

THE EXPERIENCE OF PATIENTS DIAGNOSED AND TREATED FOR HEAD AND NECK CANCER

'..moving from the country of the well across the stark frontier that marks off the land of malady....The new land is quite welcