer diagnosis on appearance and functional change and key time points within the care pathway when appearance and functional issues are important. Having considered the background and rationale to the study, the research methodology and approach will be discussed in the following chapter.

## **Chapter three: Rationale for research methodology**

### 3.1 Introduction

In the following chapter, my research aim and questions are explored. Following on from this, the rationale for using a qualitative, GT approach to my research is discussed. The various approaches to GT and my rationale for using Corbin and Strauss's approach are then presented (Corbin and Strauss, 2008). Finally, issues related to validity and relevance are considered.

### 3.2 Research aim and questions

Researchers need to be able to identify the aim and/or objective and clearly articulate the research questions (Hek, 2006; Holloway and Wheeler, 2004; Barker, Pistrang and Elliott, 2004). While the research aim is often broad, the research questions should be narrow and focussed (Willig, 2006). When contemplating the research aim and questions, the feasibility of the study should be considered in terms of the amount of time available, the experience and expertise required and the support available (Hek, 2006; Holloway and Wheeler, 2004). The involvement of service users to help shape research questions and consider ethical issues is essential and this is discussed in relation to my research within Chapter four (The Scottish Government, 2008a; Hek, 2006). Following consideration of these points and gaps highlighted in the literature within Chapter two, the following research aim and questions were developed:

#### Research aim

To explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis.

#### Research questions

1. What appearance and functional issues are important for men diagnosed with HNC?
2. How are appearance and functional issues experienced within the context of a life-threatening diagnosis of HNC?
3. At what point in the care pathway are appearance and functional issues important?

Social reality can be approached in different ways and it is therefore essential to consider the appropriateness of different research approaches (Holloway and Wheeler, 2004). The research aim and questions should dictate the methodological approach chosen (Corbin and Strauss, 2008; Hek, 2006). Philosophically, quantitative research is underpinned by a positivist tradition that proposes scientific truths or laws exist (Topping, 2006). Quantitative research designs collect numerical data which are amenable to statistical analysis and often involve a hypothesis or statement which can be tested (Lacey, 2006). This type of research seeks causal relationships and focuses on prediction and control (Holloway and Wheeler, 2004). Quantitative research was not considered to be an appropriate approach as little is known about men's experiences of appearance and functional change in the first 12 months following HNC and so no hypothesis could be formulated. Lacey (2006) argues that the choice of research methodology is the most important stage of the research process as it effects all other aspects such as data collection, analysis and the way in which the results can be applied to practice. Qualitative research was felt to be the most appropriate research method and the rationale for this choice is now explained.

### 3.3 Qualitative research

Qualitative research methods are derived from the social sciences and focus on the way people interpret and make sense of their experiences and the world in which they live (Topping, 2006; Willig, 2006; Avis, 2005; Holloway and Wheeler,

2004; Mays and Pope, 1996). Holloway and Wheeler (2004, p10) suggest that the following elements are part of most qualitative approaches and this guided my approach:

- The data have primacy; the theoretical framework is not pre-determined but derives directly from the data
- Qualitative research is context-bound, and researchers must be context sensitive
- Researchers immerse themselves in the natural setting of the people whose thoughts and feelings they wish to explore
- Qualitative researchers focus on the emic perspective, the views of the people involved in the research and their perceptions, meanings and interpretations
- Qualitative researchers use *“thick description”*: they describe, analyse and interpret
- The relationship between the researcher and the researched is close and based on a position of equality as human beings
- Data collection and data analysis generally proceed together, and in some forms of qualitative research they interact

Qualitative research is therefore a *“situated activity”* that locates the observer in the world of those being studied and consists of interpretive, naturalistic practices that make this world visible, and therefore understandable, to others (Avis, 2005; Holloway and Wheeler, 2004; Denzin and Lincoln, 2000; Popay, 1992). Additionally, the importance of listening to patient stories to inform clinical practice is increasingly recognised (Jack, 2010). These aspects determined that a qualitative approach would be the best approach for my research study.

### 3.4 Qualitative approaches

There are a variety of approaches to qualitative research and while these approaches share underlying assumptions (section 3.3), they differ in terms of their goals, research questions, techniques employed and the contribution they make to knowledge development (Gerrish and Lacey, 2006). In deciding on the qualitative approach to be used within my study, phenomenology and GT were considered which are the two main traditions used in nursing research. Both methodologies focus on the views of people involved in the research and their perceptions, meanings and interpretations however in GT, there is emphasis on developing theory from the data.

Phenomenology emerged as a discrete philosophical research tradition in the early part of the twentieth century (Holloway and Todres, 2006). Edmund Husserl is credited as the central founder of this tradition (Holloway and Todres, 2006; Rapport, 2005). Phenomenology provides a philosophical rationale for studying human experience on its own terms as a focus of study. Phenomenological research begins with gathering examples of everyday experiences, known as lifeworld or lived experiences, which are then described and studied in depth (Todres, 2005). The purpose of focussing on such experiences is to find insights that apply more generally beyond the cases studied in order to emphasise what we may have in common as human beings. When phenomenologists present their findings they usually express this in such a way as to show how a number of common themes are related.

GT methods emerged from sociologists Barney Glaser and Anselm Strauss's successful collaboration during their studies of people dying in hospitals in the 1960's. At that time, hospital staff rarely discussed or acknowledged dying and death with seriously ill patients. As Glaser and Strauss constructed their analysis of dying, they developed systematic methodological strategies which sociologists could adopt and wrote the original text on GT: "*The Discovery of Grounded Theory: strategies for qualitative research*" (Glaser and Strauss, 1967). GT is defined as "*the discovery of theory from data - systematically*



*obtained and analysed in social research*” (Glaser and Strauss, 1967, p1). GT has become the most commonly adopted research methodology amongst nurses and Gelling (2011) suggests that there is considerable fit between the core elements of nursing practice (for example communication) and the principles underpinning GT.

The theoretical framework for GT is derived from symbolic interactionism which is a theoretical perspective which assumes that society, reality, and self are constructed through interaction and thus rely on both language and communication (Mead, 1934). The defining components of GT practice are: simultaneous involvement in data collection and analysis; constructing analytic codes and categories from the data; using constant comparison; advancing theory development during each stage of data collection and analysis; memo-writing to elaborate categories, specify their properties, define the relationships between categories, and identify gaps; and sampling aimed toward theory construction (Urquhart, 2012; Charmaz, 2011; Corbin and Strauss, 2008; Glaser and Strauss, 1967). Engaging in the defining components of GT can help researchers to control the research process and to increase the analytic power of their work (Strauss and Corbin, 2008; Charmaz, 2011; Glaser and Strauss, 1967). The overall purpose of GT methodology is the generation of theory from the data which has explanatory power and advances the understanding of social and psychological phenomena (Glaser and Strauss, 1967).

There are no studies that provide a detailed description of men’s experiences of appearance and functional changes following a HNC diagnosis. Clearly, treatment impacts appearance and function but this does not explain why men respond to changes in the ways that they do or how they make sense of changes. Theories about body image, disfigurement and adaptation discussed in section 2.3 are likely to be informative but they have not specifically focussed on the experiences of men with HNC over time. Thus, a methodology that lends

itself to gathering descriptive data would address a gap in the evidence. GT was chosen as the preferred method for my study as it attempts to go beyond description and build theories about social and psychological phenomena (Corbin and Strauss, 2015, 2008; Charmaz, 2014, 2011; Strauss and Corbin, 1998, 1990; Strauss, 1987; Glaser and Strauss, 1967). Furthermore, as I used phenomenology during my Masters in Nursing Degree research, I felt that using GT would develop my research knowledge and skills.

### 3.5 Grounded Theory

Since the introduction of GT, different versions have emerged which represent fractures from the original GT methodology as they originate from different ontological foundations (Hunter et al, 2011). Dey (1999, p2) notes the widespread use of GT and states that there are “*probably as many versions of grounded theory as there were grounded theorists*”. While it is beyond the scope of this thesis to fully discuss the development of GT, the three main versions of GT are presented next (Hunter et al, 2011, p7):

1. Classic GT – represents GT in a pure form that stems from the original work in the 1960s (Glaser, 2002, 1992, 1978; Glaser and Strauss, 1967, 1965).
2. Straussarian GT – represents the first fracture from classic GT, offering a modified approach aimed at making GT more transparent to researchers (Corbin and Strauss, 2015, 2008; Strauss and Corbin, 1990).
3. Constructivist GT – the most recent remodelling of the GT approach, which explicitly assumes that categories and theories do not emerge from the data, but are constructed by the researcher through interaction with the data (Charmaz, 2014, 2011).

Hunter et al (2011, p4) suggest that “*grounded theory is often referred to but is not always understood.*” For those new to GT choosing between the many methodological versions or approaches can be difficult (Gelling, 2011). Holloway and Todres (2006) suggest that researchers have to decide for themselves what GT approach to adopt. I did not use Constructivist GT as I

believe that categories emerge from the data. The more formulaic approach to GT was developed by Corbin and Strauss (1990) in response to their students requests for a “*how to*” manual of GT and contains clear guidelines and procedures. Glaser critiqued the procedures detailed by Strauss and Corbin and argued that these would limit emergent conceptualisations and force the concepts into a preconceived mould. However, in the updated version of Strauss and Corbin (2008), the role of the coding paradigm is presented as only one of a number of analytic strategies or tools. There has been a further update to the approach by Corbin however; while this version is acknowledged, I did not use this version as a guide as the process of analysis started following initial data collection in 2010 (Corbin and Strauss, 2015). Cooney (2011) states that care in applying GT methodology correctly is the single most important factor in ensuring rigour. Nevertheless, Dey (1999) warns of the dangers of an overly mechanistic approach. Corbin and Strauss’s approach is often attractive for novice researchers and I felt that this approach and the examples of application provided the guidance to support analysis within my study (Gelling, 2011; Charmaz, 2006; Holloway and Todres, 2006).

Having briefly discussed the key components of grounded theory methodology, the application of grounded theory within my research study is now focused upon in chapter four.

## **Chapter four: Research design and method**

In this chapter, patient involvement, peer review, ethical considerations, sampling and recruitment within my study are discussed. Following on from this, patient and researcher considerations and the application of GT within my study is described, focussing on data collection, analysis and theory development.

### **4.1 Patient involvement**

As previously discussed in Chapter one, the key to improving services for people with cancer is through understanding patients' experiences and using this knowledge to make and prioritise improvements in the way care is designed and delivered (Department of Health, 2011; The Scottish Government, 2008b). Participant or user involvement has become an integral part of the research process and is at the heart of demonstrating credibility (Gelling, 2011; Beck, 1993). Participant or user involvement has considerable value and should not be an afterthought or a token gesture to appease funding bodies or research ethics committees (Gelling, 2011; Beck, 1993). Two male HNC patients from my clinical practice were identified and approached individually to discuss my research proposal.

**Table 1 - Patient involvement**

	AGE	DIAGNOSIS	TREATMENT	EMPLOYMENT STATUS	MARITAL STATUS
1.	75	Laryngeal cancer	Laryngectomy + radiotherapy	RETIRED	WIDOWED
2.	44	Oropharyngeal cancer	Concurrent chemo-radiotherapy	EMPLOYED	MARRIED

These HNC patients were approached because they had previously expressed an interest in patient involvement and “*giving back*” to cancer services. Participant 1 was a “*buddy*” providing formal peer support to other laryngectomy patients and spoke at formal study days for healthcare professionals on the topics of laryngectomy care and managing body image changes.

Initially, I discussed the rationale for the planned study with these patients and asked their views on the focus of the study. Both individuals shared their own experiences with me (loss of voice box, scarring, voice difficulties, healthcare professionals not understanding changes, hair loss, weight loss, eating difficulties and fatigue/weakness) and felt that exploring men’s experiences of appearance and functional change was an important area to focus upon. In particular, the HNC patients indicated that participants within the proposed study should be interviewed individually rather than within a group. The HNC patients thought that participants would be less open and honest during discussion when in the presence of other men, presenting a socially acceptable view of changes (strong and coping). Additionally, where possible it was suggested that participants should be interviewed on their own instead of with their spouses or important others to promote open discussion. It was felt that while the interview should be led by participants responses, questions should be developed to guide participants where necessary. Questions were suggested and incorporated into the Interview checklist (for example as shown in Appendix 12 – How did you feel when you started to interact socially again?). Once the final research protocol (including the information sheet, interview checklist/guide and consent form) was developed, the HNC patients reviewed the protocol. They found the protocol easy to read and did not suggest any changes to the content. Similarly, I presented the research protocol to NHS Ayrshire and Arran patient and carer panel at a meeting on 14<sup>th</sup> July 2010. The protocol was discussed and the panel agreed with recommendations to perform individual interviews, using a topic guide to support questioning as necessary.

Following initial analysis of all the data, a substantive theory of the experience of appearance and functional change for men with HNC was developed. A summary of the analysis was sent to one of the HNC patients (P1 was

unfortunately unable to continue to participate) and all study participants. Feedback from this review was supportive of the substantive theory developed and this is discussed in further detail within section 4.11 which focusses on validity and relevance.

## 4.2 Peer review

Potential topics/areas for research were initially discussed with a Macmillan Nurse Consultant and Macmillan Consultant in Clinical Psychology. Following discussion, a research protocol was developed and reviewed to ensure that the study fitted in with National cancer research and care priorities. The Macmillan Nurse Consultant's views were felt to be representative of nursing as she was an integral member of the Scottish and the West of Scotland Cancer Nurse Consultant group.

I presented the research protocol to the Scottish Head and Neck Oncology Nursing Forum (SHNONF) in June 2010. The study aim and questions were supported by the SHNONF and the Clinical Nurse Specialists (CNS) within the Health Board where the study was performed were fully engaged. The research protocol was also formally reviewed at regional level by the West of Scotland HNC Managed Clinical Network (MCN) research sub-group and full support was offered (Appendix 9). Furthermore, the HNC MCN Lead Clinician and the Clinical Directors and HNC Consultants within the appropriate Health Board were approached and informed of the study and again full support was offered.

Following analysis of the data, the substantive theory developed of the experience of appearance and functional change for men with HNC was reviewed by two CNS. Feedback from this review was supportive of the substantive model developed in terms of validity and relevance (Appendix 23).

### 4.3 Ethical approval

During development of the research protocol, advice was sought from the Head of Research, Development and Evaluation within NHS Ayrshire and Arran. I was advised to limit my study sample due to time constraints particularly in relation to data collection and analysis. I discussed this with my supervisors and we agreed that sampling should continue until theoretical saturation occurred. Theoretical saturation is discussed in detail in section 4.4, however it has been suggested that theoretical saturation can occur within 12 interviews (Guest et al, 2006). My sample size was therefore identified as 12 within my ethics application. If more participants were needed to ensure theoretical saturation, an amendment to my application was to be submitted. Additionally, I was encouraged by the Head of Research, Development and Evaluation (NHS Ayrshire and Arran) to apply for permission to conduct the study locally, within my area of clinical practice despite my concern about ethical issues. Although CNS input is limited following the first year after diagnosis, the CNS is an integral member of the clinical team and potential involvement in future care may concern research participants.

The University of Stirling agreed to undertake the role of sponsor for the study as outlined in the Research Governance Framework for Health and Community Care on 3<sup>rd</sup> September 2010. The School of Health Studies Research Ethics Committee form, research protocol, and supporting documents were submitted in September. Initially, the Ethics Committee at the University did not give ethical approval and I was advised that the research study should be performed out with the Health Board where I practiced clinically. This was due to potential ethical issues in relation to recruitment, participation and my involvement in ongoing care. The protocol was amended accordingly with the study site being two acute hospital sites within the nearest Health Board. Ethics Committee approval was subsequently granted on the 5<sup>th</sup> October 2010 (Appendix 7).

Following on from Health Studies Research Ethics Committee approval, contact was established with the appropriate NHS Research and Development

department to discuss the study and application requirements. The study protocol and all supporting paperwork were submitted to the West of Scotland Research Ethics Service (WoSRES 5) and NHS Research and Development department and the study was supported with a minor amendment (Appendix 7; Appendix 8). Lay representatives of WoSRES 5 suggested that the information sheet be amended to inform participants that the researcher is an experienced HNC CNS (Appendix 3). By acknowledging the researchers clinical background and knowledge, lay representatives felt that participants would be less anxious, particularly where they were experiencing challenges with communication. This proved to be important to participant 11 who had his voice box removed and had to use an electrolarynx to vocalise (hand held battery operated device placed under the mandible which produces vibration and speech). Participant 11 only used an electrolarynx with family but he felt comfortable using it with me because he was aware of my clinical background and experience. The potential value of dual professional roles of nurse and researcher has been recognised as interpersonal skills gained from nursing experience can be used in a fluid, flexible and proficient manner during the research process (Colbourne and Sque, 2004; Leslie and McAllister, 2002). The study protocol was approved by WoSRES 5 on the 24<sup>th</sup> January 2011 and I was granted access to the research sites (Appendix 7; Appendix 8). Annual progress reports were submitted to the University of Stirling and WoSRES 5 during the period of study. Additionally, a final summary of findings report was sent to WoSRES 5 within a year of study completion (Appendix 21).

#### 4.4 Sampling

The study population was all men with a diagnosis of HNC from the two acute hospital sites who were a minimum of 12 months and a maximum of 24 months post-diagnosis. To briefly recap, as discussed in section 1.2, this time period following diagnosis was chosen as quality of life data suggests that results at 12 months is indicative of longer term outcomes. Recruitment was restricted to participants who were 12-24 months post-diagnosis to limit issues with recall



and support reflection and processing of their experience. The four main types of qualitative sampling are convenience, purposeful, theoretical and snowball sampling (Procter & Allan 2006).

In GT, purposive sampling is used initially and then theoretical sampling commences. Purposive sampling is a technique widely used in qualitative research for the identification and selection of information-rich cases for the most effective use of limited resources (Patton, 2002). Purposive sampling involves selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest (Cresswell and Plano Clark, 2011). Within this study, purposive sampling was initially performed from a pool of 200 potential participants.

Theoretical sampling is then performed which is a method of data collection based on conceptualisation derived from the data (Corbin and Strauss, 2008). The purpose of theoretical sampling is to collect data from places, people and events that will maximise opportunities to develop concepts in terms of their properties and dimensions, uncover variations and identify relationships between concepts (Charmaz, 2011; Corbin and Strauss, 2008). Theoretical sampling differs from conventional methods of sampling as it is emergent and responsive to the data rather than established before the research begins (Corbin and Strauss, 2008). Theoretical sampling is used to delineate the properties of a category; check hunches about categories; saturate the properties of a category; distinguish between categories; clarify relationships between emerging categories and identify variation in process (Charmaz, 2006, p104).

Concepts are derived from the data during analysis and questions about those concepts influence further analysis and data collection (Corbin and Strauss, 2015). For example during the first interview I identified that participant one compared himself against other people undergoing treatment and this was coded as *“comparing self against other”*:

*P1: You haven't seen some of the things that I've seen, which to my mind are admirable when I see the strength of character in other people who are going through much worse, you know, with the cosmetic changes that happens in terms of their appearance. A tube's a tube. [Comparing self against others](#)*

Further analysis of the interview from participant one resulted in the following memo which highlights that comparison is often with people who are worse off which was coded as “downward comparison” and how this impacted on his interpretation of change:

#### P1: Downward comparison

*P1: The nasal tube, it is a bit different. You feel very self-conscious about it when you have got it in. It was in for some time. Even attending clinics, you would go up to the clinics. I try to think how often I went to the clinic to begin with. I think it was every fortnight and then it came down to every 4 weeks and then every 6 weeks and then it will stretch again but you sit in amongst people and you are conscious of it but then you see another guy that has got it or a lady that has got it or you see a guy who has obviously had plastic surgery and had a section of his lip removed and had new skin put in and you think ok I might be self-conscious about a tube going up my nose but it is there for a purpose and then I got to the stage when I got fed up with it.*

Both on the phone when organising this interview and peppered throughout this interview are examples of downward comparison. The patient is comparing himself against others who have more advanced disease, have had more extensive treatments or are more unwell. The resilience that others showed was revered and comparing himself against these individuals allowed this participant to “normalise” what was going on, allowing him to view his experience more positively.

As data analysis progressed and categories emerged, I followed up on recurrent patterns in participant data and asked participants to give more information on categories that appeared central to the emergent theory such as comparing self against others and downward comparison as seen below in Participant 12's interview:

*R: Some of the other patients have said to me when I have been interviewing them that they have talked to other patients or seen them when they were on the ward and used them as a kind of benchmark or these kind of things. Did you speak to any other patients or meet any other patients on the ward?*

*P12: I was on that ward and there were four of us. As far as I was concerned I was the best of the four.*

*P12 continues: That is another thing that got me as well, you think you are in a bad way but when you see some of the other people, you're not really.*

I also returned to previously analysed data and reviewed it again as I developed theoretical sensitivity (section 4.10) as indicated by Corbin and Strauss (2015; 2008). For example when I reviewed the data again, comparing different interviews, it was evident that when an individual's condition deteriorates during treatment, they don't identify themselves as the person who others may compare themselves against. The psychological process of cognitive reappraisal was evident with a focus on the necessity for treatment and impact on the cancer. Theoretical sampling is about intentionally looking for events and situations, making those comparisons, and in the process further developing concepts.

Using theoretical sampling, a younger participant (P9) was recruited to explore the potential impact of age as a couple of participants alluded to the fact that appearance change had not affected them as they were older. However, age was not found to influence interpretation of appearance change and this was another example of participants performing social comparison with others

interpreted as being more affected or being worse off. A second participant who had undergone a laryngectomy (P11) was also recruited to explore the challenges of multiple changes to appearance and function and to develop properties and dimensions in relation to changes being understood by others.

Within a GT study, theoretical sampling occurs throughout the study and continues until the point of saturation however it can prove difficult to identify when saturation has been achieved (Backman and Kyngas, 1999). Charmaz (2006) suggests that the most common error occurs when researchers confuse theoretical sampling with gathering data until they find the same patterns occurring. These researchers have not focussed data-gathering towards explicit development of theoretical categories from analysis and instead focus on patterns to describe empirical themes in the research field (Charmaz, 2006). Saturation as a concept is frequently misunderstood but occurs when no new concepts can be found which are important for the development of emerging theory (Smith and Biley, 1997).

#### 4.5 Sample

Theoretical sampling can potentially raise challenges during the process of ethics review as the sample and interview questions are not fully known at the start of the study and may change throughout the research process (Holloway and Todres, 2006). Morse (1995, p147) suggests that “*saturation is the key to excellent qualitative work*” but noted that “*there are no published guidelines or tests of adequacy.*” The suggestion of sample sizes in the literature varies between 20 and 30 (Creswell, 1998) and 35 (Morse, 1995) for grounded theory studies. Kuzel (1992) relates his suggestions to sample heterogeneity and research objectives, recommending six to eight interviews for a homogenous sample and twelve to twenty when trying to achieve maximum variation. However none of the research literature noted above presents evidence for

their recommendations. To address these issues, Guest et al (2006) attempted to provide an evidence-based foundation regarding sample sizes. Using data from a study involving 60 in-depth interviews with women in two West African countries, the authors systematically documented the degree of data saturation and variability over the course of thematic analysis. Guest et al (2006) proposed that data saturation had for the most part occurred by the time they had analysed 12 interviews, although basic elements for meta-themes were presented as early as six interviews. After analysis of 12 interviews, new themes were found to emerge infrequently and progressively so as analysis continued. It is therefore suggested that a sample size of 12 is satisfactory when exploring individuals' experiences in a relatively homogenous sample (Guest et al, 2006).

I therefore applied for ethical approval with the plan to recruit 12 participants and would have applied for further approval if a larger sample was required to address gaps and reach theoretical saturation. However, following discussion with my academic supervisors, data collection was concluded after 12 interviews. Analysis suggested that the categories, how the categories related to each other and the core category were well developed and no new concepts which were important for the development of the emerging theory were being identified latterly.

#### 4.6 Recruitment process

The following criteria were used to determine participant eligibility:

Table 2 - Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Males over 18 years of age	Males under 18 years of age
Males who are able to provide	Males who are unable to provide

informed consent	informed consent
Men who can communicate in English	Men unable to communicate in English
Men with a diagnosis of HNC within the 2 study sites who are more than 12 months and less than 24 months post-diagnosis	Men with a diagnosis of HNC out with the 2 study sites and/or less than 12 months and/or more than 24 months post-diagnosis

Cross-cultural qualitative research is rare and challenging because of difficulties of collecting reliable and valid information when conducting research in a language other than the researcher's primary language (Lopez et al, 2008). On average it takes 12 hours to transcribe a two hour interview from source language to target language (Lopez et al, 2008). Due to time constraints and financial constraints involved in translation support, patients who were unable to communicate in English were excluded from this study.

The CNS within the two acute hospital sites identified eligible patients from their patient caseload. Potential participants were given verbal information about the study and asked if they would like written information (Appendix 3). The participant information sheet was developed in accordance with Royal College of Nursing and Central Office for Research and Ethics Committees guidelines. The individual was asked if they would consent to the researcher contacting them by telephone to answer any queries and to identify if they would like to participate within the study. Telephone contact was made a minimum of 24 hours after receiving study information to give the individual time to consider their participation within the study. During telephone contact, I reminded patients verbally that they were under no pressure to participate, that they could withdraw at any time and that this would not influence their clinical care in any way. Where an individual agreed to participate, an interview was arranged at a time and venue (participant's home/NHS facility) which was acceptable to the individual. Only one participant requested that the interview be performed in an NHS facility, with all other interviews being performed within the patient's home.

The CNSs were told when a participant agreed to an interview and informed of the scheduled interview date.

#### 4.7 Participant information

Data on participant's diagnosis, disease staging, socioeconomic status, employment status and marital status was obtained from the CNS when the patient agreed to participate in the study (Appendix 13). The table which follows presents participant information in relation to: age; diagnosis/staging; treatment; marital status; social deprivation category and educational level. Participants were predominantly over 55 of age. Three quarters of participants had extensive disease and underwent multi-modality treatment (surgery plus (chemo) radiotherapy or combination chemo-radiotherapy). Eight participants were married and four participants were widowed, divorced or single. Additionally, three quarter of participants lived in areas of high social deprivation. Four participants were retired, three were unemployed and four were employed. Worthy of note is the fact that two of the participants had to retire and three were unemployed as a direct result of cancer treatment. Overall, the participants recruited to the study were representative of men with HNC within the WoS as previously discussed in Chapter 1 (section 1.1).

T=tumour, N=node, M=metastases (for staging information refer to TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition, UICC)

SIMD - social deprivation quintile, 1= least deprived, 5 = most deprived

**Table 3 – Socio-demographic participant information**

P	AGE	DIAGNOSIS/ STAGING	TREATMENT	STATUS	EMPLOYMENT	SIMD	EDUCATIONAL LEVEL
1	63	T1N2aM0 left oropharynx	Left neck dissection Post-operative chemo-radiotherapy	Married	Retired (Independent insurance/ pension broker)	1	Secondary
2	58	T4N1M0 left oropharynx	Major surgery with reconstruction Post-operative chemo-radiotherapy	Widowed	Unemployed	5	Secondary
3	63	T4bN2BM0 oropharynx	Chemotherapy Chemo-radiotherapy	Married	Employed (Contract manager for a haulage company)	5	Secondary
4	55	T4N2cM0 larynx	Laryngectomy Chemo-radiotherapy	Married	Unemployed (Professional darts player)	4	Secondary
5	61	T1N2aM0 left oropharynx/ T1N1 right oral cavity	Chemo-radiotherapy	Married	Retired (Security Director)	2	Secondary
6	68	T2N2aM0 left base of tongue	Chemo-radiotherapy	Widowed	Retired (Fire fighter)	5	Secondary HND
7	65	T2N0M0 oral cavity	Major surgery with reconstruction Post-operative radiotherapy	Married	Retired (Security officer)	5	Secondary
8	58	T2N0M0 tongue	Major surgery with reconstruction	Married	Staff nurse	5	Secondary
9	57	T2N1M0 tongue	Major surgery with reconstruction Post-operative chemo-radiotherapy	Married	Merchant seaman	5	Secondary
10	26	Muco-epidermoid cancer hard palate	Wide local excision with obturator Delayed reconstruction	Single	Project manager (Marketing/ communication agency)	1	University (BA honors)
11	56	T4N2bM0 larynx	Laryngectomy & right neck dissection Post-operative radiotherapy	Divorced/ Single	Unemployed (Handyman)	4	College - modules
12	64	T2N0M0 right oral cavity	Major surgery with reconstruction	Married	Engineer	4	Secondary



## 4.8 Patient and researcher considerations

Many HNC patients have challenges with speaking. Communication difficulties (such as dry mouth and fatigue) were anticipated and participants were advised that interviews could be stopped, resuming when the participant was comfortable or rescheduled as necessary. However, all participants managed to continue with the interviews without breaks. Additionally, it was acknowledged that participants may experience distress during or after disclosure of their personal experience. Participants were advised that if they became distressed during the interview, the recording could be stopped and restarted or rescheduled. Only one participant became slightly emotional when talking about his cancer diagnosis and his family, nevertheless he chose to continue with the interview. At the end of the interview all participants were reminded that they could contact their CNS if they had any clinical issues or support needs. The CNS was informed of interview dates for research participants in case they contacted them for support but no participants contacted them in relation to the study. Participant 2 stated that he felt the interview was helpful as it was the first time he had really thought about what had happened to him and shared this with anyone. As discussed previously, a letter was also sent to the individual's General Practitioner and Consultant informing them about the study and the patient's participation in the study (Appendix 10).

As 11 out of 12 of the interviews were conducted within the individual's home, safety protocols developed by the Cancer Care Research Centre (University of Stirling) and Paterson et al (1999) were followed. This involved performing a risk assessment (considering and anticipating risk and response); carrying a charged mobile phone; performing interviews as early in the day as possible (within working hours); using a navigation system to find the location; ensuring car is fully functioning; informing a named person of the interview time, date and location; and contact with the named individual directly before and after the interview. Only one interview had to be conducted in the evening due to the participant's work commitments. The participant was called on the evening to confirm arrival time and I was driven to the participant's home where my colleague waited for me.

Consideration was given to my clothing with smart casual clothing being worn as this was felt to be appropriate to the interview setting. I had regular contact with both academic supervisors during the study period to provide emotional support and research guidance. The supervisors could also be contacted out with established contact periods.

#### 4.9 Data collection

On the day of interview, informed consent was obtained. For consent to be informed, it was important that the participant had been given written and verbal information and had the opportunity to ask the researcher or the independent contact any questions about the study. It was also essential that participants were aware that they could stop the interview or withdraw from the study at any time without this influencing their ongoing care. The participants signed the consent form prior to data collection starting (Appendix 4). As previously mentioned a letter was sent to the participant's General Practitioner and Consultant and the CNS was informed of the interview date to ensure that support was available if the participant needed it following the interview.

GT methodology is often used when there is little known about a subject or problem (Morse, 1994). The researcher can use many sources of data including interviews, observations, videos, documents, drawings, diaries, memoirs, newspapers, historical documents, autobiographies and other data sources (Corbin and Strauss, 2008). As indicated in Chapter two, research literature was accessed to develop the research questions and proposal and throughout data analysis. Furness et al (2006) performed a GT study of appearance change following disfiguring facial surgery and identified that focus group discussion was more superficial in comparison to individual interviews. Within focus groups, the minority view may not be verbalised (Furness et al, 2006; Holloway and Wheeler, 2004). As discussed previously, men may potentially present their experience in a different light in front of other men, to conform to masculine ideals. Additionally, I felt that using focus groups as the source of data collection would limit the opportunity for comparative analysis.

Interviewing is a useful method of interpretive enquiry which allows in-depth exploration of a particular topic or experience (Charmaz, 2006). Interviews are the most commonly used data collection method in qualitative research (Taylor, 2005). Interviews were semi-structured to allow discovery while providing sufficient detail to convince research and ethics departments that no harm would be done to participants. Charmaz (2006) suggests that a well-thought out list of open-ended questions is useful and this was felt to be particularly important for participants who had previously not reflected on their experience (Appendix 12). Attempts were made to ensure that questions were clear, unambiguous and aimed at the participant's level of understanding at all points, with advice being sought from previous HNC patients during development. Analysis from initial interviews and emerging categories provided direction for subsequent interviews. Data collection and analysis therefore proceeded in parallel, interacting at each stage of the research process.

As stated previously, HNC patients involved in development of the research protocol also suggested that participants should be interviewed on their own (Section 4.1). Therefore, a single one-to-one interview was requested with participants to explore the experience of appearance and functional change in men with HNC. Only one participant (P12) asked for his wife to be present and participate in the interview as they had "*gone through this together.*" Another participant's wife (P7) asked if she could be present to hear what her husband had experienced as he had never spoken to her about this, however the participant did not engage with this request and waited in silence until his wife left the room. While this felt a bit awkward, it was clearly evident that the participant did not want his wife listening or involved in the interview. Participant 7 became emotional during the interview when talking about his family and I believe this was his way of protecting his wife and allowing emotional disclosure.

Longitudinal or sequential interviews can allow more in-depth and better quality data to be collected as the participant and researcher relationship develops and the evolving experience of the participant is captured (Tod, 2006). However, I had to consider the potential for withdrawal from subsequent interviews and the time

required to both perform and analyse multiple interviews. Molassiotis and Rogers (2012) performed a longitudinal study with 16 patients with HNC over 12 months (4 interviews - 3, 6, 9 and 12 months) however there was gradual withdrawal, for a range of reasons, with only 10 participants in the final interview at 12 months. On reflection, I decided that for the purposes of my study, a single retrospective interview would be performed and participants who were between 12 and 24 months following diagnosis would be recruited to facilitate recall.

All participants, except one which occurred within NHS facilities, had the interview performed within their own home. While the home may or may not be the ideal interview environment, it is important for the participant to feel relaxed, at ease and able to concentrate. I tried to minimise disruptions by careful scheduling of interviews and requesting equipment (such as telephones and televisions) be switched off where possible. It was felt that interviews should last a maximum of 60 minutes as participants could experience dry mouth, communication difficulties and fatigue. Interviews were performed at the pace of the individual, allowing for pauses where necessary.

Interviews can allow the exploration of hidden and suppressed views (Charmaz, 2006). However, it was also recognised that men may view interviews as threatening because they occur within a one-to-one relationship, render control of interaction ambiguous and foster self-disclosure, risking loss of public persona (Schwalbe and Wolkomir, 2002). Charmaz (2006) suggests that men's potential discomfort may heighten where the topic of the interview may challenge their masculinity claims. It is acknowledged that many factors such as social class, age and gender of the researcher and participant can affect interviews (Manderson et al, 2006). Gender in particular can influence emotional disclosure. However while male participants tend to avoid discussing emotion with female researchers, Manderson et al (2006) found that female researchers consistently return to questions around emotion and mood while ensuring that questions are light and can be deflected (Manderson et al, 2006). An interview allows emotion, distress, anxiety and silence to be interpreted within the correct context, and permits the researcher to respond

accordingly. In particular I listened carefully when participants appeared to be re-experiencing feelings as they described an incident (such as diagnosis).

I am experienced in the use of interviews to obtain information from patients in the clinical setting; nevertheless within the research context I recognised that different skills are required. In clinical practice, the interview is generally more controlled by the clinician, responding openly to patients' questions and identified issues. Although I had experience of interviewing during a previous research study, local training on interview techniques was undertaken. Charmaz (2006) states that within interviews the researcher should listen, observe with sensitivity and encourage the individual to respond. I applied interview techniques such as summarising, silence and non-verbal prompts to check and develop understanding and allow the pursuit of emerging issues. Key to this was learning how and when to explore a point further as I became sensitive to the participants' concerns and vulnerabilities (Charmaz, 2006). I used probes such as *"I wonder if you can tell me more about it?"* or *"and how did that make you feel?"* Charmaz (2006) indicates that how you construct the questions and conduct the interview shapes how you achieve a balance between making the interview open-ended and focussing on significant statements. I also attempted to display confidence, tranquillity and credibility as these are fundamental qualities for researchers to possess (Legard et al, 2003). My academic supervisors reviewed interview transcripts and provided positive feedback on my interview technique.

#### 4.10 Field notes and memos

Holloway and Wheeler (2004) suggest researchers write field notes to document observations and thoughts in relation to interactions, interruptions, non-verbal communication and feelings during the interview. Examples of field notes are provided in Appendix 14.

Memos work alongside other sources of data such as transcripts and fieldnotes to provide supportive documentation for a study (Birks and Mills, 2011). While

transcripts and fieldnotes can be incorporated into memos (for example memos can include quotes), memoing directly within the transcript may blur the distinction between a participant's comments and a researcher's conceptualization (Glaser, 1978). Glaser (1978) encourages researchers to consider memo writing as a priority to ensure the retention of ideas that may otherwise be lost. Memos are the written version of an internal dialogue which occurs during research as ideas, concepts and theoretical perspectives emerge (Strauss, 1987). Memo writing is an analytical strategy which guides the researcher to base abstract ideas in the reality of the data (Corbin and Strauss, 2008; Holloway and Wheeler, 2002). Memoing is therefore a reflective activity which gets the researcher writing from the beginning of the research study and these actions serve as an investment in the future course of the work (Charmaz, 2011).

Memos are written records of analysis, separate from transcripts, which the researcher compiles at the beginning of the analytic process and continues throughout data collection and analysis (Corbin & Strauss 2008). I used memos to record my thoughts and ideas as they emerged during analysis of the data and as I developed the properties and dimensions of categories (Appendix 15). Theoretical questions also emerged and these questions were recorded for exploration in subsequent interviews. Memos were kept throughout the study and while initially they were simple, they became increasingly theoretical as the study progressed, with the development and refinement of ideas (Appendix 16). Memos and field notes increase transparency and support the research process (Corbin and Strauss, 2008).

#### 4.11 Data analysis

Interviews were digitally recorded and transcribed by an NHS secretary *verbatim* removing any identifying information and using participant identification numbers to maintain anonymity. The secretary was bound by confidentiality. I then listened to each recording multiple times to verify accuracy of transcription and start the data analysis process. This process took about five hours per interview. Data was secured and stored following research and ethics guidance on an NHS computer

which had encryption software and was password protected. Software packages primarily support the organisation and management of data which contributes to analysis. Dey (1993, p227) suggests that “*computers can help us confront data more effectively, by making it easy to analyse data in different ways.*” However, Charmaz (2006) argues that where researchers are closely involved with the participants and need sensitivity, computer analysis may have a distancing effect. Computer aided analysis packages can over-emphasise a concern with parts and this can obscure an understanding of the text as a whole (Holloway and Todres, 2006). Furthermore, Corbin and Strauss (2008) caution that researchers can be so concerned about learning and using the software programme that the research becomes secondary or lost somewhere in the process. Even the most sophisticated software programmes for qualitative analysis only do what their users tell them. Analysis is about thinking and thinking is the one thing that a computer is unable to do (Corbin and Strauss, 2008). I therefore did not feel that it was essential to use a programme but acknowledged the importance of storing, retrieving, organising and reorganising data while ensuring the process was transparent to others.

Strauss and Corbin (1998, p35) define theoretical sensitivity as “*the ability to respond to the subtle nuances of, and clues to, meanings in the data.*” Researchers develop theoretical sensitivity through reading and with personal and professional experience (Corbin and Strauss, 2008; Glaser, 1992; Glaser, 1978; Glaser and Strauss, 1967). Strauss and Corbin (1998) believe that theoretical sensitivity increases as the researcher interacts with the data because they think about emerging ideas, ask further questions and see these ideas as provisional until they have been examined and confirmed by the data. When performing analysis, it allows significant data to be differentiated from less important data. However, the researcher must be careful not to rely on prior assumptions or research developed by others (Corbin and Strauss, 2008; Charmaz, 2006; Holloway and Todres, 2006). As a researcher, I developed sensitivity as the research study and analysis progressed and I became immersed in the data and accessed relevant research literature. Analysis of interviews was very time consuming initially however the time required reduced as I developed theoretical sensitivity. One of the most challenging aspects of the research process was developing confidence in my research skills.

Analysis is an intuitive process and the researcher must trust themselves to make the right decision (Corbin and Strauss, 2008).

Analysis involves taking raw data and raising it to a conceptual level (Corbin and Strauss, 2008). Miles and Huberman (1994, p56) describe coding and its relationship to analysis in the following way: *“to review a set of fieldnotes, transcribed and synthesized and to dissect them meaningfully while keeping the relations between the parts intact is the stuff of analysis. This part of analysis involves how you differentiate and combine the data you have retrieved and the reflections you make about this information.”* Analytic tools can help promote interaction between the analyst and the data and assist the analyst to understand possible meaning. These tools can be used to probe the data, stimulate conceptual thinking, increase sensitivity, provoke alternative interpretations of data, and generate the free flow of ideas (Corbin and Strauss, 2008). The thoughtful use of analytic tools can also promote awareness of bias and assumptions which may influence the direction of analysis.

Analytic tools should be used with discretion and matched to the analytic issues that arise during coding (Corbin and Strauss, 2008). Corbin and Strauss (2008) describe 13 analytic tools and within my study I used eight of these: the use of questioning; making comparisons; thinking about the various meanings of a word; using the flip-flop technique (look at the opposite or extreme range of a concept to bring out its significant properties); looking at language; thinking in terms of metaphors and similes; looking for negative cases (case that does not fit the pattern) and *“so what”* and *“what if.”* Corbin and Strauss (2008) state that the actual procedures used for analysing data are not as important as the task of identifying the essence or meaning of the data and that the greatest tools are the researcher’s mind and intuition.

Initially, I read and re-read each transcript before starting to code the data. Coding began after the first interview was completed and between each interview because analysis served as the foundation for further data collection and analysis. Corbin suggests that natural breaks in the transcript are used as cutting off points for analysis as this generally denotes a change in topic and then each section is



examined in depth (Corbin and Strauss, 2008). Open-coding requires a brain storming approach, to ensure that the analyst opens up the data to all potentials and possibilities contained within it (Corbin and Strauss, 2008). Coding is the process by which the researcher identifies and attaches initial labels to the data (Urquhart, 2012; Corbin and Strauss, 2008; Charmaz, 2006; Holloway and Wheeler, 2004). Coding does not simply involve taking a phrase from the raw data but instead requires searching for the right word or two which best describe conceptually what the researcher believes is indicated by the data (Corbin and Strauss, 2008). For example:

Table 4: Open coding

Excerpt from Interview Transcript – P6	Open Coding
<p><i>I had a pain in my throat you see. I had been <u>bothered with sore throats all my life</u> which is probably why the cancer got to that stage <u>before I went and did anything</u> about it because I was getting a sore throat and I was <u>assuming it was the old problems</u> so I would say I would go to the Doctor but within a couple of days it would go away so <u>I didnae (did not) bother myself. I think that went on for certainly a year maybe more.</u> I was just assuming it was the old problem that was clearing up and <u>then I got one that wouldnae go away</u> and I went to my Doctor and she assumed the same looking at my history. She just assumed it was the same and put me onto antibiotics and when it didnae shift it, she sent me up here.</i></p>	<p>Interpreting symptoms.            Feeling responsible.            Prior health knowledge.            Delaying presentation.            Interpreting changes as different from usual.            Healthcare professional reinforcing interpretation.            Being referred to specialist.</p>

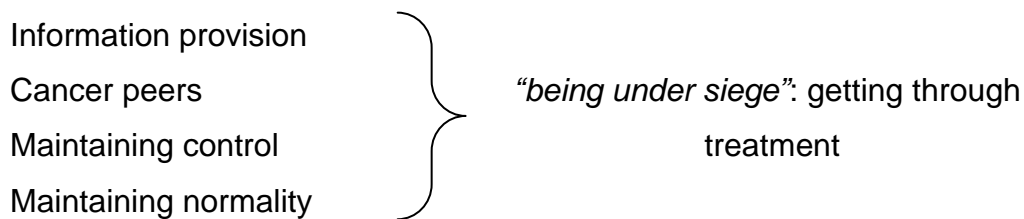
Specific phrases which were vivid and descriptive and used by the participants were considered and given a code, known as in-vivo coding:

P4: *You're under siege as far as the treatment is concerned.* “Being under siege”:  
[getting through treatment.](#)

This first stage of data analysis produced a large amount of open codes. Corbin and Strauss (2008) suggest that detailed work like this in the beginning leads to rich and dense description in addition to well-developed theory. In the second edition of Strauss and Corbin's basics of qualitative research book, axial coding was presented as though it occurred separately from open coding (Strauss and Corbin, 1998). The distinction between open and axial coding is really for explanatory purposes only, with both types of coding occurring simultaneously during analysis.

Axial coding puts the data back together in new ways by making connections between a category and its subcategories as exemplified in diagram 1 (Corbin and Strauss, 2008).

Diagram 1: Sub-categories and category



Through constant comparison, I made tentative decisions about coding which underwent further revision. Properties, dimensions and processes were analysed using the following definitions:

- Properties: characteristics that define and describe concepts
- Dimensions: variations within properties that give specificity and range to concepts
- Process: the flow of action/interaction/emotion that occurs in response to events, actions or problems

(Corbin and Strauss, 2008, p159, p158, p87)

Each time a category arose, it was compared with other times that category arose in terms of both similarities and differences. The published literature was also reviewed to determine any links to existing theory.

Selective coding is the final stage of data analysis, which involves integrating and refining the categories and identifying the core category which will have explanatory power (Corbin and Strauss, 2008). Glaser (1978) and Strauss (1987) identify the characteristics for the core category as a central phenomenon in the research which is linked to all other categories establishing a pattern. The core category occurs frequently, explains variations in the data and emerges naturally towards the end of the analysis process. The core category is considered to be the social-psychological process involved in research that occurs over time and explains changes in the participants' behaviour, feelings and thoughts. Theory development is a complex activity which denotes a set of well-developed categories that are systematically interrelated through statements on relationship to form a theoretical framework that explains some phenomenon (Hage, 1972). Theories may be substantive, middle range or formal (Corbin and Strauss, 2008). As my study was specific to a group and derived from one substantive area, a substantive theory was developed. The cohesiveness of the theory occurs through the use of an overarching explanatory concept which when taken with other concepts, explain the what, how, when, where, and why of something (Corbin and Strauss, 2008).

#### 4.12 Quality

Quality in qualitative research is something that we recognise when we see it; however explaining what it is or how to achieve it is much more difficult (Seale, 2002). There has been considerable debate over whether qualitative and quantitative methods can and should be assessed according to the same quality criteria (Mays and Pope, 2000). There are broadly two opposing positions taken:

1. Qualitative research is a distinctive paradigm which cannot be judged by conventional measures of validity, generalisability and reliability. This position rejects the belief that there is a single, unequivocal social reality which is independent of the researcher and the research process; instead there are believed to be multiple perspectives of the world that are created and constructed in the research process (Lincoln and Guba, 1985).

2. Others suggest that it is possible to assess different perspectives offered by different research processes against each other and against criteria of quality common to both qualitative and quantitative research, particularly those of validity and relevance. Assessment of validity may be modified to take account of distinctive goals of qualitative research (Mays and Pope, 2000).

I engaged with a number of techniques to ensure validity and relevance including respondent validation or “*member checking*”. During interviews, summarising and paraphrasing was used extensively to ensure I had interpreted the participant’s experience correctly. Participants within this study were sent a summary of findings. While it is acknowledged that findings do not directly represent the individual’s experience, the essence of the experience is usually similar and individuals inhabit a social world with others and recognise others’ reality to some extent (Holloway, 2001). I received positive feedback and validation from multiple sources including two CNS, a HNC patient involved in study development and a study participant (Participant five):

*P5: Your report in many respects is very incisive and as I read and re-read it I found myself reaching for my pen to circle a remark here and a comment there and generally mentally applauding how precise your report was!.....I think you have put down on paper, what I’m sure a lot of men including myself, can and do find difficult to put into words, especially to our nearest and dearest.* (Appendix 22)

Further techniques to improve validity include a clear explanation of methods of data collection and analysis, attention to negative cases and reflexivity (Mays and Pope, 2000). Throughout this chapter, decision-making within this study has been presented including: development of the research questions; methodology; sampling; data collection; analytic tools; and analysis including open, axial and selective coding and development of the core category. Searching for negative cases was performed which involved exploring alternative explanations for the data collected and elements which seem to contradict the emerging explanation of the phenomenon under study (Mays and Pope, 2000).

Reflexivity is the continual process of critical self-reflection on research experience, decisions, interpretations, biases and theoretical predispositions during data collection, analysis, interpretation and writing up (Charmaz, 2006; Gerrish and Lacey 2006; Holloway & Wheeler 2004). While there is agreement that reflexivity is important during data collection and analysis, Cutliffe (2003) questions how reflexivity can be applied when what transpires frequently occurs within the deeper levels of consciousness. Finlay (2002, p532) states that reflexivity is a valuable tool to:

- examine the impact of the position, perspective and presence of the researcher
- promote rich insight through examining personal responses and interpersonal dynamics empower others by opening up a more radical consciousness
- evaluate the research process, methods and outcomes
- enable public scrutiny of the integrity of the research through offering a methodological log of research decisions

Researchers experience emotion and these emotions can be conveyed to participants during data collection, influencing participant's responses (Corbin and Strauss, 2008). I was particularly aware of my feelings when participants who had a laryngectomy discussed feeling responsible for their own healthcare as general healthcare professionals lacked knowledge. Reflexivity is evident in previous sections where decisions around data collection and methodological approach were examined. Additionally, I made a conscious effort to ensure that my interpretations were grounded in the data and not my clinical experience. If a self-critical stance to research and the researcher role, relationship and assumptions is assumed, the study will become more credible (Seale, 2000).

The substantive theory generated must emerge directly from the field of study, be readily understandable and applicable in terms of relevance (Glaser and Strauss, 1967). As highlighted above, the theory generated is readily understandable by healthcare professionals and people with experience of HNC. The theory adds to existing knowledge and this is discussed in detail in Chapter six.

#### 4.13 Data storage

Participant data was managed in accordance with the Data Protection Act (1998). Participants were given a unique identifier number and interview transcripts were anonymised. All hard copies of data (including patient information and consent forms) were kept in a locked filing cabinet in NHS Ayrshire and Arran premises during the research period. Interview recordings, transcriptions, data analysis, field notes and memos were anonymised and stored on a password protected file on the University of Stirling hard drive. Only the researcher and research supervisors had access to the password protected file. Following study completion, the University of Stirling will securely store all data pertaining to the study for a period of 10 years. Thereafter, all information will be safely destroyed and research governance will be ensured by the Research and Enterprise Office at the University of Stirling.

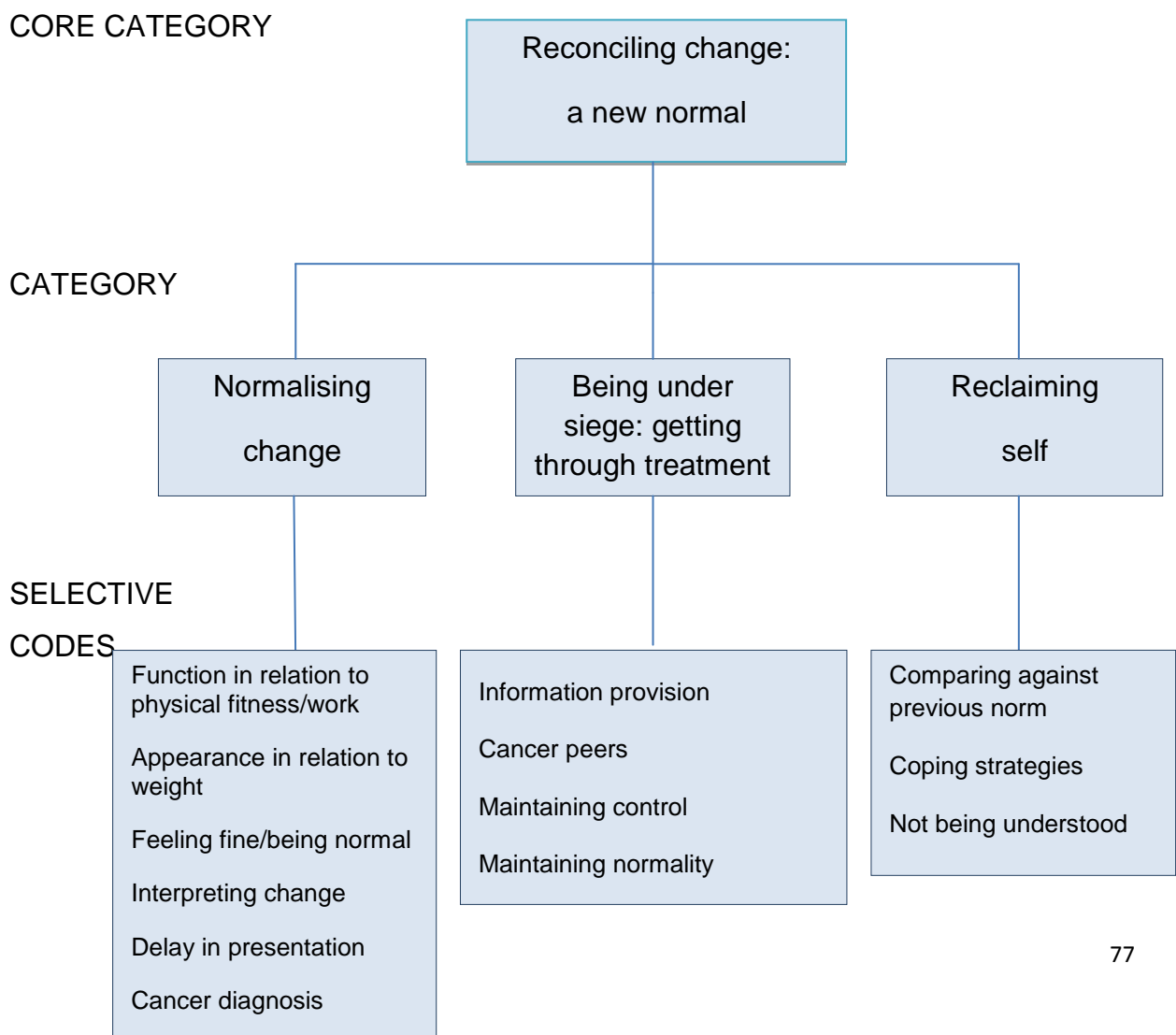
In summary, GT was considered to be the best approach for my study and the Corbin and Strauss' version of GT was utilised as it provided clear guidance on analysis. Having discussed analytic tools and processes, the study findings are detailed in Chapter five.

## Chapter five: Findings

### 5.1 Introduction

The findings of my study are presented in this chapter. Diagram two summarises the findings and analytic process from selective coding to categorisation and identification of the core category. Findings are then presented in relation to each category and participant quotations are used *verbatim* to illustrate the process of analysis and categorisation. These quotations highlight properties and dimensions of categories and reflect similarities and differences in participants' perceptions and experiences. Finally, the relationship between these categories is described and the core category is explained.

Diagram 2: Findings and coding/categorisation process



## 5.2 Normalising change

### 5.2.1 Appearance and function before diagnosis

At the start of the interview each participant was asked to consider what they thought and felt about how their body looked (appearance) and worked (function) before they were diagnosed with cancer. This means of starting the interview was done with the aim of focussing the interview and to try and gauge if there were any particular bodily attributes which were important to them before exploring the changes caused by HNC and its treatment. As discussed previously, where an individual is highly invested in a body part or function (for example muscles or fitness), this can potentially make adaptation to any changes more challenging. The majority of participants seemed to struggle to articulate what they thought or felt about their body prior to their diagnosis. It appeared as if they had taken their body for granted and gave it very little consideration as long as it allowed them to function as the following quotation illuminates:

P3 *“Em, I cannae [can’t] answer that one. Just it was fine.”*

When probed further, participants usually went on to describe their body appearance in terms of weight. While being overweight could make the participant more self-conscious, this did not seem to have a major impact on their self-esteem and self-confidence. However participants’ main focus was on function in relation to physical fitness and ability to perform activities of daily living and social roles. As shown in the following quotes, prior to diagnosis participants often maintained their physical fitness through their work or hobbies which included walking, running, football and golfing:

P8 *“Prior to me having my operation, I was absolutely fine. Because of my work, I don’t drive, so I walk everywhere. I can on average do about 50 miles a week walking.”*



P5 *“My health was perfect because I had done running all the time, half marathons and Munros [Scottish mountains] and I went to the Doctor because I was getting a sore hip.”*

Fitness and work were extremely important to participant five and this investment impacted on his experience of changes caused by HNC and its treatment. Work was mentioned by all participants who were employed at the time of diagnosis and seemed central to their self-identity which reflects research findings previously discussed. The importance of work is captured in the following quotation where participant seven talks about his work immediately when asked how he felt about his appearance and function prior to diagnosis:

P7 *“Well before it I was working 12 hour shifts 7 days a week - on 3, off 7, on 4 off.”*

R *“So was that continental shifts?”*

P7 *“Continental shifts as security. I felt good.”*

Prior to HNC, five participants had experience of cancer or chronic physical and psychological health issues. One participant described himself as *“always healthy”* and stated that his body was *“fine”* before his diagnosis. However, on further questioning it was elicited that he had previously suffered from depression and colorectal cancer. This participant's depression impacted on his physical activity and general *“vitality”* over a number of years to a variable extent and he had had a temporary stoma for many months. Two participants had musculo-skeletal conditions and it appeared as if these participants had learned to live with their limitations and incorporated coping strategies into their life to attempt to minimise the day to day impact. Such strategies included exercising, pacing and prioritising activity and taking medication. Living with chronic conditions and developing strategies to manage these conditions impacted on an individual's experience of change in appearance and function due to HNC. Additionally, a few participants described themselves as *“healthy”* even when they smoked and drank excessively at the point of diagnosis which suggests that individuals associate health with an absence of abnormal symptoms, identified disease or ill health. The participants did not associate their behaviours (smoking and harmful/hazardous drinking patterns) with the risk of cancer until they saw posters about HNC in hospital or dental waiting

areas or where behaviours were discussed during medical and nursing consultations.

Having identified participants' experiences of normal appearance and function, its influence on their interpretation of change in appearance and function is now discussed.

### *5.2.2 Interpreting change*

In general, participants initially used their own personal health knowledge and experience to self diagnose. Participants tried to “normalise” the changes in appearance and function by using everyday common ailments to explain what was happening. Individuals generally had an expectation that the body will function appropriately and take care of any issue as seen in the following quote:

*P1 “When the swelling came up on my neck I just thought it was an infection of some sort and I thought that antibiotics would clear it up and it didn’t at all. Obviously it led to more serious things. Two weeks after it appeared, it wasn’t going down and I had had these things before where the glands came up and our GP practice is not very keen on giving antibiotics for just anything and I knew that and thought ‘sit it out and wait’. In the past it had gone, the body did the work and it hadn’t moved it, hadn’t gone down. The swelling was still there and I went back to the GP.”*

Participants tried to differentiate between “normal” changes in appearance and function and changes which needed medical assessment and intervention. Generally, participants considered any bodily changes experienced to be benign, for example an ulcer, cyst or resistant infection:

*P1 continues “I just thought it is not disappearing, I have to do something about it because it is not normal. If it was normal, I would sit it out but this is not normal. I did not think cancer at all.”*

Participant one presented timeously to his GP and while he was not expecting a cancer diagnosis, this behaviour was potentially modified by his previous cancer experience. A couple of participants went to see their GP with other issues as they perceived their appearance or functional changes to be insignificant as they were not affecting their daily life. This may indicate that men are quite cautious in approaching healthcare professionals in case they are viewed as weak or time wasters and didn't want to be "a bother". In some cases family and friends tried to influence participants' interpretation of changes to appearance or function. Family and friends were seen to alert individuals to changes and legitimise the importance of the change by reassuring the person that the change is "not normal" for that individual. While this could validate the need for formal assessment by a healthcare professional, as participant four indicates, ultimately the decision to present to a doctor with symptoms lies with the individual themselves:

P4 *"I was ignorant [rude] to everybody even my wife, my son, my daughter, all my friends. They said go to the doctor and go and get it checked out and all my darts friends as well so when I said no, they know I would say that and they wouldn't mind and I told them to piss off. If I need to go, I'll go and do that myself. That was me being stupid which I realise now."*

Participant five went to see his GP about his hip pain and during the consultation the GP noticed his neck swelling (change of appearance) and treated it as a priority. This prioritisation of issues highlights the difference between lay interpretation and professional assessment of bodily change. While function appears to be prioritised by men, both appearance and function are assessed routinely during consultations with healthcare professionals as seen in the following quotation:

P5 *"I went to the doctor because I was getting a sore hip. My hip was bothering me running on the road. It was no bad on the soft ground but on the road so I actually went to the doctor and it was Dr X and I was sitting talking to him about my hip and he kept looking at me and it was the way he was looking at me and he said 'have you got some swelling on you?' I said I think it must be my glands and he came round and actually had a feel at my neck. 'I think we should be having a little look at*

*this before we can do anything with your hip. It could just be swollen glands but it is more important at this time just to get this checked out'."*

Interpreting appearance or functional changes as "normal" or "minor" had serious implications for most participants as it resulted in delays in presentation:

P6 *"I had a pain in my throat you see. I had been bothered with sore throats all my life which is probably why the cancer got to the stage before I went and did something about it because I was getting a sore throat and assuming it was the old problems so I would say I would go to the Doctor but within a couple of days it would go away so I didn't bother myself, I think that went on for maybe a year or more."*

In the case above, the GP reinforced this participant's diagnosis of a sore throat by initially treating him for his "usual problem" before referring him for further investigation when his pain and swallowing difficulties did not resolve. Additionally, when changes in appearance and function occur slowly, this can influence interpretation:

P7 *"I can't remember how it came on. It wasn't suddenly obviously, it was over the course of a few months it suddenly appeared and I thought, well first of all, I looked at it and thought it could be a bit odd so I thought it would give it a few months just to see if it would go away or what and after it had been there a good six months or something I went to the GP just to get him to have a look, not expecting anything, in my head not expecting anything too serious but I thought I would get it checked out none the less."*

While participant seven acknowledged the need to have the lump in his mouth reviewed by a healthcare professional, it actually took him six months to do this even though he had a colleague who had just completed treatment for head and neck cancer. This participant was young and considered himself to be fit and healthy and therefore he did not contemplate that this may be something which required urgent review. A lack of understanding of symptoms associated with HNC can lead to delays in presentation which may explain why HNC is often diagnosed at more

advanced stages. However even when symptoms became severe and impacted on the ability to function, the fear of diagnosis could also lead to delays in presentation as discussed by participant four:

P4 *“I thought I was dead. I thought I was dying. That’s why I didn’t want to go to the doctors.”*

Having considered interpreting change in appearance and function, the impact of a cancer diagnosis on change in appearance and functional change is now discussed.

### 5.2.3 Cancer diagnosis

Delay in diagnosis can result in greater changes to appearance and function as more radical treatment or multi-modality treatment is required. While cancer is a common illness with one in three people experiencing cancer within their lifetime, often people do not expect personally to receive a cancer diagnosis:

P7 *“Everyone thinks it’s never going to happen to you. Being young and fit and considering myself fit and healthy, I never had any reason to expect anything so I thought I would give it a few months before I went to the doctor.”*

Receiving a cancer diagnosis was a reality that patients had to try and make sense of. Perhaps interpreting the situation as unreal allows them to distance themselves from the diagnosis until they can process the information within the context of their life. Participants within this study stated that they were “*fine*” or “*normal*” and therefore it is not surprising that they found it difficult to understand or process the diagnosis in a meaningful way as indicated in the following quote:

P8 *“Me that they are talking about. It’s me that they are talking about not the guy sitting beside me you know. It’s actually me. You know, you just don’t grasp it.”*

A diagnosis of cancer immediately raised issues of a changed and uncertain future in a way which appears to be different from other chronic conditions or life-threatening

illnesses. Cancer continues to be associated with death and a death sentence despite significant improvement in survival over the last few decades. As participant two suggests, using a physical metaphor of emptiness, being diagnosed with cancer challenges your whole way of being:

P2 *“He says I’ll no know nothing until I get you into hospital and take the biopsies and when I left I was saying to myself I don’t know. It’s a feeling that is like an empty feeling.”*

R *“An empty feeling?”*

P2 *“An empty, empty feeling. Everything is just no [not] there anymore. So I thought that was it basically you know.”*

Overall, participants did not expect a cancer diagnosis and initially struggled with the uncertainty which ensued. The cancer diagnosis impacted on the interpretation of treatment and associated appearance and functional change and this will now be discussed.

### 5.3 *“Being under siege”*: getting through treatment

Participants felt that treatment was essential and spoke of the *“trade-off”* between surviving cancer and coping with any associated changes. Using death (perceived or actual threat) as a benchmark, the impact of treatment and associated changes to appearance and function were rationalised. *“Getting on with it”* appeared to be the preferred method of coping with the prospect of life-saving treatment and potential changes to appearance and function. Getting on with treatment was particularly important where participants acknowledged that they had advanced disease as participant three alludes to in the next quote:

P3 *“I know I was very lucky from when I was first diagnosed it was serious, very serious and everything happens that quick. You don’t get a lot of time to sit and worry about it sort of thing.”*

Information provision was central to getting through treatment however there were challenges identified.

### 5.3.1 Information provision

While changes to appearance and function are discussed during treatment planning to allow decision making and informed consent, it can all seem meaningless at that point as discussed below:

P2 *“He explained it would be from here round here [pointing to his neck from ear to ear] and half my jaw too but it doesnae [doesn’t] mean anything to you.”*

R *“Does it not?”*

P2 *“No. It just means a way to get rid of the cancer so your appearance doesnae [doesn’t] really come into it.”*

Participants wanted to get their treatment started as quickly as possible and the side-effects of treatment and long-term consequences were not considered to be a priority at that point. Information (for example describing incisions to be used, structures being removed and expected scarring) was crucial in trying to prepare them for the change to appearance and function. A combination of verbal and written information was provided primarily by healthcare professionals. As highlighted earlier, participants may not be able to absorb information at the time when it is discussed or it may not seem relevant to them when they feel *“fine”*:

P8 *“He did yes [Consultant talked about surgery and changes], and in fairness it just kind of went cheeeeww [as if it had gone over his head] and X [his Macmillan Cancer Nurse Specialist] said I’m going to come out and see you next week. I’ll come out and have a chat with you so I had time to think about it and obviously go over any questions which we did. She gave me a very good booklet about the operation, not that specific operation but that generalised area and the various things that they will do such as having maybe to cut down the chin or take out lymph nodes and all the various aspects of it and that was really excellent because I had time to sit down and go through that.”*

CNS were integral to the process of support and information provision at diagnosis as well as during and after treatment. While information about appearance and functional change was considered to be helpful by participants, limitations were noted particularly when extreme or unusual side-effects were experienced:

P5 *"I never considered, you read the little red booklet and there are another couple of booklets you can read all that, it doesn't really prepare you for what happens. It was unbelievable." P5 continues "The treatment finished on the eleventh of December and on the twenty-sixth, boxing day, I remember getting down the stair and the District Nurse coming in. I can't remember anything more until I remember being carried out through the snow to the ambulance in the afternoon and going to X [hospital] and that is when the system totally packed in. Nappy on, you name it. Everything was on because I had no control of my bodily function whatsoever."*

Participant 1 goes on to use the metaphor *"laid out"* which suggests he felt as if he was dying or preparing for death:

P1 *"[I was] totally unwell. Lying out and thinking this is the end. I can remember Pat coming in to visit and the neighbour up the road, and I could not communicate with them at all. I was laid out, eyes closed. I don't even know if I was listening to what they were saying. I just let them talk by themselves."*

Functional changes such as these were particularly challenging as the participants felt both a lack of control over their bodily functions and as if they were not present or connected to normal life. While healthcare professionals use their professional judgement based on research and clinical knowledge, they are unable to interpret the extent to which each individual will experience appearance and functional change. Additionally, healthcare professionals are unable to predict how each individual will cope with change experienced or the impact the change will have on the individual's quality of life. It is apparent from my analysis that there remains a dissonance for participants between knowing how things may change through information provision and experiencing change with associated experiential learning. In a similar way to not expecting a cancer diagnosis, it is suggested that participants



often consider that they will not be the one to experience changes to appearance and function which are severe and difficult to manage or control. Information provided by fellow HNC cancer patients and other cancer patients was found to be particularly helpful.

### 5.3.2 Cancer peers

Information provided by cancer peers was viewed as more relevant than that provided by healthcare professionals as identified by participant one:

P1: *“The health care professional gives you the information on a clinical basis but it is not the same as talking to somebody who has actually been through it. You can expect there will be bad days and expect that your head won’t get off the pillow but you will get through it. It is a short term thing and short term means months but in terms of your life it is short term.”*

While participants who were having their voice box removed had a meeting organised with a previous patient before major surgery, for the majority contact with other cancer patients was unplanned and occurred during hospital stays or treatment appointments:

P11 *“The voice therapist arranged for me to meet a person who had had a laryngectomy and so I felt there was ‘nothing to this’ but I wasn’t expecting what happened [head drooping]. The meeting was brilliant as he told me how he managed to speak and eat and I felt a lot more confident and relaxed about the surgery.”*

Other cancer patients could therefore act as role models and provide participants with knowledge and information about how to cope both practically and cognitively:

P9 *“Because X is so pragmatic he didn’t get too emotional about things. It wasn’t even having a deep and meaningful conversation with him. It was just seeing him coming into work and acting as normal.”*

There was a sense of camaraderie and shared understanding and this seemed to provide participants with a support network and a sense of belonging during a period when they felt detached from their usual life. However, participants spoke about the importance of being able to differentiate their situation from that of others, particularly where the other cancer patients had or went on to have recurrence. There was also an acknowledgement that information provided from other patients may not always be correct. Many participants went on to provide information to other individuals with cancer but this information could be censored to protect the individual. Furthermore, fellow patients were used as an indicator of what change may be experienced as well as how things can change over time:

P10 *“Obviously I didn’t just sit and stare, but then I thought well look at him you wouldn’t realise he had it [surgery with scarring] and that was last October and he told me he had his operation the previous year in February. So that would be a year and a half before and you couldn’t notice it.”*

Having considered the impact of information provision by healthcare professionals and cancer peers in preparing for and managing appearance and functional change, maintaining control is now discussed.

### *5.3.3 Maintaining control*

For patients who underwent major surgery, having a tracheostomy or laryngectomy, requiring suction during the immediate post-operative period or being unable to speak could be particularly distressing. Initially these changes could be shocking as they challenge an individual’s ability to function and maintain control of basic activities of daily living. Being unable to speak made participants particularly vulnerable as seen in the following quotation:

P2 *“You feel like you’re just living in a body and you have no control over it, you cannae [can’t] do nothing about it. You can make signs but it’s still like, you’re not in control, put it that way.”*

P2 continues *“You take all of it for granted, the expressions or look, the way they talk and then all of a sudden that happens [HNC and its treatment].”*

Participant two highlights both the interconnectedness of appearance and function and the way people take these aspects for granted. Having to rely on others for help in meeting basic needs related to breathing, swallowing and communication was frightening. Relying on others and not being in control seemed to challenge the participants to their core. Although some of these changes are very short-lived (less than seven days) they had a profound impact on the individual during this time and when reflecting on the change. Participants had to learn to speak and swallow again. These functions are usually performed without either thought or effort. It is the change from *“normal”* function which is distressing. As participant two indicates, he could no longer rely on his body or be certain of either function or control. While making progress in the post-operative period is desired, the experience can be daunting:

P7 *“I always mind [remember] the nurse coming up and saying I’ll give you a wee drink of water, I was like a child with a new toy. I was excited you know. At the same time I was scared as well because you hadnae [hadn’t] done it, swallowed or drank for about a fortnight or three weeks.”*

Participants felt that it was important for them to engage with healthcare professionals and do as much as they could to help themselves as a way of maintaining their self-esteem and control over the recovery process and their life:

P8 *“The way I am when I came round after the operation, a physio came round, a very nice girl and she left me a wee sheet of exercises and I did those religiously for three months prior to me getting back to work and back into the swing of it. And likewise the speech therapist, she also left me a sheet of exercises. I am a great believer, they are not giving you these for the fun of it - the idea is to help you on the road to recovery.”*

All participants used information and advice which was provided to maintain control and support self-management and recovery. The importance of a multi-disciplinary

team approach was evident with participants following advice and guidance from Consultants, CNS, Speech and Language therapists and Dietitians. Having considered the importance of maintaining control, maintaining normality is now discussed.

#### *5.3.4 Maintaining normality*

In addition to functional change in essential activities of living, changes to appearance are thought to be an important consideration for patients undergoing HNC treatment (Millsopp et al, 2006). However, within my study scarring caused by surgery did not appear to cause distress to the men. Scarring was discussed as part of pre-operative preparation and as participant one highlights he had the opportunity to discuss his hopes and expectations of scarring at this stage. Involvement in this process allowed his concerns to be highlighted and realistic expectations to be set:

*P1 "Much better than that. I showed it to her [he showed the Consultant a previous scar from bowel surgery which the participant felt was unacceptable] and said that I hope it doesn't look like that. She said don't worry about it. You will not look like that at all and I was quite surprised when I woke up from the anaesthetic and there were no stitches, no clips and I asked her about it and she said it had been glued back together. I thought okay and it was fantastic and she said that she would do the cut, where I will try to go into the folds of the skin and make it look as unobtrusive as possible. I would say 99 people out of 100 will never notice it."*

Participant one's quotation reflects how participants view the role of surgery where the broken or damaged part of their body is removed and the surgeon puts them back together again. The majority of participants who underwent surgery felt that the surgical scar lines were minimised due to strategic placement by the surgeon. While participants were aware they had had surgery, they generally felt that other people would probably not even realise this and therefore could maintain their sense of "normality" and normalise change.

Participant 12 had reconstructive surgery which involved insertion of a radial free flap (piece of tissue from the forearm with its own blood supply) into his cheek. This resulted in a patch of tissue which was paler in colour than the rest of his cheek. While this participant felt such a change in appearance was noticeable to others he felt it had little impact on him personally. Participant 12 distances himself from the mere consideration of make-up application, even from the purpose of camouflaging change, due to its association with femininity. He goes on to engage his wife in this part of the interview and she suggests that he did not consider camouflage make-up because he is not “*vain*”. The term vanity relates to “*the excessive belief in one’s own abilities or attractiveness to others*” (Oxford dictionary, 2010) and has negative connotations. It is therefore suggested that society and hegemonic masculinity dictate that men should not be invested in their appearance. In the following quotation, participant 12’s wife reinforces his masculinity and supports him in the maintenance of hegemonic masculinity:

P12 *“Mr X actually asked me that last time I was in if I wanted to go and see a make-up girl. That’s what I said to her [his wife] – can you imagine me putting on make-up before I go to my work.”*

P12 wife *“I think it is possibly that he is not vain.”*

P12 *“The thing is I don’t see it. I only see it when I am shaving, so it doesn’t bother me.”*

The quotation by participant 12’s wife would suggest that consideration should be given to how healthcare professionals describe camouflage services; however, this may not alter an individual’s perception of it. Men within this study indicated that they did not spend a lot of time focussing on their appearance either before or after surgery. Participant 12 briefly touches on the fact that he only sees the change to his appearance when he shaves as if out of sight means out of mind. In contrast, as seen in the following quotation, participant two acknowledged the changes that had occurred following surgery and actively chose not to look at his scarring. At this point, during initial stages following surgery, he may have been using denial or avoidance as his preferred method of coping to maintain normality. Participant two states that he knew it was there and that he knew what it was, again suggesting that a cancer diagnosis influences perception of appearance and functional change. Of

particular interest is the fact that participant two simply tells us that he wore a scarf and avoids the risk of emotional disclosure. At the end of the interview participant two shared that he had never spoken to anyone about his cancer before so he had possibly not considered his feelings. This participant used this form of camouflaging change until he felt he had to go out without the scarf as he began to process and accommodate the appearance change:

P2 *"I never looked a great deal at my face at the time [after surgery] because I knew it was there."*

R *"You never looked at it?"*

P2 *"Aye no at the time. I knew it was there and I knew what it was and all that."*

R *"And did the scarring or anything bother you at all or did you just accept it and get on with things?"*

P2 *"I wore a scarf occasionally and then I just said to myself 'no, no'."*

The process of accommodation is considered further in section 5.6. Camouflage was occasionally used for short periods with only one participant continuing to camouflage his laryngeal stoma due to embarrassment:

P4 *"I always cover this up [laryngeal stoma]."*

R *"So you keep it hidden?"*

P4 *"I keep it hidden."*

R *"Right."*

P4 *"My wife says why do you not show it to other people, she sees other people with it and they don't bother. I do."*

All the men who experienced hair loss described using a hat as a protective measure to prevent heat loss or sun exposure. The following quotations indicate these men wanted to make it clear that they were using the hat for functional reasons and not because of the change to their appearance:

P3 *“I did wear a hat when I was out and about. That wasnae [wasn't] vanity, it was sensibility because I had nothing to protect my head so I wore my hat then. Other than that it didnae [didn't] bother me.”*

P3 *“It went very quickly about the second week after my first big dose of chemotherapy. I was in for a whole week getting it 24 hours a day for five days and was about the second week after it before I went back for the next dose. Maybe it was after it, when I was in the Oncology Unit and a friend from the voluntary organisation came in one day and as I say it didnae [didn't] come out very neatly. It just went wherever it wanted to and she took me in one day and gave me a trim to tidy up and I never lost any more after that and it did start growing back very quickly so that didn't bother me either.”*

However, it should be noted that participant one goes on to describe his beanie hat [soft hat] as his hair suggesting that it provides both aesthetic and functional benefit. Again this suggests that men within this study do not seem to want to be associated with concerns about appearance or attractiveness as this is seen as a feminine trait:

P1 *“I knew the hair was going to come out and in fact so much so that I went to my barber and said, I am going in, I would much rather it came off now. Just get rid of it. I don't want it coming out in clumps and patches all over the place. The only thing that I found was that after he had done it, I had a very cold head so I just decided that I am going to wear a beanie [soft hat] all the time now and that will be my hair and that is how it worked in hospital and all the way through until the hair starts to grow back.”*

Participants attempted to minimise the effect of hair loss by taking control and cutting their hair prior to chemotherapy starting or while receiving treatment. Taking control of hair loss through deciding when to cut hair and how to cut it (for example to cut it shorter or to completely shave it) is commonly seen in both male and female patients who are undergoing chemotherapy. Services have developed both in healthcare and the voluntary sector to help individuals with cancer cope with different aspects of appearance and functional change both during and after treatment. Often these services are offered as part of routine care in a timely manner as seen in the previous quotation. Cutting hair prior to hair loss allowed participants to acclimatise

to the changes and potentially avoid the distress of having their hair come out in clumps. No participant who experienced hair loss within this study accessed wig services and the rationale for this decision was not elicited. It can, however, be speculated that male baldness is common and therefore considered to be acceptable. Alternatively it may be considered that male wigs are seen as a source of ridicule within society or that wig use is associated with femininity.

Participants appear to actively choose to focus on the practical implications of hair loss such as sun protection even though baldness can act as a daily reminder of disease and/or treatment. Only one participant stated that he thought he *“looked a mess”* due to hair loss. This would suggest that men may find it difficult to articulate thoughts and feelings about aspects such as appearance change and this difficulty is considered further within the discussion chapter. This participant also highlighted the importance of positive change in appearance as his hair began the process of regrowth which he interpreted as a visual sign of renewed body vitality. In the context of a cancer diagnosis, appearance is viewed both in relation to the effect of treatment on the cancer and recovery. This assessment of appearance is therefore different from the way in which a person usually views appearance in terms of attractiveness.

Participants initially thought that they could cope with the changes brought about by treatment and then had the dawning realisation over time that the combination of changes experienced were impossible for them to manage independently. Most participants who underwent radiotherapy or concurrent chemo-radiotherapy needed a nasogastric feeding tube. The need for this intervention reflects the impact of advanced disease and treatment due to ulceration, pain, secretions, taste changes, difficulty swallowing and fatigue. Participants had generally experienced extensive weight loss prior to receiving enteral nutrition and could feel hopeless at this point as they struggled to find the *“right things to eat”* and gradually realized that there *“wasn’t anything right to eat”*. When participants underwent hair loss or nasogastric tube insertion, their main social exposure was within safe environments such as the hospital or with family and friends. The hospital was interpreted as a safe environment as the participants’ main contact was with healthcare professionals and other individuals who are also experiencing changes to appearance and function. Speaking with and comparing themselves to other individuals with HNC or other



cancers was important. As discussed earlier, other cancer patients could act as mentors for new cancer patients, sharing important information and tips for self-care with them. Seeing other patients who were struggling with treatment and its side-effects also acted as a benchmark which patients often measured themselves against favourably as indicated below:

P2 *“I was in hospital, that’s all you’ve got basically, time to think. You dither about [waste time] and there are a lot mair [more] people worse off than yourself and it’s sad in a way seeing them dying.”*

Appearance for cancer patients can also therefore be used as an indicator of physical condition and health. Comparing yourself to someone worse off (downward comparison) helped to maintain the individual’s sense of coping as they consider themselves to be fortunate in experiencing less severe changes.

Of interest, when participant’s physical condition changed and they became the person with the nasogastric feeding tube or requiring support with general activities they appeared to accept this through a process of cognitive reappraisal. Cognitive reappraisal involved the participant focussing on the need for treatment and the benefit of both the treatment and any intervention which was necessary to allow them to complete treatment. For example, nasogastric feeding tubes were rationalised by participants as being necessary to allow them to function within their daily life, minimise side-effects of treatment and promote healing and recovery. Participant one states that he wasn’t *“too fussed”* at being unable to walk down to get his radiotherapy although there is a sense that he had no choice as *“he has to go with the flow”* and just get on with it. This participant seemed to have almost surrendered to the treatment. Indeed, he went on to describe how he was *“under siege as far as the treatment is concerned”* which conveys the extent to which his body was under attack and his being held until surrender or escape. This concept was shared by a number of participants:

P1 *“I remember as well, after I had had the last dose of chemotherapy, I was still on radiotherapy and instead of making my own way down to the radiotherapy suite, I*

*had to be wheeled. I didn't have the energy to walk even down the corridor or the ward."*

R *"How did that make you feel?"*

P1 *"I wasn't too fussed about it in a lot of ways. I felt okay. I know what is going on here. I know this stuff is toxic and that it is affecting my system. I have got to go with the flow. I have got to finish the radiotherapy. I can't not do it and it is the combination of the radiotherapy and the chemotherapy that is going to attack the cancer cells. I am just going to have to put up with it."*

For participant one, changes caused by the treatment were intrusive in that it affected every aspect of his daily life and he just managed minute by minute, hour by hour and day by day. A key component of *"getting on with it"* (treatment and changes to appearance and function) involves participants trying to limit intrusion into daily life by both maintaining control, maintaining normality, managing change independently and following advice from healthcare professionals.

*"Being under siege"* conceptualises the onslaught of side-effects and changes to appearance and function which were frequently intrusive to participants' lives. Having gone through treatment, participants then focussed on reclaiming important aspects of their former lives.

## Section 5.5 Reclaiming self

During treatment participants' main focus was on getting through treatment and surviving cancer. Most participants were aware that recovery could be prolonged as indicated by participant four:

P4 *"That didn't bother me [thought of having surgery to remove voice box]. They said it will take a while for you to get over it and come round. It is no just it will take like several months, maybe a year, maybe more than a year."*

Being provided with information about timelines for expected recovery was helpful in allowing participants to try and set realistic goals. Participants often experienced a cluster of treatment side-effects which included changes to saliva, taste, swallowing and speech. These side-effects resulted in weight and muscle loss which caused distress following treatment as they began to compare themselves against their previous norm.

### *5.5.1 Comparing against previous norm*

Participants who had been through concurrent chemo-radiotherapy treatment in particular spoke of looking like someone from a concentration camp. The term concentration camp refers to a camp in which people are detained under harsh conditions, usually during times of war or conflict. Comparing themselves to someone who had been in a concentration camp suggests that participants felt their weight loss was inflicted by a force beyond their control and was life-threatening. Often participants did not recognise themselves when they looked in the mirror at this point as their appearance was so different from normal:

*P11 “I lost about 1 ½ stone and it didn’t really bother me until I came out of hospital. I looked like something out of Belsen [concentration camp] and you could see every one of my ribs. When I looked in the mirror it definitely wasn’t me. I used to have a beard and I would never have recognised myself.”*

During treatment participants were primarily exposed to other cancer patients who were experiencing similar changes and they therefore felt a level of acceptance. At this time, these cancer patients seemed to form the participant’s point of reference for comparison rather than their healthy peers.

*P2 “Aye knowing that you’re in a room with one another. That’s the size of it basically – you’re accepted there.”*

While social isolation is not inevitable, participants had to make a conscious effort to socialise during treatment. Most participants naturally became more socially isolated

as treatment progressed due to the side-effects (particularly pain, weight loss and fatigue) and the time taken to attend treatment and manage the associated side-effects. Social isolation meant that they were mainly in contact with family and close friends and patients and healthcare professionals within a “safe” hospital environment. After treatment completion, although participants did not know how things were going to progress, they gradually started to compare themselves with how their bodies used to look and function and with other healthy individuals. I identified that men within this study try to distance themselves from concerns about appearance. However, being concerned about weight and muscle loss due to its associated impact on physical function and maintenance of sexual relationships appears to be seen as acceptable within hegemonic masculinity as indicated below:

P1 *“Because of the lost weight, it made you look desperately thin. It did go through my mind ‘you’re looking like a concentration camp victim here’. You are looking, your bones are showing. Now what effect did that have on me? Not pleasant it is sort of, you see the change, are not happy about it. Not attractive even in a physical sense with your wife. It is not something you feel confident about at all but that has gradually changed too.”*

Having endured the changes caused by treatment, the more common meaning of appearance in relation to physical attractiveness appears to come into focus again. The first time participants went out in public outwith an environment which was considered “safe” such as a hospital, could be particularly challenging. Other people could stare at their appearance and functional change which had the potential to increase self-consciousness. However, as seen in the quotation that follows, the effect of staring can be minimised by acknowledging the inquisitive nature of human beings or that change experienced will be temporary. Spouses and friends were essential in providing both physical and emotional support for participants as they began to socialise again:

P12 wife *“You can see people looking, you can see people looking but we don’t think too much of that [participant and his wife], because I’ve done that myself, you’ve done that yourself. You do, you know it’s a human trait. You look and go oh and look again.”*

As participants compared themselves to previous norms and tried to reengage with normal life, they utilised a number of coping strategies.

### *5.5.2 Coping strategies*

Interventions such as nasogastric feeding tubes were required by participants for a varying amount of time, in some cases many months after treatment and the need for these was beyond the individual's control. Participants were able to rationalise the use of nasogastric feeding tubes initially and for a few months after treatment. Thereafter, the nasogastric tube was seen both as a visible reminder of disease and treatment and a prolonged and uncertain recovery. The importance of eating was clear to participants but the challenge involved in finding things that were suitable to eat could not be underestimated. This process of *"not knowing"* what participants could eat, what to do for the best, if things would improve or when they would improve was found to be both difficult and frustrating. Frustration over *"not knowing"* what participants could eat was also shared by spouses/carers who provided practical support through food preparation in addition to emotional support. Additionally, participants and their spouses/carers could feel isolated when contact with specialist services following treatment completion was limited:

P1 *"Food was a big issue. It was something that I didn't seem to get to grips with. I couldn't find the right sorts of things to eat. It might have been that there wasn't anything right to eat."*

P1 *"X [P1's wife] had a hell of a time trying to find things that I could eat and I was on a nasal tube for feeding for some time and that was okay up to a point."*

While participants spoke about the advice and information they received about symptoms (including oral nutrition) given by healthcare professionals and other patients, they had to deal with daily challenges predominantly on their own. During and increasingly after treatment, participants tried to work out what they could do to improve their oral intake through a process of *"trial and error"*. Food had to be chosen carefully and eating was effortful due to the time it took to eat. Participants

also had to drink a lot of fluid when eating and reheat their food. All of these aspects along with altered taste which was experienced to varying degrees affected the enjoyment of food and the individuals' relationships with food. As discussed in section 5.2.1, prior to illness, physical function (including eating) was often given little consideration but it became a process which participants had to constantly consider.

Although progress was experienced with taste, swallowing and speech this could be variable throughout the day and between days. Mornings were particularly difficult for individuals following treatment as they got themselves going and at times when they became physically tired or other influencing factors (such as bodily position) ensued. Participants spoke about having "good" and "bad" days particularly during the initial post-treatment period:

P8 *"The bad days aren't as often nor as they were but as I say, it is just a case of keeping myself aware of it [change to speech]. You can't know what is going to happen in the space of a day. You can be speaking fine at one point in the morning and in the afternoon you can find that you start to babble again."* P8 goes on *"People basically tend to be more impressed than I am [talking about speech]."*

As the quotations from participants eight and seven highlight, the participants do not always interpret their function or progress made to be as good as others perceive it to be as they were aware of the variability in their function. Once again it can be seen that these changes to function are interpreted with reference to the stage of their cancer at diagnosis:

P7 *"I think my speech is bad but people, my consultant, nurse specialist and speech and language therapist are all very pleased with it. I was quite advanced [advanced stage of cancer]. But I find no, no disrespect to them, I don't mean that the way it sounds, are they just telling me that because you know I want to hear that. You know sometimes that goes through my head."*

R *"You wonder that sometimes?"*

P7 *"I just wonder at times that they tell me that because that is what I want to hear. They seem pleased with the way I speak. I find it at times quite bad."*

P7 *“At night-time my wife and I are sitting at night watching the television even X [wife] will say ‘what is that you are saying’ because when I get tired, my speech is very, very slow.”*

Participants became more aware of variability and nuances which were specific to them and modified their behaviours and refined techniques to try and accommodate changes and improve function over time. CNS played a key role in discussing a variety of techniques to manage appearance and functional changes both physically and psychologically during social interaction. Again family members were integral to the process of social re-integration. The participants used different methods of coping at different times and in different situations and these methods included trial and error, planning ahead and graded exposure as seen below:

P12 *“The only problem I have is eating because I can’t feel that so obviously when I am eating if there is anything that runs then I don’t know. So actually I have got a small mirror which I use when I am eating to see [when eating in the house].”*

P12 *“[if P12 and his wife are out] the wife tells me if there is anything at the corner of my mouth.”*

P10 *“I tried to prepare for different things happening when I started to go out. At first I tried to avoid people and sometimes other people tried to avoid me. I took my note pad and pen everywhere at first and had written lots of things out in case I needed it.”*

As shown in the next quotation, although participant seven did not feel able to go out for a meal in a restaurant, he started to eat out in places where he felt comfortable and knew he could make “safe” food choices:

P7 *“My wife and daughter will say let’s go for a meal. But no no. I’d love to for myself right enough. I mean I have been in and sat likes of maybe in X [local bakery] in X [local shopping centre] the other day and I had a sausage roll and I ate it. But that wasn’t any gravy or anything like that that was going to run down your chin sort of thing.”*

The combination of different changes to appearance and function could result in a loss of self-confidence and self-esteem. This loss of self-confidence and self-esteem was particularly evident for three participants who had a laryngectomy (removal of the voicebox) or experienced oral incompetence and nasal regurgitation. Lack of control of speech or bodily fluids (such as saliva and sputum) caused particular embarrassment and fear which could result in social anxiety with some participants tending to choose to limit or avoid social exposure:

P4 *“This Friday I’ve got to go into the X [hospital]. The wife’s working so I have got to jump on the bus and if I cough on the bus I can’t clean it, it’s embarrassing, really embarrassing.”*

As participants four and seven allude to, it can be particularly challenging when changes are visible (coughing up sputum/dribbling) and unpredictable and illness is not hidden or perhaps not understood by others:

P7 *“I think I’d feel embarrassed sitting in a restaurant. I mean my cancer nurse specialist and my wife say ‘well sit with your back to people, you know, and they’ll no see you.’ I’m scared of this running down my chin and liquids coming down my nose, things like that. It’s embarrassing you know.”*

For all participants the main focus in the process of recovery was for them to try and return to “normal” as quickly as possible. Participants set goals for themselves in an attempt to reclaim control and independence. Additionally, in many cases participants tried to recover important aspects of their life which defined them such as work or physical fitness:

P5 *“It was part of my life [mountaineering] and okay, I know I am conscious in saying, aye and I will be up Ben Lomond which is the nearest Munro [Scottish mountain] and I’ve done it half a dozen times with different people. That’s your goal, you and I will be back up and I was in Tinto [large hill], the hill there a few weeks ago. It was a real slog, probably too much too quick for me so I will do that again when I have built up again a bit.”*

R *“So you set yourself goals and sometimes your goals can be a wee bit high?”*



P5 *“Too high, setting them too high. I’m coming to terms with that.”*

As participants began to understand their limitations, they had to constantly reassess situations and goals which could be a painful and frustrating process. Participants who were older or had experience of chronic illness seemed to manage the process of accommodation better as they had lower, more realistic expectations. However this process could be challenging where there was a lack of understanding.

### 5.5.3 *Not being understood*

As well as trying to realise limitations personally, participants found it difficult when changes to function were not understood by others:

P4 *“Learning to speak and sometimes with the wife, I talk to her and she thinks I’m angry but it’s the way I talk. She’s a bit deaf anyway.”*

R *“Do you have to try and force it out?”*

P4 *“That’s the way I do it. I don’t mean to force it out but if I do it for a while.” P4 continues “The doctor said there are 4000 people in this surgery and you’re the only one with this in this surgery. We’re listening. You don’t need to get angry. Listen, I’ve got it and you should be telling me what I have to do, not me having to tell you which was annoying for me.”*

Participant four had to force speech out and this could be misinterpreted by others as a sign of anger or aggression. Family and friends could be over protective and sometimes other people associated altered speech/lack of speech with other disabilities. It is therefore suggested that participants who had their voice box removed could experience social stigma because the changes to appearance and function differentiate them from accepted cultural norms:

P11 *“Sometimes some of my mates can be over protective and talk to me like I am a five year old and some people talk to me as if I am deaf or stupid.” Participant 11 continues “So if I got on the bus I would have written out what I wanted but then the bus driver would shout back at me as if I was deaf.”*

There could be a lack of understanding of longer term side-effects such as fatigue which could impact on social roles and relationships could become frayed as requirements exceeded normal boundaries. Of particular concern is that participants who had a laryngectomy felt that GPs and district nurses lacked the necessary knowledge and skills to provide care or support for them:

P11 *“I used to visit the X [hospital] every Friday just about to get them to have a look at the bleeding or my stoma so I know I would be okay at the weekend. If I asked the GP or district nurse about it they just said they didn’t know and would tell me to go to the X [hospital].”*

As the quotations suggest, not being understood left participants with a laryngectomy feeling vulnerable as they perceived that they could not expect the same level of care as others who had not had their voice box removed. Furthermore, participants felt responsible for their own healthcare as if they have to tell the healthcare professional what is wrong instead of being assessed, diagnosed and treated in the usual manner. Participants with a laryngectomy therefore felt reliant on specialist services particularly in the initial period following surgery and (chemo) radiotherapy. This has direct implications for support provision.

Having considered the major categories which emerged (normalising change; *“being under siege; getting through treatment; and reclaiming self*), the core category which has explanatory power is presented.

## 5.6 Core category: Reconciling change; a new normal

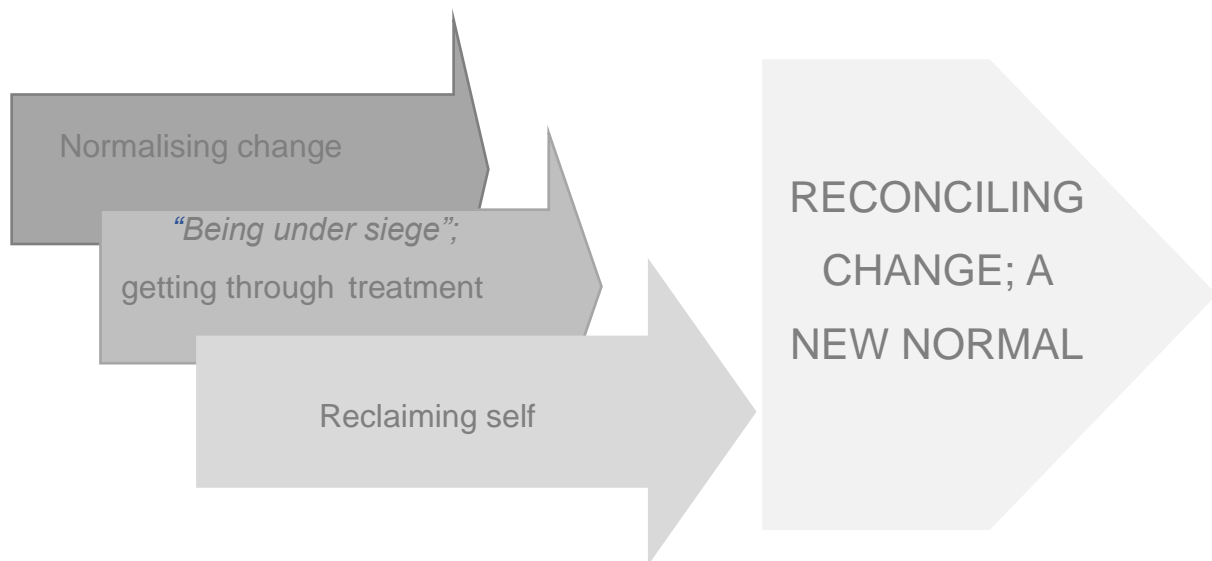
To briefly recap, GT attempts to go beyond thick description to develop theory which provides an explanation of the phenomenon under study (Glaser and Strauss, 2008). Glaser (1978) highlights the importance of the core category for GT. The generation of theory occurs around a core category. Without a core category an effort of GT will drift in relevancy and workability (Glaser 1978, p93). Strauss (1987, p36) suggests

that to qualify as the core category, the category should:

1. Be abstract, with all other major categories being related to it and placed under it.
2. Be frequently appearing in the data so that within all, or almost all, cases there are indicators pointing to that concept.
3. Be logical and consistent with the data, with no forcing of the data.
4. Be sufficiently abstract to allow research in other substantive areas, leading to development of a more general theory.
5. Grow in depth and explanatory power as each of the other categories is related to it through statements of relationship.

This criterion was used within my study to identify the core category, reconciling change; a new normal. Corbin and Strauss (2008, p107) suggest that “*diagrams can be valuable tools because integrative diagrams are abstract but visual representation of data.*” They suggest that a diagram need not contain every concept that emerged during the research process, but should focus on those that reach the status of major categories. Integrative diagrams should flow, with the logic being apparent without a lot of explanation, but they should not be overly complicated (with too many words, lines and arrows) and details should be left to the writing (Corbin and Strauss, 2008). Diagram three presents the substantive theory of appearance and functional change for men with head and neck cancer in the first 12 months following diagnosis. Following on from this, reconciling change; a new normal is explored in relation to the major categories: normalising change; being under siege; getting through treatment; and reclaiming self.

Diagram 3: Substantive theory of the experience of appearance and functional change for men with head and neck cancer in the first 12 months following diagnosis



Reconciling change; a new normal describes the basic psychosocial process of accommodating and assimilating change to appearance and function for men with head and neck cancer. Normalising change, *"being under siege"*; getting through treatment; and reclaiming self interact and inform one another, leading to reconciling change; a new normal. At the start of many of the interviews, participants said that while they were happy to participate, that really not much had changed for them and that they had seen others who had experienced more changes. Participants then went on to describe their experiences and it became apparent that they had experienced numerous and significant changes. Focus on function and ability to perform activities of daily living and social roles continued throughout. While initially there was a need to continuously consider changes experienced and how to manage them, this became incorporated into daily life, as highlighted in the following quotation:

P12 *"I can't open my mouth the same as I used to. So when I use the fork with the prongs down the food would hit my top lip and fall back down onto my plate. It got a bit frustrating but you just turn the fork round the other way. It's just things like that basically."*

By making cognitive and behavioural changes, the impact of appearance and functional changes which were experienced was minimised. Reconciling change occurred along a continuum with the majority of participants going on to develop a “new normal”. This “new normal” was evident not only for the participants but also within their wider social network:

P8 *“They all know me [staff in the local supermarkets] because I always wear a cap when I go out during the day. They all know me so I think they all sort of accept the fact that when I speak my speech isn’t always that clear. Nobody’s going to turn round and say you speak kinda funny son you know but people have learned to sort of expect that.”*

During treatment, participants became immersed in illness and waited for recovery prior to developing a “new normal”. Key to this process was getting important aspects of the participant’s life back and regaining control:

P2 *“I’m getting myself back. I’m in control. But you’ve got to see yourself moving forward if you know what I mean.”*

Reconciling change was challenging for participants where they experienced multiple or unexpected changes which impacted on their self-identity. Participant 11 suffered from head droop which prevented him from speaking without the aid of an electrolarynx and made everyday tasks such as shopping and crossing the road difficult. Participant 11 continued to wait for recovery while adjusting his expectations and therefore struggled to develop a new normal:

P11 *“I hope things change as I don’t want to live the rest of my life like this. I have lowered the bar so to speak though. I hoped that surgery would allow me to straighten my head and allow me to speak [without using an electrolarynx] but now I would settle for one or the other.”*

Similarly, following a laryngectomy and bilateral neck dissections, participant four experienced shoulder dysfunction which impacted on his career as a professional darts player which was central to his self-identity:

P4 (Professional darts player) *“I’ve been at a couple of darts tournaments since (having cancer treatment), one in Scotland down the road and there were dozens of people who knew me from years ago in Germany, people from Germany and that. I am on Facebook now and I have nearly 2,600 friends and they are all darts people and other people as well but mostly darts who all know me through the TV and they keep sending me messages when I go to tournaments, they know I’ve got cancer. It’s been in the Sun (Scottish newspaper) all the time, a big spread about me.”*

Participants four and eleven saw themselves and their future as diminished due to the social and financial impact of changes experienced. Both of these participants drank excessively prior to diagnosis and this may have impacted on their experience. Of interest, participant four continued to define himself as someone who had cancer whereas other participants distanced themselves from a cancer diagnosis. Generally, between 12 and 18 months after diagnosis, as participants’ accommodated and assimilated change to appearance and function, they began to define themselves as *“fine”* and *“good”* again:

P8 *“I don’t see myself as being a cancer patient any more. As far as I’m concerned, I had it, they got rid of it, goodbye. That’s it.”*

This may explain why there appears to be limited disclosure about cancer between men as indicated by participant five:

P5 *“You start meeting guys that you have known for long enough and I didn’t realise that they had cancer and you start talking to them. That helps you as well because you appreciate that you are not alone.”*

Despite increasing recognition that people live with and beyond cancer, cancer continues to be associated with dying and this may influence the way in which people reconcile the changes which occur. Men may feel more comfortable talking

about their cancer and treatment in retrospect allowing them to reframe their experience as a story of achievement. This also permits men to distance themselves from the emotion which may be felt during the cancer experience itself. Throughout the interviews, most participants spoke about the importance of positive thinking and finding benefit from their experience. Positive thinking seemed to allow the participants to adapt to change and see their future as enhanced. Positive changes included giving up risky or unhealthy behaviours and weight loss for participants who had previously been overweight.

In summary, after experiencing appearance and functional change participants tried to return to "*normal*". Slowly participants realised returning to "*normal*" was not possible and attempted to adapt to changes. At first this was done consciously, however, as time passed participants developed a "*new normal*", accommodating and assimilating changes to appearance and function. As highlighted, some participants struggled with reconciling change and felt they and their lives were diminished. In the final chapter, the substantive theory which emerged is discussed in relation to new knowledge and other theories, models and research evidence. Furthermore, implications for clinical practice are considered and suggestions for further research are made.

## **Chapter six: Discussion**

This thesis advances sociologically informed understandings of the experience of appearance and functional change in men with HNC in the first 12 months following diagnosis. The substantive theory of reconciling change: a new normal which emerged is discussed in relation to new knowledge and other theories, models and research evidence. The strengths and weaknesses of the research and the implications for clinical practice are then considered. Recommendations for future research complete this chapter and the thesis.

### **6.1 Summary of research findings and new knowledge**

To briefly recap, the aim of this research was to explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis. This research sought to identify: what appearance and functional issues were important; how issues were experienced within the context of a HNC diagnosis; and when issues are experienced within the care pathway. A summary of findings and new knowledge are presented under these headings.

#### ***6.1.1 Important appearance and functional issues for men with HNC***

Men attempted to distance themselves from concerns regarding appearance and generally felt that scarring was not noticeable to others. Men who experienced hair loss focussed on practical issues of heat loss and protection. In a similar way, while weight loss affected appearance, men considered it primarily in relation to ability to function and perform social roles.

Functional changes which impacted on breathing and speech were difficult to cope with even when they were experienced for a limited period. Having a tracheostomy or laryngectomy made the men feel vulnerable as they were unable to speak or clear secretions initially and had to rely on healthcare professionals. Men who had a



permanent stoma experienced a sense of responsibility over their own healthcare due to limited understanding of changes experienced by general healthcare professionals.

Radiotherapy and chemo-radiotherapy resulted in a cluster of side-effects which impacted on the men's ability to eat, a basic function which they associated with maintaining life and facilitating recovery. Multiple, extreme or unexpected/rare changes were most challenging. Men were found to be at higher risk of social anxiety and isolation where changes in function were visible and they were no longer in control of their body (for example expectorating sputum through a stoma or drooling when drinking).

Having considered important appearance and functional changes, changes experienced will now be considered in relation to a HNC diagnosis.

### *6.1.2 Appearance and functional change in the context of a HNC diagnosis*

A cancer diagnosis modified men's perception of appearance and functional change. Most men were initially focussed on understanding the impact of a cancer diagnosis and this affected how they processed information regarding appearance and functional change. Being diagnosed with HNC cancer, particularly when the disease was advanced, altered their focus and survival was their primary concern, with appearance and functional change being a secondary consideration. Appearance and functional change were therefore generally viewed as both essential and acceptable in relation to survival. Men's perceptions of appearance and functional change were also positively modified by other individuals with cancer where those individuals experienced more symptoms or had more advanced disease. However, while appearance and functional change were not an initial priority, these changes became increasingly important as the men lived beyond their diagnosis and treatment and attempted to return to "*normal*". Men's perceptions were also modified by society's association of cancer with death and the lack of public knowledge regarding survival and issues associated with survivorship.

Having considered appearance and functional changes in relation to a HNC diagnosis, changes during the care pathway will now be discussed.

### *6.1.3 Appearance and functional issues during the care pathway*

Appearance and functional issues became important to the men as the changes were experienced. Information and knowledge helped them to try to maintain control through self-management. Healthcare professionals were important in trying to prepare the men for expected changes but men had to go through their unique experience to truly understand. Information provided by other cancer patients was considered to be more relevant and of greater value and there was a sense of shared understanding, camaraderie and belonging. Changes were increasingly important at transition periods such as following surgery or following completion of chemo-radiotherapy. Camouflaging change was helpful as a short term coping strategy over a few weeks but could signify difficulty with reconciling change when used over a longer period. During treatment social isolation could occur naturally and men socialised in environments which were considered to be “safe” (such as hospitals or with family). In the first few months following treatment, men rationalised change and then started the process of reclaiming aspects of their former self. The process of reconciling change and developing a new normal then occurred as the men assimilated and accommodated change into their life. This was supported by strategies such as trial and error, planning ahead, trial and error, graded exposure and cognitive reappraisal.

Having given a brief overview of the key research findings, the substantive theory will now be considered in relation to other theories, models and research evidence. This will be discussed under the following headings: masculinity and change to appearance and function in men with HNC; body image and disfigurement in men with HNC; adaptation to change in appearance and function in men with HNC.

## 6.2 Masculinity and change to appearance and function in men with HNC

As highlighted in Chapter two, masculinity provides a broad context for understanding the ways in which men experience appearance and functioning. At the point of diagnosis, men stated they were “good” and “fine” and attempted to normalise changes to appearance and function experienced. Focus on function prior to diagnosis was significant as it influenced how men went on to experience changes to appearance and function as suggested by White (2000). Physical symptoms have previously been found to be the determining factor by help seeking by men because emotional expression and vulnerability is associated with femininity (O’Brien et al, 2005; Moller-Leimkuler, 2002). The men enacted masculinity by using their previous health knowledge to try and manage change independently and only accessed health care when symptoms were not resolving or treatment was thought to be required. As described by O’Brien et al (2005), where symptoms were not visible or considered serious, men needed validation and encouragement from their spouse or loved ones.

While there are a number of masculinities described in the literature, hegemonic ideals prevail and lead men to present themselves as independent, unrestrained and strong (Connell, 2010; Kiss and Meryn, 2001). Men distanced themselves from concerns regarding appearance to maintain masculinity although they felt comfortable expressing concerns regarding weight and muscle loss. However at times there was discontinuity within their interviews and men may therefore suppress concerns. The drive for mean muscularity in boys and men is displayed across cultures (Ricciadelli and McCabe, 2011). A muscular body is commonly thought to define masculinity and a masculine man is generally viewed as more physically attractive and desirable to the opposite sex and as more capable and competent professionally (Petrie and Greenleaf, 2011). A muscular body with defined abdomen and arms and a large, V shaped upper body communicates strength, competence, confidence, power and independence (Petrie and Geenleaf, 2013). While participants were “*under siege; getting through treatment*”, weight and muscle loss was accepted as it was associated with treatment effect and success. Thereafter,

appearance became an indicator of recovery and cultural norms became more important as men started to interact socially again. While younger men have been found to consider the aesthetics of body changes more, this was not elicited in the current study (Cecil et al, 2009). However, men frequently compared themselves to others who were considered to be worse off or those who they felt would find change more difficult (for example younger or single men).

In psycho-oncology men are perceived as unexpressive problem-focussed copers (Moorey and Greer, 1989). Changes to function which made men with HNC vulnerable and dependent on others or affected their sense of control were challenging. While strength and physical ability are integral to masculinity, expectations regarding what was important and could be achieved during the disease trajectory was modified (Stapleton and Pattison, 2015). Through cognitive reappraisal men generally assimilated the change and accepted it as necessary and the “*price to pay*”, supporting other research findings (Semple et al, 2008; Larsson et al, 2007; Larsson et al, 2003). Information and support from healthcare professionals and other patients was used in an attempt to self-manage and maintain independence. While men accepted support during treatment, following treatment they attempted to manage independently and normalise change which could lead to symptoms being more severe before support was sought or intervention accepted.

After treatment, men with HNC initially waited on recovery and tried to reclaim important aspects of self and social roles, and return to work was central to this process. Work signifies normality and forms a central basis for self-identity, self-esteem, provides financial security, forms and maintains social relationships and represents and individual’s abilities, talents and health (Wells et al, 2013). During the midlife phase of life, men construct their masculinity in relation to their work and level of income their labour produces (Evans et al, 2011). As men age and illness becomes more frequent, the inability to sustain hegemonic masculine ideals by keeping the body muscular, strong and resilient may threaten men’s self-perceptions of their masculinity and they are faced with the challenge of redefining themselves

within an idealised, masculine culture (Evans et al, 2011; Oliffe, 2006). Brennan (2001) suggests that the burden of many months of treatment often reduces opportunities for people to engage in work and other social roles which formerly provided feedback about their competence and value in the world. Illness including cancer has been shown to reduce a man's status in masculine hierarchies, shift his power relations with women and raise self-doubts about his masculinity (Stapleton and Pattison, 2015; Charmaz, 1995). Charmaz (1989) found that chronic physical illness can afford men the opportunity to examine and reconstruct their masculine identities and this was evident in the current study.

Men with HNC generally limited disclosure about their cancer diagnosis and avoided emotional expression, even with family members. Coates (2003) states that men's narratives generally focus on themes such as heroism, conflict and achievement and emotional expression and self-disclosure are largely absent. Limited disclosure also represents the traditional masculine stereotype of being "*strong and silent*" (Boehmer and Clark, 2001; Moynihan, 1998). By limiting disclosure with their healthy peers, men avoided showing vulnerability. O'Brien et al (2007) found that negotiation of masculinity occurs in accordance with the limitations which can be placed on men by their own and others understanding of the social and personal consequences of the disease. As HNC and the effects of treatment are not widely understood within society, this impacted on negotiation of masculinity. Men with HNC did engage in discussion around practical aspects of symptom management with other patients going through treatment but avoided emotional disclosure. Imparting knowledge and information reflects masculinity valuing science, reason and action (Gray et al, 2002).

Having discussed masculinity and change to appearance and function in HNC, aspects of the substantive theory will be considered in relation to body image and disfigurement.

### 6.3 Body image and disfigurement in men with HNC

Reconciling change: a new normal identified that a cancer diagnosis modifies men's perception of appearance and functional change. Multiple studies have identified that HNC patients report less appearance related concerns than patients with non-cancer related disfigurement (Furness et al, 2006; Katz et al, 2003; Newell, 1999). A previous cross-sectional study of pre-treatment body image in patients with HNC showed low body image concerns (Fingeret, 2012). Katre et al (2008) suggest that the characteristics of HNC patients (lower social income; lower levels of self-care; higher consumption of alcohol and nicotine) may mean that self-image is less important pre-treatment in comparison to published norms. Dropkin (1998; 1989) described the process of body image reintegration in the immediate post-operative period following HNC surgery. Anticipation of disfiguring surgery in HNC was associated with extremely high levels of anxiety (Dropkin, 1999; Drokin, 1989). Additionally, pre-operative coping effectiveness was found to predict post-operative coping behaviour. Cognitive appraisal of the threat of disfigurement was found to lead to behavioural responses which were indicative of body image reintegration and involved confrontation, compliance and redefinition (Dropkin, 1989). Self-care, grooming and socialisation were viewed as key elements of the process of adaptation and reintegration during the first eight post-operative days. Reconciling change: a new normal goes beyond the immediate post-surgical period and additionally considers the impact of multi-modality treatment. In contrast to Dropkin's findings (1999), men assimilated change to appearance more easily than change in function. Following the initial post-operative period, scarring was frequently described as "*unnoticeable to others*" and was not generally associated with psychological distress. Men experienced particular anxiety where they had a tracheostomy or were unable to speak, even when this was for a limited period. In support of Dropkin's findings, self-management and socialisation were central to the process of accommodating and assimilating change. The hospital environment was nevertheless seen as "*safe*" with men feeling accepted there.

Men who experienced multiple, extreme or unexpected changes found it more difficult to accommodate, assimilate and reconcile change. Life events, personality, history of changes to body image, body image coping strategies and fear of the changed body and reactions of others to it create the social context that mediates the person's response along the continuum of confrontation and avoidance (Newell, 1991). Short-term social avoidance was found to be useful for men with HNC as they assimilated change but ongoing avoidance signified difficulty adapting to change. Men who were unable to control secretions and speech were at higher risk of avoidance and social isolation. Charmaz (1983) notes that the greater the loss of control and the amount of potential embarrassment from the illness, the more likely it is that the individual's self-concept will be affected. Rhoten et al (2014) found that depression and body image issues are greatest at the end of treatment with a subsequent decrease at 6-12 weeks post-treatment (Rhoten et al, 2014). It was unclear if depressive symptoms were an outcome of poorer body image or if poorer body image was an outcome of depressive symptoms (Rhoten et al, 2014).

One of the most influential and comprehensive body image models in nursing was proposed by Price (1990). Price's model suggests that body image consists of three components: body reality; body ideal and body presentation. These three components are said to exist in a state of tension or balance to maintain a satisfactory body image. The substantive theory developed supports particular elements of Price's model. Body reality includes body attributes and function and adaptation of body ideal was found to influence men's perception of their body image. During treatment, body ideal was modified and men benchmarked themselves against other cancer patients. Within a few months of treatment, men started to reclaim function and compare themselves against their previous norm and other healthy peers. Where limitations prevented the individual from returning to "normal", this was generally reconciled with body ideal undergoing further modification. Men also identified ways to improve body reality as they became aware of factors which influenced their function. Furthermore, body presentation was changed through camouflage although generally this was for short periods only. Personal, social and environmental factors moderated reconciling change and this

supports other theories and models (Rhoten et al, 2014; Furness, 2006; Price, 1990).

Having considered body image models and disfigurement, adaptation to appearance and functional change in HNC will now be discussed.

#### 6.4 Adaptation to appearance and functional change in men with HNC

Reconciling change: a new normal reflects the process by which the individual and those in their social world manage, learn, accommodate and assimilate changes to appearance and function caused by HNC and its treatment. Following a HNC diagnosis, disruption was experienced across many aspects of men's lives, including eating, speaking, relationships, socialising, working and self-identity. Oral and eating problems including concerns about dry mouth, chewing and eating, swallowing, speech/voice/being understood and dental health/teeth comprise five of the top 10 concerns for HNC patients (Wells et al, 2015). Being female, younger and out of work, having ever had a feeding tube, having a greater number of co-morbidities and living alone predict greater levels of distress in HNC (Wells et al, 2015). Men frequently tried to normalise change experienced and carry on with daily routines to maintain control and their sense of identity. When they were unable to continue to do this, they viewed change through an acute lense and focussed on getting through treatment while waiting on recovery. During and after treatment, men's daily lives and routines were dominated by the self-care required and they frequently felt distanced and disengaged from normal life. Men experienced variation in function throughout days and from day to day and uncertainty regarding recovery. Spouses and loved ones had to negotiate changing roles which included taking responsibility for the individual's care, symptom management, monitoring the individual's health status, planning and co-ordinating care and mediating family tensions (Penner et al, 2012). Molassiotis and Rogers (2012) found that HNC patients were pre-occupied for up to nine months primarily with their treatment and managing side-effects.



When treatment was completed, issues regarding work and returning to as normal a life as possible became the main focus in patient's lives. Limitations due to eating, fatigue and socialising could prevent individuals from fully reintegrating into their previous lives and community. Men experienced variation in function throughout the day and from day to day and uncertainty regarding recovery. In a comprehensive meta-analysis, Lang et al (2013) identified six core concepts including: daily disruption; uncertainty and waiting; diminished self; making sense of the experience; sharing the burden; and finding a path. Charmaz (1983) states that in a society which emphasizes doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life. Maintaining a normal life or returning to one subsequently becomes the symbol of a valued self (Bury, 1991; Charmaz, 1983).

The majority of survivors of HNC appear to cope reasonably well, while a significant minority continue to have high levels of distress and concern (Wells et al, 2015). Resilience has been found to be a common response to a cancer diagnosis and treatment and includes the possibility of positive growth, beyond baseline functioning following a cancer diagnosis (Deshields et al, 2016). Those individuals who are more resilient may be less likely to get "*stuck*" because they are likely to reconfigure thoughts, beliefs and behaviours to adjust to ongoing demands (Lepore and Revenson, 2006). Patient's perspectives tend to diverge with most seeing the future as changed where they develop successful coping and self management strategies or enhanced with others feeling diminished (Charmaz, 1989). Only two participants experienced ongoing loss and a diminished self where they experienced pervasive change across all domains of life. Charmaz (1989) identified that chronic illness is experienced by individuals in 3 ways: as an interruption of their lives, as an intrusion, and as an immersion in illness. Restrictions can result in an all-consuming retreat into illness as the illness structures the individuals' worlds and shapes their self-concepts (Charmaz, 1983). Lasting uncertainty and the continual threat of recurring ill-health makes it difficult for people to move forward from being a "*patient*" (Little et al, 1998). Pre-operative levels of depression and negative adjustment to a diagnosis

of HNC have both been found to predict levels of depression at long-term follow up (Adachi et al, 2014).

The majority of men with HNC reconciled change and developed a new normal. The concept of a new normal has been identified in other studies of food, eating and meals following radiotherapy for HNC and caregivers of HNC patients (Ottosson et al, 2013; Penner et al, 2012). In a study of breast, lung and prostate cancer patients, Baker et al (2014) identified that patients spoke of getting back to normal but presented two distinct accounts of “*normality*”. Some, particularly those who were newly diagnosed, maintained continuity to past identity by upholding previous routines, emphasising resilience and minimising the impact of cancer. Others spoke of a new “*normality*” discontinuous with their past. Most accounts, however, evidenced elements of continuity and discontinuity often in a contradictory way. This was viewed as an intermediate stage of adjustment for some patients as they later develop a sense of being a new person, changed by cancer.

Having discussed adaptation to appearance and functional change in men with HNC, the findings will now be considered in relation to the changing profile of HNC.

## 6.5 Study findings and the changing profile of HNC

The incidence of HNC over the last 10 year period has increased in men by 7% and in women by around 16% (WoSCAN, 2013). There has also been an increase in oropharyngeal cancer which has been associated with a rise in human papillomavirus (HPV) related oropharyngeal carcinoma (Mehanna et al, 2010). HPV related oropharyngeal cancer is increasing in younger, more affluent individuals without other risk factors (Herrero et al, 2003). HPV related oropharyngeal cancer is described as a new and distinct entity and has a more favourable prognosis than non-HPV related oropharyngeal carcinoma, particularly in non-smokers (Mehanna et al, 2010). Two recent randomised controlled trials have shown significantly improved two year survival in stage III and IV HPV related oropharyngeal cancer

compared with non-HPV related cancers (87.5% and 95% compared with 67.2% and 62%) (Worden et al, 2008; Fakhry et al, 2008).

Fingeret et al (2010) found that younger patients with HNC are at greater risk of experiencing body image difficulties and these difficulties significantly increased after surgery and remained elevated. Gender failed to contribute to other body image scores in this study however it is suggested that male cancer patients are at similar risk of experiencing body image difficulties as female cancer patients although male issues may go undetected due to differences in emotional expression (Fingeret et al, 2010). Rumsey et al (2004) also found that women experienced more distress than men but there was no discussion why this may be the case. McCaughan et al (2010) explored and compared the experience of coping behaviour of men and women with colorectal cancer after chemotherapy. Three themes emerged from the interviews: new normal, living with uncertainty and support needs. Many men and women reacted similarly however there was some variation between sexes and the main difference was with regard to the long-term side-effects of the illnesses. Most women admitted experienced side-effects whereas many men indicated that they had no problems. These men engaged in practices aligned with their gender identity and view of masculinity. Through narratives men portrayed themselves as strong and unconcerned and in doing so this reconstructed positions of power. Generally, following treatment, most women appeared to want support while most men did not seem to have the same desire for ongoing support. Many women still admitted to experiencing long term side effects and developing strategies to manage these symptoms hence they did not have a great impact on their lives. In contrast many men engaged in practices that aligned with their gender identity and view of masculinity. They indicated that they had no problems and downplayed the significance of side-effects and possibly did not make attempts to incorporate the symptoms into their daily lives. At the final interview (one year), many participants appeared to have adjusted to the physical side effects and were no longer defining them as a problem. Fear of cancer recurrence was noted however this is in contrast to my findings. Women are responsible for multiple roles and it has been proposed that their sense of identity is greatly affected by a cancer diagnosis and therefore

they may experience greater disruption than their male counterparts. Many men believe they must cope and adapt quickly, leading to a shorter transition period. It is plausible that men and women suffer from the same distress but that male participants were not willing to share that experience for fear of portraying themselves as less of a man (McCaughan et al, 2010).

The changing profile of HNC will be considered further in relation to recommendations for future research (section 6.7). Strengths, weaknesses and quality of the research study will now be discussed.

## 6.6 Strengths, weaknesses and quality of the research study

The National Cancer Survivorship Initiative highlighted that more research needs to be done to understand survivorship and the ongoing needs of cancer survivors and my research study addresses these issues (NCSI, 2007). Strategically, there is a focus on patient involvement in clinical service review, improvement and development and this should also translate to clinical research. Therefore, men who had experience of appearance and functional change following HNC were consulted at key points of the research study including research design, interview schedule development and analysis. Although this study involved a limited number of participants (n=12), this was not felt to be a weakness as theoretical saturation was experienced after eight interviews as discussed in Chapters four. A further four interviews were performed to ensure that no more categories were emerging and to fully develop the categories, properties and dimensions to ensure that the research questions were answered. While the small sample may be criticised, research supports that a sample size of 12 is satisfactory when exploring individuals' experiences in a relatively homogenous sample (Guest et al, 2006; Kuzel, 1992).

Following extensive reading, I felt that grounded theory (GT) was the appropriate methodology to answer the research aim and questions. However, I found the decision regarding which version of GT to use very difficult. I decided upon the more formulaic approach of Corbin and Strauss as it provided a structure to analysis and examples which were easy to understand and analytic tools which could be used in a flexible manner (Corbin and Strauss, 2008). One of the most difficult aspects of GT

involved developing theoretical sensitivity and confidence in my analytical skills. Despite these challenges, which paralysed me at times, I remain confident that GT was the right methodology and I would use Corbin and Strauss's approach again.

It is essential to assess quality, nevertheless there appears to be little agreement on what to focus on or how to do this (Corbin and Strauss, 2008). Although participants were recruited quickly in two stages (six participants at a time), it took nine months to complete interviews to allow adequate time for analysis between interviews and development and refinement of the substantive theory. To support transparency and analysis, all interview transcripts, field notes and memos were uploaded onto the University of Stirling secure server. This allowed my supervisors to review the data which supported discussion around analysis and theoretical development. I took strategic action through prolonged engagement with the data, negative case analysis, extensive description and peer review during the course of my research to increase validity and reliability (Corbin and Strauss, 2008; Creswell, 1998). All participants who had been involved in the study development were sent a brief summary of study findings and the theoretical model which emerged (Appendix 21). It should be noted however, that there have been minor changes to coding and the theoretical model since this occurred. One of the HNC patients involved in study development and one of the participants fed back that findings resonated with their experience (Appendix 22). Chapters of this thesis were also reviewed by two clinical nurse specialists with extensive HNC experience and they found the substantive theory to be clinically relevant (Appendix 23). It is therefore argued that while the study involved small numbers, the theory developed is representative of the reality of the substantive area. Furthermore, it is argued that the theory may also have generality, being applicable in different but related contexts (for example men with different types of cancer).

Having discussed the strengths, weaknesses and the quality of the research, implications for clinical practice will now be now presented.

## 6.7 Implications for clinical practice

The Quality Strategy has provided the blueprint for improving the quality of care that patients and carers receive from the NHS across Scotland (The Scottish Government, 2010). Three Quality Ambitions emerged: safe, person-centred and effective and all healthcare policy is being aligned to deliver these ambitions. There is increasing recognition that health services should be developed around patient experiences. However, patient involvement programmes and Transforming Care after Treatment projects have continued to focus on breast, colorectal, lung and prostate cancer. To develop clinical practice and services within other cancer specialities, it is imperative that patient experience is understood. The substantive theory, reconciling change: a new normal which emerged provides health and social care practitioners with insight into the experience of change to appearance and function in men with HNC to directly inform their clinical practice.

This theory suggests that participants normalise change and present primarily with change in functioning which commonly resulted in delays in presentation. Participants demonstrated behaviours associated with hegemonic masculinity and tried to initially manage change independently. There was also a lack of awareness of HNC symptoms and associated risk factors. These findings should influence public health strategies and cancer awareness programmes. Specifically, cancer awareness programmes must go beyond breast, lung and colorectal cancer and specifically consider ways to target more deprived “*at risk*” populations. The Irish Cancer Society has produced generic cancer posters with pictures which show how to identify unexplained, persistent or unusual change and subsequent action required. These posters are available in a wide range of locations including toilets within sporting venues and this approach should be considered for wider implementation. However, it should also be recognised that symptoms of HNC may not be evident until disease is advanced and therefore the impact of cancer awareness programmes may be limited. Furthermore, within clinical practice there should also be a focus on “*teachable moments*” to support secondary prevention and general health promotion.

Participants were shocked by their cancer diagnosis and survival was prioritised at this time with little consideration of short and long term changes to appearance and function. Clinicians should consider this finding particularly in relation to communication, information provision and informed consent. Healthcare is increasingly target driven with shorter times from diagnosis to treatment and this can reduce the opportunity for repeated detailed discussion regarding treatment and rehabilitation. CNS are in a unique position to assess patients and provide staged information and support and it is suggested this support continues beyond the acute post-treatment period. The study highlights the limitation of verbal and written information and the importance of experiential learning for patients and this should be recognised in clinical practice. It is suggested that discussions related to self-management and support should be this influenced by men's prioritisation of function. For example weight loss should be considered in the wider context of muscle loss, strength and ability to perform activities of daily living and social roles. While the benefit of *"buddy"* support prior to surgery and informal peer support during treatment was evident, consideration should be given to the establishment of formal buddy support particularly during the rehabilitation phase. This would help to manage expectations and support goal setting

Men attempt to maintain independence and control and frequently presented themselves as unchanged. Support should therefore be provided proactively during and after treatment as men do not generally disclose needs or initiate support. Holistic needs assessment is central to support provision and where possible this should be done at key time points around diagnosis, at end of treatment and 3 months after treatment to allow the development of care plans. The Scottish Patient Experience Survey found that cancer patients who had a care plan had more positive experiences across all aspects of their cancer care (The Scottish Government, 2016).

Coping strategies identified as important in reconciling change included trial and error, goal setting, graded exposure, challenging negative thoughts and social skills training. Education and training is central to service provision and there are a number of direct and online courses available such as motivational interviewing;

advanced communication skills; holistic needs assessment; asset management; 10 minute cognitive behavioural therapy; nutrition in cancer; body image and cancer; and social skills. Education and training needs should be identified within and across the multi-disciplinary team to ensure a skilled workforce who can provide lower levels of psychological care provision.

It is suggested that clinicians should appreciate that holding contradictory orientations to normal and new normal is functional. Health and social care professionals should support and encourage men to reconcile change and develop a new normal. Men who experience body incompetence or severe changes may suffer from social anxiety or find their illness is intrusive and require additional and ongoing support to develop a new self-concept. Clinical support and education should be provided for laryngectomy patients and community healthcare professionals to try and improve the experience of ongoing care. Interventions to address work related issues need to be patient-centred acknowledging the work-related goals or outcomes that are important to the individual.

This study would indicate that support should be provided to relatives and carers to reduce isolation and increase understanding of changes and the rehabilitation process. Men and their carers could also be encouraged to attend health and well-being events or participate in rehabilitation programmes by focussing on physical recovery and strength.

Having considered the clinical implications of the research, recommendations for future research will now be presented.

## 6.8 Recommendations for future research

Reconciling change: a new normal is the overarching concept, which when taken with the concepts of: normalising change; "*being under siege*": getting through treatment; and reclaiming self, explains the social-psychological process of appearance and functional change for men with HNC. The majority of research into



men's experiences of cancer has focussed on prostate cancer. However, acknowledging the changing profile of HNC and McCaughan et al's findings (2010), further research should examine the substantive theory in relation to women and younger men with HNC. My findings would also suggest that further research should be performed on individuals who have a laryngectomy and their general healthcare professionals to explore issues further and determine how support provision could be improved.

## 6.9 Conclusion

In conclusion, this research thesis has provided the rationale for the study performed and the methodology used. Issues related to GT have been articulated and the aim of going beyond thick description was highlighted. This is the first study specifically focussing on the experience of appearance and functional change in men with HNC. Reconciling change: a new normal is the overarching concept which when taken with the concepts of function, normalising change, "being under siege": getting through treatment and reclaiming function explains the social-psychological process of appearance and functional change for men with HNC. The theory has provided new knowledge and both supported and challenged other theories and evidence. The direct implications drawn from the theory which emerged for clinical practice are significant and should improve care for men with HNC.

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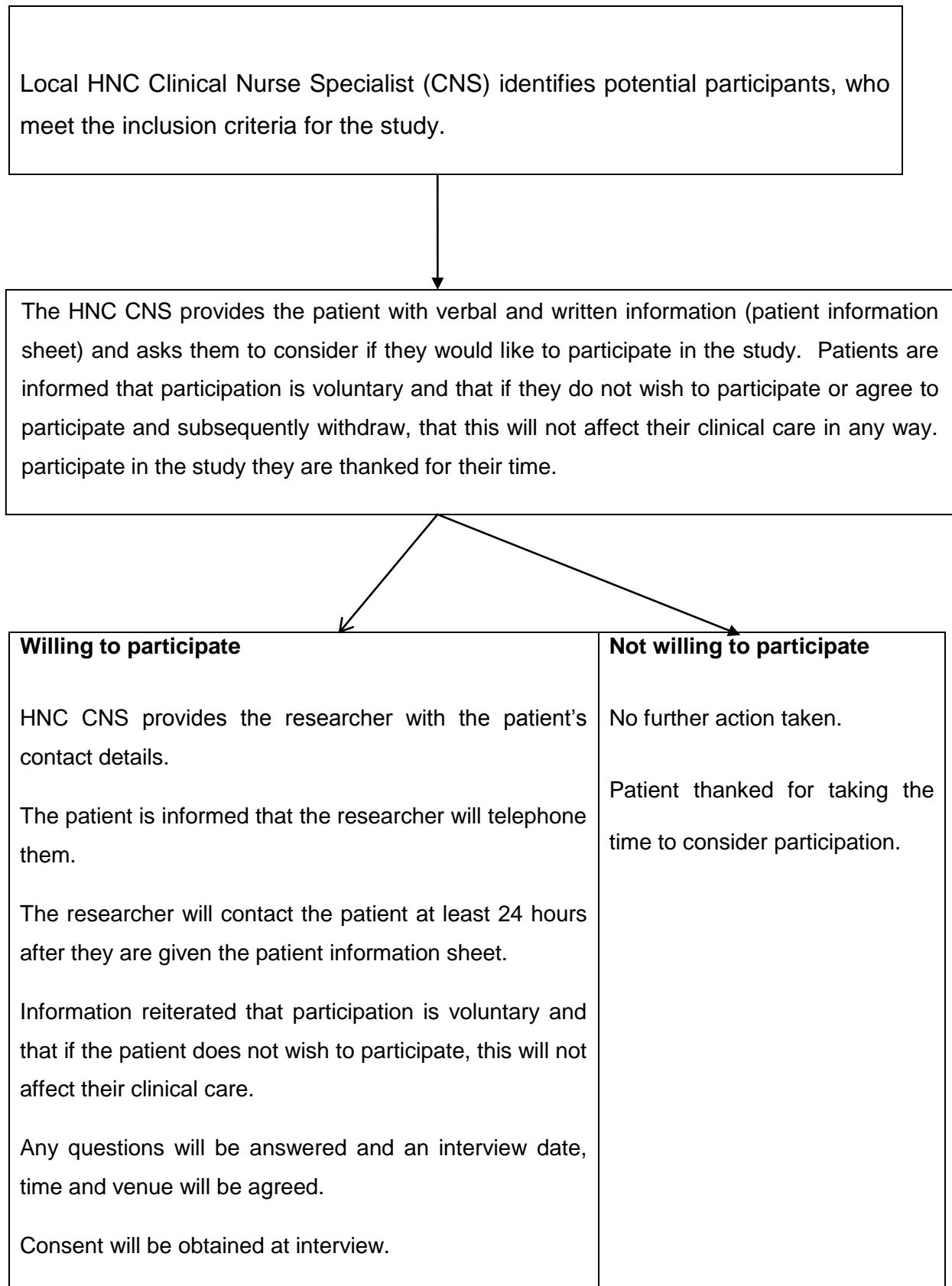
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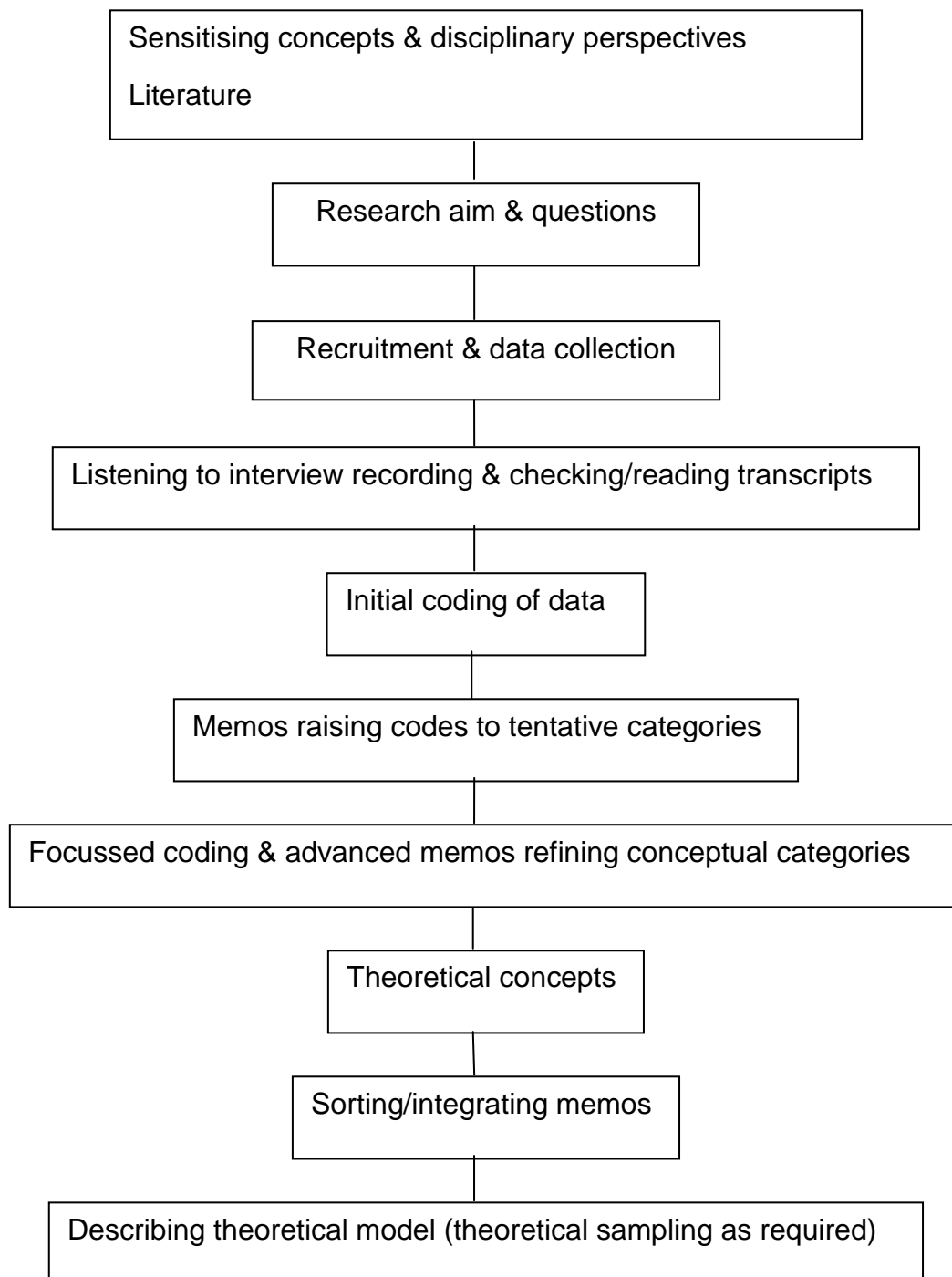
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## Appendix 1: Flow chart for participant identification and recruitment



## Appendix 2: The grounded theory process



## **Appendix 3: Participant information sheet (V2-15 January 2011)**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

### **Participant Information Sheet**

**Study Title: experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer.**

**Researcher: Caroline Hood**

#### **An invitation to take part in a research study**

You are being invited to take part in a research study. Before you decide if you want to take part, it is important for you to understand why this study is being done and what it will involve. Please ask us if there is anything that is not clear or you would like more information.

#### **What is the purpose of the study?**

People with head and neck cancer often have to deal with a number of changes to the way they look (e.g scarring, weight loss, feeding tubes) and the way their body works (e.g swallowing, speech, voice). The aim of this study is to understand the experience of these changes for men with head and neck cancer in the first 12 months after diagnosis. Most other studies have looked at appearance change in women or focused on a change in function (e.g voice). It is hoped that this study will identify issues experienced, how these issues change over time and the way this is experienced by men. This is a student research project which is being performed as part of a Clinical Doctorate Programme in Nursing at the University of Stirling.

#### **Why have I been chosen?**

You are being invited to take part in this study because you have been diagnosed with head and neck cancer and will probably have experienced some changes to your body (appearance and/or function).

#### **Do I have to take part?**

No. It is up to you to decide whether to take part. Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time. You do not have to give a reason for withdrawing and it will not affect your future medical care or your relationships with staff looking after you.



Please keep this information sheet for your reference. If you decide to take part in the study you will be asked to sign a consent form.

### **What does the study involve?**

The study involves an individual interview which will last approximately an hour. The interview can take place either in your own home or at the out-patient department of your local hospital. If interviews are performed at your local hospital then travelling expenses will be reimbursed by the researcher. Interruptions and disruptions will try to be avoided as much as possible.

You will be asked to sign a written consent form at the start of the interview. The interview will be recorded on a mini-disk and the recording will be typed up by a secretary. Medical, social and demographic information will also be accessed from your Cancer Nurse Specialist. A total of twelve people will be interviewed for this study.

### **Will my taking part be kept confidential?**

Yes. Each person is given a participant number so you will not be named in any reports or research articles that are written about the study. All data, including your consent form, will be kept in a locked filing cabinet and computer that is password protected. Only the researcher will have access. All data will be destroyed after 10 years.

With your permission, we will inform your head and neck cancer consultant and GP of your participation in this study.

### **What if I wish to complain about the study?**

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint through the University of Stirling, who are acting as the research sponsor. Details are available from the research team and their contact details are provided on the next page. Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process.

### **Who is supervising the study?**

Dr Kathleen Stoddart, Clinical Doctorate Programme Leader, University of Stirling and Dr Gill Hubbard, Senior Research Fellow, Cancer Care Research Centre, University of Stirling.

### **Who is funding the study?**

NHS Ayrshire and Arran.

### **Has the evaluation been reviewed by an ethics committee?**

This study has been reviewed by an NHS Research Ethics Committee who had no objections to the study.

### **What happens next?**

If you agree, your Cancer Nurse Specialist will give the researcher (Caroline Hood) your contact details. The researcher will contact you by phone at least 24 hours after you have been given information about the study and answer any questions you may have. If you wish to take part in the study then an interview will be

arranged at a date, time and location which is suitable for you. If you do not wish to take part, this will not affect the care that is provided in any way. The researcher works in Head and Neck Cancer as a Clinical Nurse Specialist in another health board however she cannot provide any clinical advice. If you need any clinical advice or have any concerns about the interview/study you can discuss these one of your local Clinical Nurse Specialists:



**What about the results of the study?**

The results of the study will be written up and submitted by the researcher to the University of Stirling to meet the requirements of the Doctorate Programme. Results will also be published in an appropriate journal. A summary of results will be sent to you if you participate and tick the box on the consent form and you will be asked if the results represent your experience.

**Who do I contact for further information?**

Please contact Caroline Hood who is the researcher performing this study.

<b>Primary contact</b> Caroline Hood Researcher Room 500 Level 5 West Crosshouse Hospital Kilmarnock KA2 0BE Tel: 01563-545501 Email: caroline.hood@aaaht.scot.nhs.uk	<b>Independent contact</b> Professor William Lauder Department of Nursing and Midwifery University of Stirling Stirling FK9 4LA Tel: 01786- 466345 Email: william.lauder@stir.ac.uk
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**Thank you for taking the time to read information sheet and consider participating in the study**

## **Appendix 4: Participant consent form V2 - 15 January 2011**



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**Study title: the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer.**

### **PARTICIPANT CONSENT FORM**

	Please initial box if you agree
1. I confirm that I have read and understand the information sheet (V2 15 January 2011) for the above study.	
2. I have had the opportunity to consider the information provided and have had any questions answered.	
3. I understand that my participation is voluntary and I can withdraw from the study at any time without giving any notification or reasons.	
4. I understand that withdrawing from the research study will not affect my treatment in any way.	
5. I understand that medical, social and demographic information will be accessed from my Cancer Nurse Specialist.	
6. I understand that all information from this study will be stored in a password protected computer and locked filing cabinet. Only the researcher will have access to this information.	
7. I consent to audio taping of the interview and understand that my name will not be mentioned in any reports or articles.	

8. I agree to my head and neck cancer consultant and GP being informed that I am involved in this study.	
9. I agree to participate in this research study.	
10. I would like a summary of the project findings.	

Name of participant

Signature

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of researcher

Signature

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Copy 1 – participant    Copy 2 – to be retained by the investigator

## Appendix 5: Lead clinician letter



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

Level 5 West,  
Crosshouse Hospital,  
Kilmarnock

KA2 OBE

17<sup>th</sup> January 2011

Dear Mr [REDACTED],

**Study title: the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer**

As part requirement of the Clinical Doctorate Programme at the University of Stirling, I would like to perform an exploratory study of the experience of appearance and functional change in men with head and neck cancer in the first 12 months following diagnosis. I work as a HNC Clinical Nurse Specialist within NHS Ayrshire and Arran and due to ethical issues I would like to recruit participants from the [REDACTED] Hospital.

My research proposal has been approved by: [REDACTED] Clinical Directors; the West of Scotland HNC Managed Clinical Network research sub-group; the Department of Research and Ethics Committee (University of Stirling); the West of Scotland Research and Ethics Service (WoSRES 5) and approval from Greater Glasgow and Clyde Research and Development Department is currently awaited.

The study is a qualitative, grounded theory study. Grounded theory goes beyond other methods of qualitative research which provide exhaustive description of the phenomenon under study. The overall purpose of grounded theory methodology is the generation of theory which has explanatory power and advances the understanding of social and psychological phenomenon. The study involves a single retrospective unstructured interview (using a brief topic guide) which will last an hour and 12 participants will be recruited with the support of the clinical nurse specialists from the [REDACTED] hospitals. I would be grateful if you would inform me if you consent to the recruitment of patients under your care. If you require any further information about the study or wish to discuss it in detail please do not hesitate to contact me.

Yours sincerely,

Caroline Hood (RGN, BN, MC Cancer Care)  
Tel: 01563-545501/E-mail: caroline.hood@aaaht.scot.nhs.uk

## Appendix 6: University of Stirling Health Studies Research Ethics Committee

FH/SG

07 October 2010

Caroline Hood  
4 Lugar Wynd  
Kilmarnock  
Ayrshire  
KA3 6FA



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
**NURSING AND MIDWIFERY**

Email: [nursingmidwifery@stir.ac.uk](mailto:nursingmidwifery@stir.ac.uk)  
Web: [www.nm.stir.ac.uk](http://www.nm.stir.ac.uk)

Fiona Harris  
Chair (Acting)  
Dept Ethics Research Committee

Department of Nursing & Midwifery  
University of Stirling  
Stirling FK9 4LA

Tel: +44 (0) 1786 46 6104  
Fax: +44 (0) 1786 466333  
Email: [fiona.harris@stir.ac.uk](mailto:fiona.harris@stir.ac.uk)

Dear Caroline

**An exploratory study of the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer.**

Thank you for submitting your proposal, which was considered at the DREC meeting on Tuesday 5<sup>th</sup> October 2010. The Committee noted the amendments made to your research design/methods and we are happy to approve this.

We wish you well with this very interesting piece of work.

Yours sincerely

Dr Fiona Harris  
Chair (Acting)  
Department of Nursing and Midwifery Research Ethics Committee

Highland Campus:  
Centre for Health Science  
Old Perth Road  
Inverness IV2 3JH

Tel: +44 (0) 1463 255655  
Fax: +44 (0) 1463 255654

Stirling Campus:  
Stirling  
FK9 4LA

Tel: +44 (0) 1786 466340  
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Western Isles Campus:  
Western Isles Hospital  
MacAulay Road  
Stornoway Isle of Lewis HS1 2AF

Tel: +44 (0) 1851 708243  
Fax: +44 (0) 1851 706070

## Appendix 7: NHS Research and Development department approval



Coordinator: NB/BR  
Telephone Number: 0141-211-8544  
E-Mail: [Nathaniel.Brittain@ggc.scot.nhs.uk](mailto:Nathaniel.Brittain@ggc.scot.nhs.uk)  
Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

R&D Management Office  
Western Infirmary  
Tennent Institute  
1<sup>st</sup> Floor 38 Church Street  
Glasgow, G11 6NT

24 January 2011

Mrs Caroline Hood  
Head & Neck Cancer Clinical Nurse Specialist  
Room 500  
Level 5 West  
Crosshouse Hospital  
Kilmarnock  
KA2 0BE

### NHS GG&C Board Approval

Dear Mrs Hood

<b>Study Title:</b>	<b>An exploratory study of appearance and functional change in the first 12 months following diagnosis for men with head and neck cancer</b>
<b>Principal Investigator:</b>	<b>Mrs Caroline Hood</b>
<b>GG&amp;C HB site</b>	<b>Royal Alexandra Hospital &amp; Southern General Hospital</b>
<b>Sponsor</b>	<b>University of Stirling</b>
<b>R&amp;D reference:</b>	<b>GN100N414</b>
<b>REC reference:</b>	<b>10/S1001/72</b>
<b>Protocol no:</b>	<b>Version 1 dated 18 October 2010</b>
<b>(including version and date)</b>	

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file.

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[www.nhsggc.org.uk](http://www.nhsggc.org.uk)

165



2. **For all studies** the following information is required during their lifespan.
- a. Recruitment Numbers on a quarterly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments – Substantial or Non Substantial
  - d. Notification of Trial/study end including final recruitment figures
  - e. Final Report & Copies of Publications/Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,



Dr Nathaniel Brittain  
Research Co-ordinator

**Cc: Carol Johnstone, Business Development Manager, Research & Enterprise, University of Stirling**



## **Appendix 8: West of Scotland Managed Clinical Network HNC research sub-group**

**Study: the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer**

Thank you for asking me to review this research proposal Caroline. Overall, I think this is a well prepared and structured research proposal which is clearly described and addresses the important issues. I am unfamiliar with this type of sociological research methodology. However, the project is appropriately supervised and appears carefully thought out on the basis of previously published methodological research. It is likely that it will be possible to recruit the inception cohort of patients. The study appears feasible. I think the major ethical issues have been addressed.

I am not persuaded that the aim and objectives are achievable. Specifically, objective 3 states that the study will identify at which point issues of function and appearance become important. I think a longitudinal study design rather than the cross sectional one planned here would be required to do that. Objective 4 states that the influence of masculinity and its impact will be evaluated. I am not clear how this will be achieved. In the introductory statement it is coherently argued that masculinity is a concept. I wonder if the influence of the fact of male gender is actually being explored.

Will the findings of this study be generalisable is an unanswered question to my mind. The issue of the potential for the influence of interviewer bias is not addressed by the proposed study design. Subconscious bias leading subjects to preconceived concepts must be a risk with this type of study. I doubt whether this problem can be overcome without another researcher being involved. Nevertheless, I do think the study will provide interesting data and a basis for further exploration of this issue.

██████████  
HNC Managed Clinical Network Research Lead/Consultant Maxillofacial Head and Neck Surgeon, ██████████, Glasgow

## Acute Services Division

### Regional Services Directorate

1<sup>st</sup> October 2010

Ref: JMcM/TP/

## REGIONAL MAXILLOFACIAL UNIT

Southern General Hospital

1345 Govan Road

Glasgow

G51 4TF

Switchboard telephone 0141 201 1100

Hospital fax 0141 201 2999

Reception telephone 0141 201 1980

Secretary telephone 0141 201 2842

Department fax 0141 232 7508

[Tracey.Peterson@ggc.scot.nhs.uk](mailto:Tracey.Peterson@ggc.scot.nhs.uk)



Ms C Hood  
Clinical Nurse Specialist  
Ayrshire & Arran Health Board  
Crosshouse Hospital  
Kilmarnock  
KA2 0BE

Dear Ms Hood

Thanks very much for your recent research proposal which was considered by the Head and Neck MCN research Sub Group. This proposal has been peer reviewed and comments by the reviewers appropriately addressed. The research sub committee therefore gives this research proposal its' support.

Kind regards  
Yours sincerely

A handwritten signature in black ink, appearing to be 'J McMahon', written over a light blue wavy background element.

**Mr Jeremy McMahon**  
**Consultant Head & Neck/ Maxillofacial Surgeon**  
**Chair Research & Audit Sub Group, Head & Neck Managed Clinic Network, West of Scotland**

## **Appendix 9 - GP letter (V1-18 October 2010)**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

Date:

Dear

Patient details:

I am writing to inform you that [patient name] has agreed to participate in a research study. The overall aim of the study is to understand the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer. An interview will be performed which will last approximately one hour and will take place either within the patient's home or local NHS hospital.

This study is being undertaken as part requirement of a Doctor of Nursing Programme and is academically supervised and sponsored by the University of Stirling. This study has received ethical approval from the Department of Nursing and Midwifery Ethics Committee, University of Stirling and the West of Scotland Research Ethics Service. The study has also received NHS Greater Glasgow & Clyde and NHS Ayrshire & Arran Research and Development Management approval. If you require any further information about this study or have any questions, please do not hesitate to contact me by telephone on 01563-545501 or by e-mail at [caroline.hood@aaaht.scot.nhs.uk](mailto:caroline.hood@aaaht.scot.nhs.uk),

Yours sincerely,

Caroline Hood RGN, BN, MN [Cancer Care]

## **Appendix 10: Interview schedule (V1-18 October 2010)**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

### Interview schedule

At the start of the interview, the researcher will reiterate her role. The researcher will highlight the purpose of the study again, clarifying any issues or answering any questions which may have arisen from the last point of contact. Consent will then be obtained and the recorded interview will commence.

The following key areas will be explored during the interview:

- Appearance change
- Functional change
- Support (accessed and received)
- Impact (self-identity; social identity; roles)

The key areas were developed through discussion about the study with two men with head and neck cancer. The wording and sequencing of questions around the key areas will directly relate to responses gained.

Charmaz (2006, p30) suggests that *“no interview should end abruptly or with searching questions.”* The following questions will therefore be utilised to bring the interview to a close:

After having the experience(s) you have discussed, what advice would you give someone else with a head and neck cancer diagnosis?

Is there anything you might not have thought about before that occurred to you during this interview?

Is there anything else you think I should know to understand your experience better?

Is there anything you would like to ask me?

Finally, the researcher will ensure that participant has the Clinical Nurse Specialist contact information so that they can access support if they experience any emotional distress following the interview.

## **Appendix 11: Interview checklist**

- E-mail [REDACTED] to inform her of interview participant's address & contact details & date/time of interview
- If the interview is out with working hours then a research buddy will be arranged
- Arrange time to contact research buddy following interview
- Check digital recorder before interview
- Discuss purpose of interview & establish expectations & any anxieties

The purpose of this study is to explore how men with head and neck cancer experience appearance and functional change over time. A few questions will be asked to gain this information and I will also ask questions to clarify answers and to probe further. You can take a break or stop the interview at any time and this will not affect your care. I would be grateful if we could try and minimise any disruptions and the interview will last no longer than 1 hour.

- Ask participant to complete consent form, explain about results
- Complete demographic data collection sheet
- Undertake interview
- Take notes as required

### Questions

How did you feel about how your body looked (appearance) and worked (function) before your cancer diagnosis?

How did you feel about the possible changes to appearance and function when you were given your HNC diagnosis?

Can you describe your experience of appearance and functional change?

How did this change over time?

How did you feel when you first started to interact socially again?

Can you tell me a bit more about that?

How did you decide what changes/side-effects of treatment to seek support for?

After having the experience you have discussed what advice would you give someone else with a HNC diagnosis?

Is there anything you might not have thought about before that occurred to you during this interview?

Is there anything else you think I should know to understand your experience better?

Is there anything you would like to ask me?

#### Following interview

- Thank patient for participating in interview/research
- Complete field notes
- Give secretary digital recording for transcription
- Listen to digital recording a few times before commencing initial analysis
- Listen to digital recording against transcript for accuracy
- Commence line by line coding

## Appendix 12: Data collection sheet (V1- 20 August 2010)



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
**NURSING AND MIDWIFERY**

Stirling campus  
Department of nursing & midwifery  
Stirling  
FK9 4LA  
Tel: +44 (0)1786 466340  
Fax: +44 (0) 1786 466333

Name:

Age:

Diagnosis:

Staging:

Treatment:

Social deprivation category:

Marital status:

Employment status:

Educational level:



## **Appendix 13: Field notes**

### Field note: prior to first interview

I have been increasingly anxious about doing my first interview. In fact I feel almost paralysed by fear. What am I anxious about – who knows? Failure probably as always. I feel unprepared. I want the interview to go well and to get good data and I am not fully in control of this. Kathryn my clinical supervisor would ask me what evidence have I got which would support these thoughts. Well realistically there is nothing but what I know and how I feel are two different things. I don't want to speak with my university supervisors about this as I feel it is part of the process which I have to work through. I have spoken to Mhairi (Doctoral student) who understands and says she felt this way after her first interview worrying how she could analyse the data properly. God I haven't even got that far in terms of worrying!! I have decided that I need to embrace my concerns and see interviewing as a process. I won't get it right first time but the clinical doctorate is as much about developing me, my research skills and my thinking as it is about writing a doctoral thesis. So I am embracing the slight anxiety I have hoping that it will help me to perform well on the day. I am an experienced clinician and spend my whole day using my communication skills and socratic questioning so this will stand me in good stead. However I need a bit of control and I am going to spend some time formulating a checklist so that I don't forget anything related to the interview process. I will also consider questions I may wish to ask and how I wish to phrase these based on research evidence and my clinical experience. I won't use these questions to rigidly guide the interview as this will be determined by the answers given by the participant however they will be helpful if I run in to problems with my thought process during the interview or with the detail provided by the participant.

My other main concern is that the digital recorder will work. I have had trial runs with it, changed the batteries etc and again feel it is totally beyond my control. I will watch the digital recorder occasionally during the interview to see the red light, rec

and the time changing. I need to remember that if the recorder did not work I can take field notes and may have to perform an additional interview on another participant.

#### Field note: participant 2 post-interview

I felt this was a difficult interview initially. The patient told me that he had not spoken to anyone about his diagnosis or treatment and I think he found it difficult to articulate his experience. I had to ask more direct questions and probe more and I was mindful of this as I did not want to influence the interview. The interview was a bit chaotic in comparison to Interview 1, jumping back and forth in sequence. I wonder if this is because participant 1 had reflected on the experience and talked it through with his wife. I checked the transcription against the file from the digital recorder but could not make out 2 sentences and when I tried to recheck the file I was unable to access it on my hard drive. It appears I had saved a short cut only to the file and not the file itself before deleting it from the recorder. I will have to ensure that this does not happen again.

#### Field note: participant 6 post-interview

This interview was really hard work. The man spoke really quickly and while he was keen to help in any way, I felt as though I had to drag information out of him. During the interview I thought this patient down-played his emotions and changes experienced. After consideration I think he sees all changes as small and necessary as he relates them to survival. He also is used to managing chronic illness and has adapted his lifestyle to reflect limitations. Down-playing change also means that he does not have to alter his self-concept.

## **Appendix 14: Memoing**

### Participant 2: normal body image

Participant 2: 'I wasn't overweight, about 15 stone and see my body was really working, well it was reasonably working.'

In a similar essence to the first interview it would appear that often when considering appearance men immediately think about their weight – perhaps this is considered to be an indicator of health. It also seems as though when the body is functioning to an acceptable level, there is no real consideration given to function. Our bodily function appears to happen most frequently at a subconscious level and it is only when there are changes which cause limitations that it comes to the fore. The second participant lived with a chronic back condition which changed his function however he appears to have accommodated this into his life – a new 'normal' per se. Is this what happens after the changes caused by cancer?

### Participant 4: feeling alone/being misunderstood

There is something within the data about this patient feeling alone, isolated or misunderstood. On a number of occasions he speaks about his local GP surgery not understanding what has happened to him and the implications for his ongoing medical care. Even more concerning is the fact that he feels that they just don't care:

Researcher: Do you think there is a part of it that you just have to experience, go through it on your own?

Participant 4: Aye, that's what I've been doing. Doing it myself. No point asking the doctor down there, they know nothing about it. Dr Wong is the only one that's studied a bit on it. Dr Park doesn't know nothing about it. None of the doctors do. What I do is ask for Dr Wong instead of Dr Park and Dr Park is my doctor.

Researcher: Sometimes it is good to go and see the same person. Does it make you lose confidence in people if they don't know what has happened or they don't understand what has happened to you?

Participant 4: Especially professionals if they are not interested in learning about it. Dr Wong the girl said she is learning. So I gave her that (information) and I said that's for Dr Robertson as she knows nothing about it. She might learn because she might see me again and I want them to tell me what's wrong.

Participant 4: I was running out and I still had a wee bit oramorph but not much and they didn't want to order the oramorph cause I already had enough, I already had some. But by the time I got it, it was a drama, it would take 48 hours to get it, 7 days all in if it was a holiday but they weren't looking at it like that. It was annoying me so I had to explain to the Doctor. She didn't look that happy. She said there are 4000 people in this surgery and you're the only one with this in this surgery. We're learning. You don't need to get angry. Listen, I've got it and you should be telling me what I have to do, not me having to tell you which was annoying for me. I wasn't happy about it all.

Researcher: Something that's really difficult about people not understanding and you feel that their not even compassionate to you?

Participant 4: No they don't care. The stuff I've had from doctors – no they don't care.

I think this reflects the difficulty with patients who experience something that is quite rare and unique. It must be frightening for them to not only deal with the changes themselves but have to try and make others understand, including HCPs.

#### Participant 6 - delayed diagnosis

Again in this interview the patient shows signs of being an expert in terms of his body. He assessed his throat problems in relation to his previous health history. This led to a delay in diagnosis when the symptoms were intermittent initially and perhaps not severe enough for him to consider that something else was going on. His thoughts appear to have been mirrored by his HCP initially. Patient 6 points out

at an early stage of the interview that there was not a great prognosis associated with his diagnosis/staging. He goes on to discuss that treatment options were limited in terms of his quality of life. Most patients with HNC are diagnosed at a late stage and there interpretation appears to affect their perception of appearance and functional change.

Researcher: and then you were diagnosed with cancer and what took you to the Doctors?

Participant 6: I had a pain in my throat you see. I had been bothered with sore throats all my life which is probably why the cancer got to that stage before I went and did anything about it because I was getting a sore throat and I was assuming it was the old problems so I would say I would go to the Doctor but within a couple of days it would go away so I didnae bother myself. I think that went on for certainly a year maybe more. I was just assuming it was the old problem that was clearing up and then I got one that wouldnae go away and I went to my Doctor and she assumed the same looking at my history. She just assumed it was the same and put me onto antibiotics and when it didnae shift it, she sent me up here.

Researcher: Did it come as quite a shock when you got the diagnosis?

Participant 6: Aye, aye, because I mean, it was very well developed. There wasnae a great prognosis with it you know.

## **Appendix 15: Memo showing comparative analysis/theory development**

### Memo 5: defining cancer as an interruption

I feel that the patients I have interviewed so far define their diagnosis and treatment as an interruption - a crisis followed by treatment and then recovery. Participant 5 spoke about returning to work and the challenges in recognising his limitations. Participant 4 also had more extensive change and visible change which was permanent and seemed to be describing illness as an intrusion because of the care he had to do throughout the day to manage his stoma and voice. Charmaz found that people experience chronic illness in 3 ways including as an interruption to their lives. Charmaz suggests that defining illness as an interruption assumes that illness is temporary, of short duration and with a predictable outcome: recovery (P13, Good days, bad days). This involves temporary putting aside their identities and selves while they recoup and wait for recovery and means that illness remains external to the self. Charmaz states that “*before and after*” contrasts can become quite striking and these contrasts can call into question their taken-for-granted notions about their capabilities. Charmaz identifies that ill people limit their activity and autonomy rather than tacitly affirm that they have suffered further physical losses. This means that they do not have to acknowledge decline as this symbolises an intolerable assault on their self-concept. Defining chronic illness as temporary fosters experiencing time as waiting time – waiting for results, waiting for treatment, waiting for recovery and return to normal. Charmaz states that “*they wait to get through the present so that ‘real life’ can go on in the future just around the corner*” which reflects my findings.

## **Appendix 16: Participant progress report**



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

Room 500  
Level 5 West  
Crosshouse Hospital  
Kilmarnock  
KA2 0BE  
01563-545501

2<sup>nd</sup> October 2012

Dear

**Study title: the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer**

I am writing to update you on my progress with the study which you took part in last year. Interviews were performed between April 2011 and December 2011. The process of analysing the data is nearly finished and I am about to start writing up my thesis. My aim is have this done by June 2013 and I will send you a copy of the results when they are available. Once again I would like to thank you for your participation in this study,

Best wishes,

Caroline Hood (Lead Researcher)

## Appendix 17: Participant consent form (V1 - 18 October 2010)



**UNIVERSITY OF  
STIRLING**

DEPARTMENT OF  
NURSING AND MIDWIFERY

**Study title: the experience of appearance and functional change in the first 12 months after diagnosis for men with head and neck cancer.**

### PARTICIPANT CONSENT FORM

	Please initial box if you agree
1. I confirm that I have read and understand the information sheet (insert version and date) for the above study.	
2. I have had the opportunity to consider the information provided and have had any questions answered.	
3. I understand that my participation is voluntary and I can withdraw from the study at any time without giving any notification or reasons.	
4. I understand that withdrawing from the research study will not affect my treatment in any way.	
5. I understand that medical, social and demographic information will be accessed from my Cancer Nurse Specialist.	
6. I understand that all information from this study will be stored in a password protected computer and locked filing cabinet. Only the researcher will have access to this information.	
7. I consent to audio taping of the interview and understand that my name will not be mentioned in any reports or articles.	
8. I agree to my head and neck cancer consultant and GP being informed that I am involved in this study.	
9. I agree to participate in this research study.	
10. I would like a summary of the project findings.	

Name of participant

Signature

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of researcher

Signature

Date

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



## **Appendix 18: In-vivo code “being under siege”**

P1 uses a war metaphor when describing treatment (chemo-radiotherapy) and the changes experienced. “*Being under seige*” appears to capture the exerieence for men when they are focussed on getting through treatment while navigating changes. It suggests that the individual is in a war zone and what is happening is beyond their control. The participant goes on to explain that food choices and finding the right thing was impossible (“*not knowing*”) and had to be endured. He didn’t want to be percieved as awkward especially when he didn’t know what he could eat. “*Being under seige*” fits with social context of the battle against cancer and masculinity where content of conversation focuses on heroism, conflict and achievement.

P1: *“I don’t know. You just sort of triggered it in my head now and I am wondering. Maybe you’re just not in the right frame of mind. You’re under siege as far as all the treatment is concerned. You’re not thinking right. You are presented with options on food. You don’t want to be a bugger. You have got other guys in the ward. You’ve got women in the ward. You’ve got people doing their best. Do you want to be a pain in the neck? I don’t know. I think there is an element of that in it.”*

P1 goes on to use the metaphor “*laid out*” when talking about how incapacitated he was. His visitors were talking over him about normal life which he seemed removed from.

## **Appendix 19: Transcript participant 12**

R: If we can just get started, I would like to just ask you a wee bit about before your cancer diagnosis, if that's okay. About how you felt about your appearance and function, so how you looked and how your body worked before that.

P12: Everything was fine before [Feeling fine](#). To let you understand this is the second time I have had this [Situating self: prior experience of cancer](#). I had this in the 90s and had a skin graft in there and I was clear for 10 year [Surviving cancer](#).

R: Inside your cheek?

Picipant 12: Yes, it was internal. So I was clear for 10 year. That's how I knew that it had come back [Recognition of symptoms due to prior experience](#). That it was cancer.

Researcher: You felt things changing.

Participant 12: Well it started off I couldn't brush my teeth there. I couldn't get a toothbrush down there because the growth was there [Acknowledging change from normal](#). So that stopped me getting there. That's when I went to the doctor, but I knew before I went to the doctor [Expecting cancer diagnosis](#). I just phoned the doctor so he would send me to hospital but I actually think they would just cut it into another skin grafting, but he told me that wasn't going to happen this time [Expecting a treatment plan based on prior experience](#).

Researcher: So your experience previously was quite good in a way because it sent you to the doctors fairly quickly rather than trying other things beforehand. So in the lead up to this cancer diagnosis you were fairly fit, your appearance and things you were quite happy with.

Participant 12: Yes, everything was fine up until then [Feeling fine](#).

Researcher: Then you went to your GP and you got referred up to the Southern. When they first started talking to you about what they were going to do and giving you information about the surgery you were going to get, how did you feel about that?

Participant 12: I was actually okay about it, I don't know why. I actually got to the stage where I actually knew if I didn't have the surgery it would have just grown and I would have ended up dying or I would have ended up with a tube up my nose because I couldn't chew [Rationalising treatment as there is no alternative](#). Obviously if you get a growth in there it's not going to get smaller. It's going to get bigger which means it will stop you chewing which would stop you eating [Trade off](#).

Researcher: So what you are saying is that when they were talking about surgery or different things, at the back of your mind the main thing is about surviving cancer.

Participant 12: Yes [Priority to survive cancer](#).

Researcher: Getting it out and getting past it sort of thing.

Participant 12: Basically, because I am getting to that age where I don't have a lot of time to waste. I started off feeling sorry for myself and what have you and all the rest of it and then I decided I was just wasting my time [Coming to terms with diagnosis](#).

Researcher: Was that before you had your surgery?

Participant 12: Yes. I probably sorted myself out maybe 2-3 weeks before actually I went in [Coming to terms with diagnosis](#).

Researcher: So when you first found out you had the cancer back it took the feet from you a bit.

Participant 12: Yes. I started feeling sorry for myself, and why me and stuff like that. Talking to Mr Wales seemed to help it an awful lot because there was no hiding anything with him. He told me straight, everything that was going to happen he

didn't hide anything or say maybe this will happen or maybe that will happen [Being prepared through information provision](#). He basically told me the worst case scenarios [Being prepared for the worst](#). He told me that if it was an operation it would be 3-6 months I would be off my work and if I needed radiotherapy I would be off for a year. So when I was actually going into hospital for the operation I was just looking at it that I was going to be off for a year [Preparing self for maximum treatment](#).

Researcher: So you prepared yourself for the worst in a way and then anything else as you say, when you found out you didn't need radiotherapy was a bonus to you. So getting information about exactly what was going to happen in a sort of best case scenario and worst case scenario really helped you then?

Participant 12: Yes, because depending how quickly I healed I would be back at work within 3 months [Situating self: employment](#). If I need radiotherapy then it would be a year. As it turned out I was back at work in 3½ months.

Researcher: When they were talking to you about what they were going to do in surgery with the flap and different things, how did you feel about that?

Participant 12: I felt okay about it, I don't know why but as I say I basically wanted rid of the cancer [Focus on removing cancer](#).

Researcher: So it was a kind of payoff.

Participant 12: Yes, I didn't care what he did. If he got rid of the cancer I was quite happy with everything else [Focus on getting rid of cancer](#). But I mean he did tell me everything. He even had my hand and he was showing me how you have two lots of veins going into your hand and that you only need the one because he would be taking away the other one because you have got to have the blood vessels and what have you [Detailed information](#).

Researcher: So they took the reconstruction from your forearm.

Participant 12: Yes, and he also took - there is a nerve goes through here from my bottom lip, basically I can't feel my bottom lip now [Loss of sensation to lip](#). If I am drinking I have got to use a straw which doesn't particularly bother me [Using a straw to prevent dribbling](#). I am now going to the Dental Hospital as well to try and get some teeth [Trying to return to normal: dentition](#).

Researcher: Right. So did they take out teeth at the time of surgery?

Participant 12: Yes, they also took bone as well and he did a neck dissection as well to take the gland [Having scarring](#).

Researcher: And in terms of the scarring and things like that?

Participant 12: It doesn't bother me, if it bothers other folk it doesn't bother me [Not being concerned about others perceptions](#). They actually told me to put cream, I have got that E45 and I put that on there and I put it on my neck as well [Self management: following HCP advice](#).

Researcher: And that just helps to moisturise it.

Participant 12: Well I think it helps. I think that looks very good actually [Feeling positive about scarring](#).

Researcher: I think it looks good as well. So you had your surgery and then you came home, and as you say the first few weeks after your diagnosis when knew you were going to get surgery was a wee bit hard but then with the information you started to get your head around things and just think about getting on with it.

Participant 12: In fact, I am more nervous about going into the Dental Hospital to try and get these teeth than I was going to get this done [Feeling more nervous about cosmetic procedures \(v essential\)](#).

Researcher: Are you?

Participant 12: Which is rather strange? I don't know if it is because I had to go to the hospital to get this done, whereas going to the Dental Hospital, I don't feel there is a need to go and get teeth [Essential v cosmetic](#).

Researcher: So were you scared then of the dentist before.

Participant 12: I hate the dentist, I don't like the dentist.

Researcher : Right.

Participant 12: I mean I go to the dentist every six months [Situating self: self-care](#). It shows how quickly that came, the dentist always checked that when I went. I went to see him, I think it was in May and it was okay, but by the August it had kicked in [Cancer developing over a short time period](#).

Researcher: So within a few months.

Participant 12: Yes, because the dentist always checked it every time I went and I went every six months because she could see into my mouth better than I could see [Feeling reassured at dental reviews](#). But that is how quickly that actually kicked in.

Researcher: And was it painful when you were brushing your teeth or what was it that you noticed.

Participant 12: No, it was just because I couldn't put the brush down there because the growth had actually come out [Presenting due to growth](#). Because I have the beard you couldn't see, whenever I shaved, I had to shave before I went in, and whenever I shaved you could see the lump in my cheek [Growth hidden externally by beard](#).

Researcher: So your beard tended to hide it a wee bit.

Participant 12 wife: Can I speak?

Researcher: Of course you can.

Participant 12: You know his family is predisposed to jowls, like wee hamsters and we didn't any of us really notice it because of the fact that, well he had a lot more weight, he was carrying a lot more weight at the time and his face was puffy. But that was the way he was he had been like that for ages and you know you just think oh well he is getting older [Others not seeing/recognising growth](#).

Participant 12: And getting fatter, that's what she thought, but she's not saying that.

Participant 12 wife: The night he took the beard off before going into hospital, boy could you see it, but the beard disguised that [Growth disguised externally by beard to pt and others](#).

Researcher: Did you have a heavier growth then because you have quite a light growth now.

Participant 12: I am actually shaping it around that, you know to keep the two sides even [Camouflaging scarring with beard](#).

Researcher: Sometimes, you know other people have said that if they have had beards and then lost their beards and things like that, although it is a minor thing, it can be difficult because when you look in the mirror sometimes you sort of sometimes don't feel like yourself in a way.

Participant 12 wife: Well you were quite fortunate because you can actually still keep your beard and moustache and everything else, you were quite fortunate [Feeling fortunate/Being normal](#).

Researcher: So that kind of helped in a way.

Participant 12: Well I am just basically back where I was [Returning to normal](#).

Researcher: How did you feel once you got home about going out and different things?

Participant 12: I actually came home on the Thursday then the Friday was the day when all that snow started last November. So it was a bit dodgy, I just didn't want to go out in case I fell. The clinical nurse specialist was here as well and she told me that when I got out of hospital I would feel tired [Information provision/Being prepared for possible fatigue](#). If I was going to walk anywhere to remember I had to come back. But when I was in the hospital I used the stand, you know that the drip was in, and I used that as a crutch and I started walking about with that, I mean you're not doing anything else in hospital so I was just walking about [Self-management/setting goals to improve mobility and strength](#).

Researcher: So did that kind of break up your day.

PATIENT 12: Well I thought so, and I was sitting doing my neck exercises that they gave me [Control/Self-management](#). But then when they stopped giving me the drip 24 hours, it was just at night and the stand wasn't there anymore. I started walking then although I had to walk along the wall. It was amazing how much weight I was actually putting on that stand [Needing support to mobilise initially](#). I didn't realise that stand was as much a crutch as it was until I didn't have it then I realised I was using that more than I thought I was using it. So then I just walked along the wall and just built myself up [Setting goals/Building self back up](#). Then when I came out I felt okay [Feeling okay](#).

Researcher: So when the snow passed and things like that did you start going out?

Participant 12: Yes, we were walking everyday [Self-management](#).

Participant 12 wife: In actual fact we were still out when it was snowing.

Participant 12: She wouldn't let me go out myself, I had to go out with her [Rehabilitation being supported by family](#).



Participant 12 wife: When he did come out he wasn't tired. Elaine had said perhaps he would want to go for a sleep in the afternoon or that type of thing. In actual fact when he came out, certainly we were sitting about a lot and the district nurses had to come in every second day, initially anyway, to dress cause he had a skin graft here. The weather was snowy and icy and I was a wee bit concerned about that but we did actually go out I think maybe the second week you were home. We walked a sort of square and then got it bigger and bigger [Gradual improvement in mobility and strength](#). He never ever was exhausted or needed to go for an afternoon nap or any of those things [Comparing against information provided](#).

Researcher: I think if you are quite fit beforehand then that stands you in good stead. Had you always kept yourself quite fit?

Participant 12: I did walk quite a lot as well. We always walked as well even when we were on holiday we walked a lot as well [Situating self: walking for fitness](#).

Participant 12 wife: That was one of the things that Mr Wales had said, you know his fitness level was good and that helped him a lot and also your positivity as well [Physical fitness/having a positive attitude](#). Your positive attitude to what you were doing and he said that helped him as well and obviously the fact that whenever we got the news that he didn't have to go down the therapy route [Having a positive attitude](#). That was a bonus as well. We were fortunate in that sense that we didn't then have the worse case scenario to follow [Benefit-finding: feeling fortunate as no other treatment required](#).

Researcher: As you say you were off your work for less time and things like that. I know though you were quite honest and if it had to have been, it would have had to have been and you would have built yourself up from the surgery and got on with it. But I suppose it lets you return to your normal life quicker doesn't it. So your physical fitness you built back up and things. And how was it for you going out socialising or going out to the shops or different things like that?

Participant 12: That was not a problem. The only problem I actually have is eating because I can't feel that so obviously when I am eating if there is anything runs then

I don't know [Dribbling when eating](#). So actually I have got a small mirror which I use when I am eating to see [Using a mirror to check self when eating](#). But I still go out to restaurants and what have you [Continuing to socialise/eat in social environments](#).

Researcher: Good.

Participant 12: We have not stopped going out [Continuing to socialise](#). I still go out, I may make the napkin a wee bit dirtier than I used to do but apart from that I have got to watch what I am eating as well [Adapting diet to minimise dribbling when socialising](#). Obviously when I am out I don't eat things that has a lot of gravy or things like that.

Researcher: So you kind of modify and you are a wee bit careful.

Participant 12: Uh-huh where as before I could eat anything [Change from normal](#). I stopped actually, I used to have soup all the time but because soup is obviously runny I didn't have soup when I was out [Adapting diet to minimise dribbling when socialising](#). I would have it in the house but not outside the house [Feeling more secure in the home](#).

Researcher: So when you're out do you use your wee mirror to check or does your wife tell you.

Participant 12: Yes she tells me if there is anything at the corner of my mouth or what have you [Coping strategy: having a system of informing](#).

Participant 12 wife: If we are out socially, well obviously most people understand [Feeling understood](#). What we do is, you know if he is eating and a bit just sort of lodges there I just kind of go (nods head) ..... and he takes the napkin. It's not really a problem [Incorporating coping strategy into life](#).

Researcher: So you have a wee signal or system that you have developed. That's good.

Participant 12 wife: It wasn't really a conscious thing to say – oh I kind of don't really want to go out, and it was initially for you a bit of a hassle, well not really a hassle but maybe a wee bit self-conscious initially, when you went out at first but he didn't want to stop doing it [Feeling self-conscious/returning to normal](#). Of course obviously he plays golf, he is over at the club so all those things he had to keep on doing and of course he always drinks with a straw now [Returning to normal: maintaining prior interests](#).

Participant 12: It was rather strange to start with when you are standing in the golf club and people saw me drinking out of a straw [Feeling strange initially when adopting coping strategies](#). Now when I go over there and ask for a pint they just put a straw in the pint now [Others becoming aware of coping strategies/A new normal](#).

Researcher: There will be no thought about it.

Participant 12 wife: In fact we really feel quite fortunate because we haven't come up against any pit falls [Feeling fortunate](#). Naturally obviously when we went out at first, and you have said yourself sometimes, you can see people looking, you can see people looking but we don't think too much of that, because I've done that myself, you've done that yourself [Being aware of others looking at changes](#). You do, you know it's a human trait [Rationalising this as a human trait](#). You look and go oh, and look again.

Researcher: Absolutely.

Participant 12 wife: What patient 12 normally does is just give somebody a wee smile [Using non-verbal communication to engage others](#). In actual fact we hadn't seen a chap around, a local guy that we know, we hadn't seen him for a wee while, and when he saw patient 12 at first he thought he had been in an accident and that's why he hadn't seen you around and then he saw you. A couple of people have thought that and said to me – what happened to your husband is he alright [Disclosing changes](#). Maybe some people think he has just had a bad accident with the car, that kind of thing [Others making assumptions about cause of changes](#).

Participant 12: Mr Wales actually asked me that last time I was in if I wanted to go and see a make-up girl. That's what I said to her (his wife) – can you imagine me putting my make up on before I go to work [Threat to masculinity](#).

Participant 12 wife: I think it is possibly that he is not vain [Considering concerns about appearance as vanity \(negative connotation\)](#).

Researcher: Just to try and colour it a wee bit.

Participant 12: The thing is I don't see it. I only see it when I am shaving, so it doesn't bother me [Not 'seeing' changes](#).

Researcher: As you say I think sometimes when you are so positive and it doesn't bother you, then it doesn't bother other people in the same way.

Participant 12 wife: It is something that we haven't really come up against any real pit falls [No negative experiences](#).

Researcher: In a way just at the beginning when you are adapting to the changes it sounds as if as you say sometimes you are a wee bit more conscious at that very beginning point. And as you get used to things like using the straw, or working out what to eat in restaurants or developing a wee signal thing you're a wee bit more self conscious but after that it just goes back to normal.

Participant 12 wife: There are times sometimes when we are out, I sometimes do it at home as well if we are sitting having dinner and he gets a bit stuck there, I'll go – clean your mouth [Coping strategy](#). But there are times when we are out I forget you know because you have just adapted so well and from coming out of hospital and now again I think that is a way of eating [A new normal: way of eating](#). You know you would eat with a knife and fork and the prongs down, he goes the other way now he turns the fork and eats that way because that seems to work better [A new normal; way of eating](#).

Participant 12: I can't open my mouth the same as I used to [Having altered mouth opening](#). So when I use the fork with the prongs down the food would hit my top lip and fall back down onto my plate. It got a bit frustrating but you just turn the fork round the other way [Feeling frustrated](#). It is just little things like that basically [Making small changes to adapt](#).

Researcher: A wee bit of a process.

Participant 12: Yes, just finding the right way to do things [Finding the right things to do](#).

Participant 12 wife: And really now you don't even think about it at all. Do you.

Participant 12: When I started eating soup in the house as well I would use a smaller spoon instead of a soup spoon. Just whatever suits me [Finding the right things to do](#). It's the little things, things that nobody would ever think about but because it's me I have got to think about them [Becoming aware of the little things](#).

Researcher: Finding out what works for you in different situations. Because you are doing that all the time is kind of second nature to you.

Participant 12: That's why I don't have soup outside because they give you a soup spoon which is actually too big for my mouth. I suppose I could ask for a different spoon right enough. Or you can eat something else [Finding alternatives](#).

Participant 12 wife: He carried straws with him for his work and if we are out, sometimes you take stuff with you, but I now always carry a couple of straws in my bag so if we don't get a straw or whatever, you know we always have one [Being prepared: planning ahead](#).

Participant 12: Normally every place you go there are straws in her bag anyway [Being prepared: planning ahead](#). Even if we go out for meals there will be straws

because it is normally a soft drink I have anyway. So a straw will come with the soft drink anyway [A new normal](#).

Researcher: And did you say that you had lost weight after the operation.

Participant 12: I lost about 2 stones [Marked weight loss](#). Well I actually went 10 days without eating because I had the tube up my nose because I wasn't allowed to eat or drink for 10 days, so the weight could be because I wasn't eating or drinking [Being unable to eat and drink](#).

Participant 12 wife: You had the tube here as well. He had a trachy in for 10 days so obviously he couldn't eat or drink [Changes to eating and breathing](#).

Participant 12: That came out in high dependency.

Participant 12: That's right so it did. But he was just fed through the tube for 10 days and the weight just fell off of him.

Participant 12: That's why I lost the two stones.

Participant 12 wife: Which was a benefit [Benefit finding](#).

Participant 12: I wouldn't advise it as a diet right enough.

Researcher: So you lost weight.

Participant 12: About two stones.

Participant 12 wife: And he has kept it off [Maintaining positive changes](#).

Participant 12: The reason I kept it off is I don't eat as much outside now. Like when I went over to play golf, after the golf we would have something to eat, but I don't do that any more [Altered patterns of eating](#). When I was out I would eat different things. I mean I can't eat a roll any more. So I couldn't go and buy a roll on sausage or a

roll on bacon or anything like that because it is too thick. Any bread I eat has to be thin bread [Impact of an altered diet](#).

Researcher: So that you can get your mouth open.

Participant 12: Yes. The rubbish is eliminated basically and obviously I can't eat crisps either. So all the things that were bad for me have been cut out my diet which is why I kept the weight off [Benefit finding: having a healthy diet](#).

Researcher: But you feel better for it, it is not like you have lost the weight and you have lost a lot of your muscle and you don't feel as good because of it.

Participant 12: No. I prefer the way I am at the moment. I am quite happy [Feeling happy](#). I would have liked to have lost the weight before but I didn't have the willpower [Benefit finding](#).

Participant 12 wife: And of course you were boosted by how many people have actually said, oh you are looking really good.

Researcher: Some of the other patients have said to me when I have been interviewing them that they have talked to other patients or seen them when they were on the ward and used them as a kind of benchmark or these kinds of things. Did you speak to any other patient's or meet any other patient's on the ward.

Participant 12: I was on that ward and there were four of us. As far as I was concerned I was the best of the four [Downward comparison: comparing self to others worse off](#). There was a guy across that I was speaking to who smoked and he had one of those special cigarettes. You know you just kept puffing it all the time.

Researcher: One of the wee inhalators.

Participant 12: No, he got it from abroad, I can't remember what it was but you smoked it and you got the smoke and everything else but it didn't burn down, it wasn't lit. To light it you just dragged on it. Now when he was going away his two

daughters came in because he was always going to get fed through the tube and it was in through his belly button and that was him. Now as far as I'm concerned I am a lot better off than he was [Downward comparison: comparing self to others worse off](#). And the other two guys that were in there one of them actually walked out and he wanted to die. He walked out, it was actually at a change of shift. The day shift people were going away and the night shift was just starting and the head nurse on day shift was telling the night shift people all that went on that day. Well he always just went for a walk, but he walked out and went to the lifts and walked outside. They brought him back but he didn't want the doctors to see, he just wanted to die. I was a lot better than he was [Being faced with mortality/Downward comparison: comparing self to others worse off](#).

Participant 12 wife: It makes you think, you know, I think in a sense how lucky patient 12 was and he said that himself – I am very lucky here [Feeling lucky to survive](#).

Participant 12: So as far as I was concerned I was the best of the lot. That is another thing that got me as well, you think you are in a bad way but when you see some of the other people, you're not really [Interpreting personal situation in relation to that of others](#).

Researcher: How did you find it, you said you were off for the time and these changes happened you adapted to what had happened and the changes that you had and then you went back to work. How was it when you went back to work?

Participant 12: Not very well. I preferred when I wasn't working which is why I am going to retire next April anyway [An altered future outlook](#). I will be 65 next April. I actually enjoyed that time when we were off. I don't know why but we were spending all day together so we hadn't thought about anything [Altered priorities/spending time together](#). Before this all happened I would get up in the morning to go to my work and I would just have my breakfast in the kitchen. Whenever I stopped we would get up together and come down and we would sit at the table having breakfast. Since I have went back to work we still do that [Benefit finding: a positive change in relationship](#). We still get up in the morning and sit at the table and have breakfast



together and we have done that since I went back to work. It's wee silly things like that that change as well [Benefit finding: a positive change in relationship](#).

Participant 12 wife: Sandy works, he is not going to work. He works from home.

Participant 12: I cover the whole of Scotland. I actually calibrate the equipment in garages. If you take your car in for an MOT all the equipment used to check your car I calibrate that. So I cover the whole of Scotland. So like this week I was up in Inverness and Aberdeen. I could be down at Dumfries or Stranraer things like that [Situating self: working at home and away from home](#).

Researcher: So do you just travel on a daily basis or do you stay.

Participant 12: Well this week I was staying overnight in Aberdeen.

Researcher: So does that mean from what you are saying that having had the cancer and been through the treatment that it has made you think about your life in general.

Participant 12: Well it made me discover that I am not immortal, I am going to die [An uncertain future](#). I never ever thought about dying [Being faced with own mortality](#). But I have worked now since I was 16, so I reckon I am due a couple of years of quality time [Changing priorities](#).

Researcher: So your priorities just change a bit.

Participant 12: Yes.

Participant 12 wife: Yes, just slightly. I retired 3 years ago, it made me think I do want participant 12 to retire when he is going to retire because we thought at that point that was him retired. It has just made me sometimes think – slow down a wee bit [Changed priorities: a shared future](#). We don't spend every waking hour together but it makes you think well there is that time there that we should maybe put aside. It's the old cliché, all the things that you think are important aren't really that important at

all [Changed priorities](#). It does in some respect give you food for thought and you think – slow down a wee bit, there are lots of other things out there to do. The minutia is not important [Changed priorities](#).

Researcher: That you want to do. It sound as if it has had a positive effect in as you say you just maybe appreciate each other. Or you make the effort to sit down and have breakfast, whereas before it was just something you had to do to get out the house to get to your work.

Participant 12 wife: Patient 12 obviously doesn't go to the office or go to work every day where he sees the same people, although you do see the same people but it could be six months apart [First contact with people](#). So you are seeing different people every day which in the beginning must have been a wee bit difficult, because everybody wants to know – oh what happened to you, you haven't been in here for three months, you know - what happened to you? [Disclosing information when meeting people for first time](#).

Researcher: How was it when you were telling people for the first time?

Participant 12: I just told them [Being confident to disclose information](#). A lot of people wouldn't ask. A lot of people didn't even mention [People not wanting to ask](#).

Researcher: Did they not?

Participant 12: I mean even when I went in at first I never told anybody [Lack of disclosure initially](#). I didn't tell anybody at the golf club either, I only told one guy and then when I never turned up they asked him why [Selective disclosure](#). Because I didn't want to over there and people asking me questions. I wanted to go over there and play golf not to have 40 questions thrown at me [Wanting to socialise as a distraction](#). That basically why I didn't tell anybody. Which was a bit selfish I suppose on the friend that I did tell because it meant that he had to tell other people, but I didn't want to go over there and have a conversation about what I was going through and people feeling sorry for me [Avoiding repeated disclosure/pity](#).

Researcher: Are you talking about, just so that I am clear, before you went in and had you surgery?

Participant 12: Yes. I never told anybody. Obviously I told people at work because I was going to be off and also my family but that's it [Selective disclosure](#). I didn't bother telling anybody else.

Researcher: I suppose it's not really selfish. It is just allowing you to get your head around things, isn't it. And so afterward when you go out and meet different people that haven't seen you for a while if come out and ask you do you just tell them.

Participant 12: Yes. I just tell them.

Researcher: And if they don't say anything do you say something or do you just leave it and just get on with things?

Participant 12: It's like a lot of other things, what do you say to somebody if their father or mother dies? It's just something like that. If somebody wants to ask me I will tell them. If they don't say anything I don't bring it up because it can be a bit of a conversation killer as well [Acknowledging social awkwardness in discussing cancer](#).

Researcher: Is there is a point where you want to move past it as well? You know you have had that experience.

Participant 12: Well I have moved past it. I am just carrying on [Moving on/carrying on](#).

Researcher: Just getting on with life.

Participant 12: Yes.

Researcher: Is there anything in terms of what you have been through, advice that you would give to somebody else that was going to go through the same thing.

Participant 12: Don't smoke. I was perfectly happy with everything, even from the nurse specialist coming to see us and going into hospital. Everybody told me the truth which I think helped me [Being informed](#). Because people try to sugar coat things and then something happens, but I was told the best case or the worst case as well, nothing was held back from me [Detailed information](#).

Researcher: So accurate and realistic information so that you can have a plan in your mind helped you.

Participant 12: A complete picture so you know exactly what's happening [Having the complete picture](#).

Researcher: It sounds as if as well, when you were in the rehabilitation stage, when you were getting back on your feet, the more you could do for yourself helped, you said earlier about doing the neck exercises and starting to get yourself more mobile.

Participant 12: Basically it was because the nurse specialist said I'd be tired when I got out so that's why I started walking around the hospital [Self-management/goal setting](#).

Participant 12 wife: I think the thing is you know, the advice would be to take on board, I know a lot of people can't face what they are being told but you were in a position where you were facing what you were being told and this was what was happening and there wasn't really another path at that point and doing what you are told to do, taking the advice that is given to you [Taking HCP advice: helping yourself](#). Not being big headed but, the things that you were told to do, you did and I think it is good to take the advice. It may be perhaps difficult at sometimes, it may be painful sometimes but if that is the advice you are given 99% of the time that is what is good for you so do what your are told to do [Taking HCP advice: helping yourself](#).

Participant 12: Even the physiotherapists were good as well. They came in and told me everything I needed to do [HCP support](#). It was even the same with my arm, they said when you are walking move your arm, because you have a big bandage on it

don't just let it hang. Keep it moving and that will help it heal better as well [HCP advice/self-management](#).

Researcher: Some people have said to me that, it's kind of a split camp I suppose, some people finds that information really prepares them and helps them through the experience. Other people hear the information but actually sometimes they feel there is no preparing them for the experience that they are going to go through.

Participant 12: It might depend on your age as well, how young or how old you are [Age changing experience](#). Maybe it is because how old I am that I was wanting to get this done, get it over and carry on with what I have got left [Making the most of life left](#). If you were maybe in your 20s or you 30s you might start panicking, thinking well I am too young for this, I don't know it could be.

Researcher: And not taking it on board in the same way.

Participant 12: Yes.

Researcher: Is there anything else that you want to tell me that you think would be important and we haven't spoken about the changes that you have experienced?

Participant 12: No, not really.

Participant 12 wife: I think it has to be said that for what patient 12 had, in the short time that it took him to recover he healed very quickly [Healing quickly](#). Everything seemed to just flow, and I know that is not everybody's experience. For us from being told exactly what was wrong every piece of information was given to us and there was nothing held back [Having detailed information](#). I was brought into it, you know I obviously came with him the first couple of times he went [Involving the family](#). Even just the initial things you know, when he went for the first appointment and then it was the CT scan that day, wasn't it, and biopsies as well. All in the one day. Of course we knew ourselves obviously what was happening but then you are given the information. We were given exactly what was going to happen. There was nothing held back, everything just flowed even to the point that he was given a cancellation a

week earlier than he should have done [Having detailed information on pathway](#). So the day he should have been operated on he was already a week down the line already [Benefit finding: feeling fortunate](#). He was on recovery a week earlier and everything just flowed and touch wood luckily it had from that point [Recovering as planned](#). So our experience from the start to where we are now was very very positive [A positive experience](#). So from our perspective it seems like everything has just gone according to plan [Everything going according to plan](#). I know that is not the same for everyone else, but our experience has been very positive from the start to where we are now [A positive experience](#).

Researcher: It sound to me, listening to you, that your positivity is, well you know the way that you approach things and get on with things, has made those changes easier.

Participant 12: As I said before I did feel sorry for myself at the start [Feeling sorry for self at diagnosis](#).

Researcher: What sort of things were you thinking of at that point?

Participant 12: Basically just why me. Why couldn't this have happened to somebody else? Why did I have to have this again and feeling sorry for myself [Bargaining stage following a cancer diagnosis](#). But eventually it does wear away [Accepting diagnosis](#). Well I talked myself round it anyway so I was okay [Self talk](#). In fact when I actually went that day and Mr Wales came up to get things signed and what have you, he also told me then that if there was a problem with the blood flow, they may have to take me back in again, because I was in intensive care I wouldn't know anything about it. He actually asked me before and I had signed a paper for that as well. Then when the anaesthetist, I can never get my tongue round it, when she came to see me as well the same day. She actually told me she was about 20 hours one day in an operation, that's a long time. I thought I was a long time and I was 9 hours. She says it was a walk in the park with me at 9 hours [Downward comparison: comparing case to others worse off](#).

Researcher: I meant to ask you before, I am not very good at remembering things, you were talking about your teeth. I guess trying to get your teeth is the kind of final part?

Participant 12: They are actually making a plate at the moment and they have taken another CT scan. But they say they need to put bone in to build up the bone if they want to put implants in [Reconstructing bone to allow implants](#). I am not actually 100% about that, whether I want to go through another operation and get bone taken out my hip [Thought of considering reconstruction for aesthetics and functional reasons](#). So I am going to see how this plate works and if the plate works we will just leave it at that.

Researcher: Do you miss having your teeth?

Participant 12: I suppose I do. You know I can't eat an apple anymore [Altered diet](#).

Participant 12 wife: It sounds as though you are obsessed by food.

Participant 12: I used to have an apple everyday but I can't eat an apple anymore [Altered diet](#). I can't even cut an apple and put it in my mouth because if don't have anything on the top. If I want apples my wife just stews them [An altered diet; adapting to change](#). So I just eat them that way so I still get apples but not like sitting down to an apple.

Researcher: So if the plate worked that would be the icing on the cake. And if it doesn't you will have to make a decision.

Participant 12: Yes, well I have went 11 months, well it will be 12 months next week, without teeth. So if I can survive a year, I can survive [Surviving without teeth](#). So whether I have teeth or not, I mean the Consultant at the Dental Hospital says it will look better facial wise if I had teeth in. You see I never see my face except when I shave [Being unaware of appearance](#). If anybody else doesn't like my face they can look at something else [Others being aware of appearance](#).

Researcher: Well I suppose after 11 months you are kind of used to it, aren't you?

Participant 12: Yes. When I came out of hospital at first my wife had to mash everything up, everything was pureed, but then eventually you just move on [Making progress/moving on](#). It is like everything else you adapt to anything if you want to keep living [Adapting for survival](#).

Participant 12 wife: Strangely enough he didn't have prominent teeth. Even when he smiled teeth weren't a big thing. In actual fact he doesn't really look that much different [Looking normal](#). You know facially he doesn't look that much different [Looking normal](#).



## **Appendix 20: Final summary report (ref: 10/S1001/72)**

### Research aim

To explore how men with head and neck cancer experience appearance and functional change in the first 12 months following diagnosis?

### Research questions

1. What appearance and functional issues are important for men diagnosed with head and neck cancer?
2. How are appearance and functional issues experienced within the context of a life-threatening diagnosis of head and neck cancer?
3. At what point in the care pathway are appearance and functional issues important?

### Methodology

Semi-structured interviews were performed with 12 men with head and neck cancer who met the inclusion criteria. Grounded theory methodology was utilised following guidance from Corbin and Strauss (2008). Following initial open coding, selective coding and categorisation was performed as indicated below:

<b>SELECTIVE CODES</b>	<b>CATEGORY</b>
Feeling fine; Being normal; Appearance in relation to weight; Function in relation to physical fitness/work; Living with a chronic illness; Health beliefs/knowledge	Functioning
Cancer as a death sentence; Limited/gradual disclosure; Processing diagnosis; Speed of cancer pathway; Risky behaviours	Normalising change

Information provision/experiential learning; Rationalising change; Downward comparison; Peer support; Camouflaging/concealing change; Self-care; Support as standard care	'Being under siege': getting through treatment
Not knowing; Variable days; Trial and error; Goal setting; Graded exposure; Modifying expectations (cognitive reappraisal); Not being understood	Reclaiming self
Focus on returning to normal; Planning ahead; Acknowledging loss; Benefit finding; Essential 'v' cosmetic change; A changed future	Reconciling change; a new normal ( <b>Core category</b> )

### Summary of key findings

- Participants routinely described themselves as 'fine' or 'normal' when asked about appearance and function before diagnosis. At this time point participants spoke about appearance in relation to weight and function in relation to physical fitness and ability to perform daily activities to fulfil their role within family/society. For those men who worked, their work seemed central to their sense of self and self-identity.
- Interpretation of changes to appearance and function prior to diagnosis was based on the participant's understanding/experience of health and illness. Participants presented to healthcare professionals when changes could not be explained by their health knowledge and changes in appearance/function were impacting on their ability to function.
- Friends and families could influence participant's interpretation of changes experienced by legitimising the importance of those changes and prompting formal assessment by a healthcare professional.
- A diagnosis of head and neck cancer was not expected by most participants and this influenced how participants processed information given about their diagnosis, treatment and the associated impact on appearance and function.

- A cancer diagnosis immediately raised issues of a changed and uncertain future in a way which is different from other life-threatening illnesses. Participants who smoked and drank heavily prior to their diagnosis (known risk factors) felt responsible for their cancer diagnosis. These factors impacted on participants by altering their perception of treatment and changes to appearance and function.
- Using death as a benchmark, the impact of cancer and its treatment were minimised and interventions (such as feeding tubes and catheters) and treatment side effects were rationalised as a necessary evil for the greater good . Participant s main focus, particularly during the initial period following diagnosis was on getting through treatment with the ultimate aim of surviving cancer.
- Information (verbal and written) provided by healthcare professionals was crucial in preparing the participants for changes to appearance and function. However information provision has limitations and did not fully prepare participants for their experience, particularly where there were rare complications, severe side-effects and multiple changes. When participants are feeling well it is difficult for them to process the potential changes to appearance and function in a meaningful way.
- Information and support to help manage changes to appearance and function were provided by healthcare professionals routinely before and during treatment. Following treatment was more challenging when contact with healthcare professionals was limited and there was a sense of not knowing what would help and learning through trial and error and experience.
- Participants identified the benefit of support and information provided by head and neck cancer patients and other cancer patients who they came into contact with during treatment. There was a sense of shared understanding between people with a cancer diagnosis. Participants also compared themselves to other cancer patients who were worse off (in relation to side-effects or prognosis) as a way of minimising the changes they were experiencing and their own situation (downward comparison).

- Concealing and camouflaging changes and avoidance, which could be conscious or subconscious, was used particularly within the immediate post-treatment period until participants processed and accommodated appearance change.
- Changes to breathing and speech could be particularly distressing as they challenged an individual's ability to maintain control of essential activities of daily living.
- During the treatment period participants had a limited capacity to socialise due to the time involved in treatment and general fatigue. Going out in public or into social situations could be a catalyst for an increased awareness of appearance and functional change.
- Due to rapid weight and muscle loss participants compared themselves to concentration camp victims. This conveys the drastic nature of changes in appearance and the helplessness felt at times.
- Participants found that following advice from healthcare professionals or engaging in self-care (e.g. doing exercises to help speech or swallowing) helped them to feel that they could influence their recovery and gave them a sense of control.
- The process of recovery in relation to speech, swallowing, taste and tiredness could vary from day to day and hour to hour. This could prove frustrating for participants as their function was not always reliable and recovery was uncertain.
- Participants underwent a process of reclaiming self over the first 12 months following diagnosis by adapting behaviour and accommodating changes both physically and psychologically. Family and friends were integral to this process. However some side-effects such as fatigue were poorly understood particularly when they continued for an extensive period (>1yr) and impacted on the participants role within the family and this resulted in tension within relationships.
- Where participants experienced multiple changes or felt unable to control their body or bodily secretions this often resulted in avoidance of social situations.

- Participants adapted and refined techniques to support coping over time using trial and error (e.g different food textures), planning ahead (e.g taking drinking straws to limit drooling) and graded exposure (e.g going out to family engagements before socialising more generally) .
- The main focus for participants was to try to return to normal as quickly as possible. Setting goals was used to reclaim control, independence and important aspects of their life which defined them in many cases (e.g work, physical fitness).
- Participants with a laryngectomy (removal of the voice box) faced specific challenges as general practitioners, district nurses and other people they met did not understand the changes to appearance and function. This led to feelings of fear and isolation and a concern about their ongoing general healthcare within the community.
- Cosmetic procedures such as dental rehabilitation were considered important for rehabilitation but could cause concern for participants particularly where it involved surgery as this was felt to be non-essential.
- Where participants were unable to return to normal they underwent a process of reconciling self. Reconciling changes was a cognitive process which happened on a daily basis over a prolonged period (12-18 months). This led to construction of a new normal for participants.
- There was a sense of loss for some where participants experienced multiple changes (e.g basic functions, appearance, and ability to socialise) or there was a change which was integral to the participant's sense of self (e.g ability to work, role within relationships).
- While some participants felt robbed of their planned future, most engaged in "*benefit finding*" where they acknowledged positive changes (e.g relationships and changed priorities) from having and surviving cancer.

## Conclusion

This research study has led to development of a theoretical model identifying how men with head and neck cancer experience appearance and functional change in the first 12 months following diagnosis. Initially participant's focus was on surviving cancer and getting through treatment. Changes to appearance and function were more important following treatment completion and a process of trying to reclaim self occurred in addition to reconciling change (core category) as individuals tried to integrate a "*new normal*" as their frame of reference. The model identified increases knowledge in this area to improve healthcare professionals understanding and influence support provision.

## **Appendix 21: Participant letter (P5)**

Dear Caroline,

Thank you for sending me your research paper on men with head and neck cancer.

It was very interesting reading your report and as I read through it, I found myself like the “*nodding dog*”, as I identified with different aspects of your report!

Although it is now almost three years since my operation and two years since our interview. It’s amazing how fresh events remain in my memory.

Your report in many respects is very incisive and as I read and re-read it I found myself reaching for my pen to circle a remark here and a comment there and generally mentally applauding how precise your report was!

When I spoke to my daughter about your report, she was adamant she wants to see it when she next visits. As you pointed out, the support of family is paramount in the “*healing*” process and I think, having greater insight and overview of shall we say ‘the bigger picture’ can only help to shed more light on the overall situation.

I think you have put down on paper, what I’m sure a lot of men including myself, can and do find difficult to put into words, especially to our nearest and dearest.

Thank you, again, Caroline and may I take the opportunity to wish you every best wish for your career.

Kind regards,

Signed Participant 5.

## Appendix 22: CNS feedback



Room 300  
Level 3 West,  
Crosshouse Hospital  
Kilmarnock  
KA2 0BE

15<sup>th</sup> February 2016

Dear Caroline,

My very grateful thanks for allowing me to read chapters of your thesis. Doing so has brought back to mind years of clinical practice in head and neck cancer. It's clear to me that you have thoroughly examined the research in this area and your distillation of this, together with vivid patient narrative has adeptly highlighted the sequelae of treatment. My congratulations on achieving a remarkable and highly applicable piece of work.

With warmest wishes,

Oighrig Park

Oighrig J. L. Park  
M.N. (Cancer Nursing), B.N., R.G.N., R.M.  
NMC: 84J0091S  
Macmillan Upper GI Clinical Nurse Specialist (previously Head & Neck  
Cancer CNS)





Macmillan Head and Neck Clinical Nurse Specialist

Queen Elizabeth University Hospital

1345 Govan Rd

Glasgow

G51 4TF

16/03/16

Dear Caroline

It was with pleasure that I read the chapters of your thesis. Having worked as a CNS in Head and Neck Cancer for 15years I am aware of the difficulties patients face in their day to day lives.

There is very little research into how men view and cope with appearance and functional difficulties of treatment. Your work has given voice to these concerns and I hope it will influence clinical practice and support for this patient group.

Kind Regards

*Elaine Ross*

Elaine Ross

Macmillan Head and Neck Clinical Nurse Specialist

## **Appendix 23: Draft article for publication**

### Title

A new normal; reconciling change in appearance and function for men with head and neck cancer

### Abstract

The aim of this study was to explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis. Grounded theory methodology (GT) was chosen as the overall purpose of GT is the generation of theory from the data which has explanatory power and advances the understanding of social and psychological phenomena. Twelve retrospective semi-structured interviews were performed with men who were 12 to 24 months post-diagnosis.

Three categories emerged from the data which were inter-related: normalising change, *“being under siege”*; getting through treatment and reclaiming self. The core category was reconciling change; a new normal which reflects the social and psychological processes involved in accommodating and assimilating change in appearance and function for men with HNC. The substantive theory provides insight into how men with HNC prioritise function and actively distance themselves from concerns regarding appearance. Furthermore, it identifies men who are at risk of social anxiety and isolation due to multiple changes or body incompetence. This study builds on theories of masculinity, body image and disfigurement. The substantive theory developed provides health and social care professionals with new knowledge to support clinical practice and improve care provision.

### Keywords

Head and neck cancer, masculinity, body image, appearance change, functional change

## Introduction

Head and neck cancer (HNC) is a term that describes cancers that arise from the surface mucosa of the upper aerodigestive tract and involves over 30 specific sub-sites in the head and neck region (NICE, 2004). The main tumour sub-sites are the oropharynx, oral cavity, and larynx and the majority of cancers are squamous cell cancers. There are a disproportionately large number of patients diagnosed with HNC per annum in Scotland (NHS Scotland, 2012). HNC is the fifth most common cancer in the West of Scotland, where this study was performed, with 596 new diagnoses each year and this accounts for half of all HNC diagnosed in Scotland (WoSCAN, 2013). There is a marked gender difference, with increased incidence and mortality in males (WoSCAN, 2013). Tobacco and alcohol remain the major risk factors for HNC which together account for approximately 75% of cases (SIGN, 2006; NICE, 2004; Cruz et al, 2002; Bagnardi et al, 2001; Corrao et al, 1999). Furthermore, HNC primarily occurs in the over 60 age group and the most disadvantaged socio-economic groups. However, HPV related oropharyngeal cancer is increasing in younger, more affluent individuals without other risk factors (Herrero et al, 2003). In HNC, 60% of patients present with advanced stage disease and this affects both treatment options and mortality (WoSCAN, 2013; SIGN, 2006).

Patients who present early with localized disease can be treated with either surgery or radiotherapy, whereas combined treatment is usually necessary for more advanced disease (SIGN, 2006). In the most recent West of Scotland audit, 41% of patients had surgery and 53% had radiotherapy, either as a sole modality or in combination with surgery and/or chemotherapy (WoSCAN, 2013). HNC treatment can result in multiple changes to appearance and function. Changes can include scarring; oral dryness; taste changes; weight loss; fatigue; oral drooling; nasal regurgitation; swallowing, speech or breathing or speech difficulties. Identification of patient needs and tailored support during treatment and beyond is necessary to facilitate self-management and recovery. While many cancer patients will complete their primary treatment and return to similar levels of health and well-being, a significant proportion will experience a wide range of distressing physical, social,

financial and emotional long-term problems (NCSI, 2013; Macmillan Cancer Support, 2013; Department of Health et al, 2011).

Overall, when looking at men's health, what is striking is the absence of knowledge grounded in the everyday experiences of men themselves (Watson, 2000). While this has improved over the last decade, studies have primarily focussed on men's experiences of prostate cancer due to the impact of disease and treatment on continence and sexual function. A number of theories and models of body image and disfigurement exists; however most of these are conceptual (Rhoten et al, 2014; White, 2000; Newell, 1999; Price, 1990). Other theories have solely focussed on disfigurement (Furness, 2006; Dropkin, 1989). It was therefore felt that a study to explore how men with HNC experience appearance and functional change in the first 12 months following diagnosis was required. The research questions were:

1. What appearance and functional issues are important for men diagnosed with HNC?
2. How are appearance and functional issues experienced within the context of a life-threatening diagnosis of HNC?
3. At what point in the care pathway are appearance and functional issues important?

### Methods

Grounded theory (GT) was the methodological approach chosen as it attempts to go beyond description and build theory about social and psychological phenomena (Corbin and Strauss, 2015, 2008; Charmaz, 2014, 2011; Strauss and Corbin, 1998, 1990; Strauss, 1987; Glaser and Strauss, 1967). The theoretical framework for GT is derived from symbolic interactionism which assumes that society, reality, and self are constructed through interaction and thus rely on both language and communication (Mead, 1934). Strauss and Corbin's approach to GT was followed as it offers a modified approach aimed at making GT more transparent to researchers (Corbin and Strauss, 2015, 2008; Strauss and Corbin, 1990).

## Participants

The study population was all men with a diagnosis of HNC from two acute hospital sites within the West of Scotland (WoS) who were a minimum of 12 months and a maximum of 24 months post-diagnosis. This time period following diagnosis was chosen as quality of life data suggests that results at 12 months is indicative of longer term outcomes (Millsopp et al, 2006). In GT, theoretical sampling is used to collect data from places, people and events that will maximise opportunities to develop concepts in terms of their properties and dimensions, uncover variations and identify relationships between concepts (Charmaz, 2011; Corbin and Strauss, 2008). Men who met the inclusion criteria were approached by their Clinical Nurse Specialist and given verbal and written information regarding the study. If the individual was willing to participate, the researcher made contact after 24 hours to answer any questions and assess ongoing participation. Data on participant's diagnosis, disease staging, socioeconomic status, employment status and marital status was obtained from the CNS when the patient agreed to participate in the study (Table 1). Overall, the participants recruited to the study were representative of men with HNC within the WoS.

T=tumour, N=node, M=metastases (for staging information refer to TNM Classification of Malignant Tumours, 7<sup>th</sup> Edition, UICC)

SIMD - social deprivation quintile, 1= least deprived, 5 = most deprived

Table 1 – Socio-demographic participant information

P	AGE	DIAGNOSIS/ STAGING	TREATMENT	STATUS	EMPLOYMENT	SIMD	EDUCATIONAL LEVEL
1	63	T1N2aM0 left oropharynx	Left neck dissection Post-operative chemo-radiotherapy	Married	Retired (Independent insurance/ pension broker)	1	Secondary
2	58	T4N1M0 left oropharynx	Major surgery with reconstruction Post-operative chemo-radiotherapy	Widowed	Unemployed	5	Secondary
3	63	T4bN2bM0 oropharynx	Chemotherapy Chemo-radiotherapy	Married	Employed (Contract manager for a haulage company)	5	Secondary
4	55	T4N2cM0 larynx	Laryngectomy Chemo-radiotherapy	Married	Unemployed (Professional darts player)	4	Secondary
5	61	T1N2aM0 left oropharynx/ T1N1 right oral cavity	Chemo-radiotherapy	Married	Retired (Security Director)	2	Secondary
6	68	T2N2aM0 left base of tongue	Chemo-radiotherapy	Widowed	Retired (Fire fighter)	5	Secondary HND
7	65	T2N0M0 oral cavity	Major surgery with reconstruction Post-operative radiotherapy	Married	Retired (Security officer)	5	Secondary
8	58	T2N0M0 tongue	Major surgery with reconstruction	Married	Staff nurse	5	Secondary
9	57	T2N1M0 tongue	Major surgery with reconstruction Post-operative chemo-radiotherapy	Married	Merchant seaman	5	Secondary
10	26	Muco-epidermoid cancer hard palate	Wide local excision with obturator Delayed reconstruction	Single	Project manager (Marketing/ communication agency)	1	University (BA honors)
11	56	T4N2bM0 larynx	Laryngectomy & right neck dissection Post-operative radiotherapy	Divorced/ Single	Unemployed (Handyman)	4	College - modules
12	64	T2N0M0 right oral cavity	Major surgery with reconstruction	Married	Engineer	4	Secondary

### Data collection

Twelve semi-structured interviews were performed with participants as interviews can allow the exploration of hidden and suppressed views (Charmaz, 2006). It is suggested that a sample size of 12 is satisfactory when exploring individuals' experiences in a relatively homogenous sample (Guest et al, 2006). All interviews were performed during 2011 within the men's homes, except for one, which occurred within NHS facilities. A discussion guide was developed in conjunction with two men with HNC consisting of introductory comments, open questions for discussion and closing questions. Interviews lasted 45 to 60 minutes and were digitally recorded and transcribed by an NHS secretary *verbatim* removing any identifying information and using participant identification numbers to maintain anonymity. Ethical approval for the study was obtained from the University of Stirling Health Studies Research Ethics Committee, the West of Scotland Research Ethics Committee and NHS Research and Development department.

### Analysis

The defining components of GT practice are simultaneous involvement in data collection and analysis; constructing analytic codes and categories from the data; using constant comparison; advancing theory development during each stage of data collection and analysis; memo-writing to elaborate categories, specify their properties, define the relationships between categories, and identify gaps; and sampling aimed toward theory construction (Urquhart, 2012; Charmaz, 2011; Corbin and Strauss, 2008; Glaser and Strauss, 1967). These components were followed and the core category emerged which along with the other categories explained the social-psychological process that occurs over time and explains changes in the participants' behaviour, feelings and thoughts.

### Findings

Diagram 1 represents the substantive theory of reconciling change: a new normal which emerged from the data.

Diagram 1: Findings - Reconciling change: a new normal



Participant quotations are used *verbatim* to illustrate categorisation and highlight properties and dimensions of categories. P= participant (Table 1); R = researcher.

### Normalising change

Prior to a HNC diagnosis, men struggled to articulate what they thought or felt about their body prior to their diagnosis. The body was taken for granted and little consideration was given to it as long as it allowed the men to function:

P3 *“Em, I cannae [can’t] answer that one. Just it was fine.”*

Participants’ main focus was on function in relation to physical fitness and ability to perform activities of daily living. Work was central to men’s self-identity. Appearance was discussed in terms of weight and while being overweight could make men slightly self-conscious; this did not impact on their self-esteem and self-confidence. Three participants described themselves as *“healthy”* or *“fine”* despite having chronic conditions which impacted on physical activity and general *“vitality”*. These participants incorporated coping strategies into their life to minimise the day to day impact.

Men generally presented to a healthcare professionals due to changes in function rather than appearance. Change was interpreted as *“normal”* or *“minor”* and this resulted in delays in presentation:



P6 "I had a pain in my throat you see. I had been bothered with sore throats all my life which is probably why the cancer got to the stage before I went and did something about it."

Family and friends legitimised the importance of the change at times by reassuring the men that the change was "*not normal*" and that they should be present to a healthcare professional. Overall, there was a lack of awareness of HNC symptoms. A diagnosis of cancer immediately raised issues of a changed and uncertain future which impacted on the experience of changes to appearance and function.

#### "Being under siege": getting through treatment

Following a HNC diagnosis, information regarding change to appearance and function was difficult for the men to process. A cancer diagnosis modified their perception of change which was viewed as a "*trade-off*" for survival.

P8 *"He did yes [Consultant talked about surgery and changes], and in fairness it just kind of went cheeeeww [as if it had gone over his head] and X [his Macmillan Cancer Nurse Specialist] said I'm going to come out and see you next week."*

Changes which influenced basic function such as breathing or speaking increased vulnerability and loss of control.

P2 *"You feel like you're just living in a body and you have no control over it, you cannae [can't] do nothing about it. You can make signs but it's still like, you're not in control, put it that way."*

Scarring was considered to be "*unnoticeable to others*" and therefore men could present themselves as unchanged. Avoidance of scarring and camouflage were occasionally used but only during the initial post-operative period. Hair loss was discussed in functional terms in relation to scalp protection or heat loss and men actively distanced themselves from concern regarding appearance:

P3 *"I did wear a hat when I was out and about. That wasnae vanity, it was sensibility because I had nothing to protect my head so I wore my hat then. Other than that it didnae bother me."*

Chemo-radiotherapy caused changes to saliva, taste, swallowing and speech which resulted in marked weight and muscle. During treatment, men compared themselves to other cancer patients who were worse off (downward comparison). Of interest, when men's physical condition changed and they became the person with the nasogastric feeding tube or requiring support with general activities, they appeared to accept this through a process of cognitive reappraisal. Cognitive reappraisal involved the participant focussing on the need for treatment and the benefit of interventions which allowed them to complete treatment.

P1 *"I remember as well, after I had had the last dose of chemotherapy, I was still on radiotherapy and instead of making my own way down to the radiotherapy suite, I had to be wheeled. I didn't have the energy to walk even down the corridor or the ward."*

R: *How did that make you feel?*

P1: *"I wasn't too fussed about it in a lot of ways. I felt okay. I know what is going on here. I know this stuff is toxic and that it is affecting my system. I have got to go with the flow. I have got to finish the radiotherapy. I can't not do it and it is the combination of the radiotherapy and the chemotherapy that is going to attack the cancer cells. I am just going to have to put up with it."*

A key component of "getting on with it" (treatment and changes to appearance and function) involves men trying to limit intrusion into daily life by both maintaining control, managing change independently and following advice from healthcare professionals. Other cancer patients provided information which was meaningful and allowed the men to view their experience as normal:

P1 *"The health care professional gives you the information on a clinical basis but it is not the same as talking to somebody who has actually been through it."*

There was a sense of camaraderie and shared understanding between patients and this provided men with a sense of belonging during a period when they felt detached from their usual life. Much of the focus on information sharing was related to the practical management of changes with little emotional disclosure:

P9 *“Because X is so pragmatic he didn’t get too emotional about things. It wasn’t even having a deep and meaningful conversation with him. It was just seeing him coming into work and acting as normal.”*

### Reclaiming self

Participants often experienced a cluster of treatment side-effects during (chemo)radiotherapy which included changes to saliva, taste, swallowing and speech. These side-effects resulted in severe weight and muscle loss which caused distress following treatment. During treatment men were primarily exposed to other cancer patients who were experiencing similar changes and they therefore felt a level of acceptance. At this time, these cancer patients formed men’s point of reference for comparison rather than their healthy peers.

P2 *“Aye knowing that you’re in a room with one another. That’s the size of it basically – you’re accepted there.”*

While social isolation is not inevitable, men had to make a conscious effort to socialise during treatment. Socially isolation frequently occurred as treatment progressed due to the side-effects (particularly pain, weight loss and fatigue) and the time taken to attend treatment and perform self-care. Social isolation meant that men were mainly in contact with patients and healthcare professionals within a “safe” environment and family.

After treatment completion, men started to compare themselves with how their bodies used to look and function and with other healthy individuals. While men initially distanced themselves from concerns about appearance, they became concerned about weight and muscle loss due to its associated impact on physical function and maintenance of social roles. The importance of eating was evident but the challenge involved in finding things that were suitable to eat could not be

underestimated. This process of “*not knowing*” - what participants could eat, what to do for the best, if things would improve or when they would improve was found to be both difficult and frustrating. Men spoke about having “*good*” and “*bad*” days and variability across the day particularly during the initial post-treatment period:

P8 *“The bad days aren’t as often nor as they were but as I say, it is just a case of keeping myself aware of it [change to speech]. You can’t know what is going to happen in the space of a day. You can be speaking fine at one point in the morning and in the afternoon you can find that you start to babble again.”* P8 goes on *“People basically tend to be more impressed than I am [talking about speech].”*

Men became more aware of variability and nuances which were specific to them and modified their behaviours and refined techniques to try and accommodate changes and improve function over time. Cancer nurse specialists played a key role in discussing a variety of techniques to manage appearance and functional changes both physically and psychologically during social interaction. Family members were integral to the process of social re-integration. Men used different methods of coping at different times and in different situations and these methods included trial and error, planning ahead and graded exposure.

The combination of multiple changes to appearance and function could result in loss of self-confidence and self-esteem. This loss of self-confidence and self-esteem was particularly evident for those men who had a laryngectomy or experienced oral incompetence and nasal regurgitation. Lack of control of speech or bodily fluids (such as saliva and sputum) caused embarrassment and fear which could result in social anxiety and isolation. Men who had a laryngectomy experienced social stigma and felt that others did not understand changes experienced which increased vulnerability:

P11 *“I used to visit the X [hospital] every Friday just about to get them to have a look at the bleeding or my stoma so I know I would be okay at the weekend. If I asked the GP or district nurse about it they just said they didn’t know and would tell me to go to the X [hospital].”*

### Reconciling change: a new normal

Men experienced numerous and significant changes to function in particular, which they incorporated into their life. There is a sense of freedom which is affected when everyday tasks have to be consciously considered to varying degrees. Participants learned to live with the changes to function by acknowledging loss and then accommodating to limitations imposed. Key to this process was getting important aspects of the participant's life back and regaining control:

P2 *"I'm getting myself back. I'm in control. But you've got to see yourself moving forward if you know what I mean."*

While participants reclaimed aspects of their former life and self, often they began to realise that they were changed forever by the experience of both a cancer diagnosis and changes to function and/or appearance. As time went on, participants had to consciously consider changes to function less often, and they developed a 'new normal'. This "*new normal*" was assimilated into their daily lives by both the individual concerned and others who know them as the following quotations suggest:

P12 *"It was rather strange to start with when you are standing in the golf club and people saw me drinking out of a straw. Now when I go over there and ask for a pint they just put a straw in it."*

P8 *"They all know me [staff in the local supermarkets] because I always wear a cap when I go out during the day. They all know me so I think they all sort of accept the fact that when I speak my speech isn't always that clear. Nobody's going to turn round and say you speak kinda funny son you know but people have learned to sort of expect that."*

For most participants, feeling diminished was a temporary experience, however for a few participants their life and future was diminished. Further medical intervention was considered for issues of concern which participants felt were critical to function. However, while dental rehabilitation was important to men, they could struggle with the thought of further surgery for cosmetic purposes.

For a few of the participants who worked at the point of diagnosis, changes experienced to function led to a change to their duties or early retirement. This could be difficult to cope as it wasn't planned. The importance of work in maintaining self-identity was evident and men generally felt diminished where they were unable to work. For those participants who kept working or returned to work a few months after treatment, continuing with *"normal life"* allowed them to distance themselves from illness and marginalise the impact of changes to function in terms of their life.

There is limited disclosure about cancer and the cancer experience between men thus reducing opportunities for support:

P5 *"You start meeting guys that you have known for long enough and I didn't realise that they had cancer and you start talking to them. That helps you as well because you appreciate that you are not alone."*

Despite increasing recognitions that people live with and beyond cancer, cancer continues to be associated with dying in a way that other chronic illnesses are not. Men may feel more comfortable talking about their cancer and treatment in retrospect allowing them to reframe their experience as a story of achievement. This also permits men to distance themselves from the emotion which may be felt during the cancer experience itself. Throughout the interviews, men spoke about the importance of positive thinking and finding benefit from their experience. Positive thinking allowed the men to adapt to change and see their future as enhanced. In general, having cancer made the participants reconsider priorities. While the impact of a cancer diagnosis cannot be underestimated, there comes a point, generally between 12 and 18 months after diagnosis, where men assimilated change to appearance and function and defined themselves as *"fine"* and *"good"* again:

P8 *"I don't see myself as being a cancer patient any more. As far as I'm concerned, I had it, they got rid of it, goodbye. That's it."*

## Discussion

This is the first study specifically focussing on the male experience of appearance and functional change in HNC. Theory development is a complex activity which denotes a set of well-developed categories that are systematically interrelated to form a theoretical framework that explains some phenomenon (Hage, 1972). Reconciling change: a new normal is the overarching concept which when taken with the concepts of normalising change, "*being under siege*": getting through treatment and reclaiming self explains the social-psychological process of appearance and functional change for men with HNC.

The Quality Strategy (2010) has provided the blueprint for improving the quality of care that patients and carers receive from the NHS across Scotland (The Scottish Government, 2010). Three Quality Ambitions (safe, person-centred and effective) were developed and all healthcare policy is being aligned to deliver these ambitions. Patient involvement programmes and Transforming Care after Treatment projects have primarily focussed on breast, colorectal, lung and prostate cancer. The substantive theory developed provides health and social care practitioners with insight into the experience of change to appearance and function in men with HNC to directly inform their clinical practice.

This theory suggests that men with HNC focus on function and actively distance themselves from concerns regarding appearance. Men's focus on function should be considered in relation to HNC awareness to improve earlier presentation and diagnosis. Discussions related to self-management and support should be this influenced by men's prioritisation of function. Men attempt to maintain independence and control and frequently present themselves as unchanged. Support should therefore be provided proactively during and after treatment as men generally do not disclose needs or initiate support. The importance of work for men in the maintenance of self-identity should be recognised and vocational rehabilitation should be offered as part of routine care. It is also suggested that holistic needs assessment should be done at key points to support care planning, particularly at the end of treatment and a couple of months after treatment completion. Coping strategies which should be supported to facilitate reconciling change included trial

and error, goal setting, graded exposure, challenging negative thoughts and social skills training. Support should also be given to relatives and carers so that they understand the rehabilitation process and do not feel isolated. Men who experience body incompetence or severe changes may suffer from social anxiety or find their illness is intrusive and require additional and ongoing support to develop a new self-concept. Clinical support and education should be provided for laryngectomy patients and community healthcare professionals to try and improve the experience of ongoing care.

The unique benefit of support from other cancer patients should be recognised and healthcare professional should offer formal 'buddy' support to supplement informal peer support. Buddy support may be particularly important at the end of treatment and during the rehabilitation period to support realistic goal setting. Men and their carers could also be encouraged to attend health and well-being events or participate in rehabilitation programmes by focussing on physical recovery and strength.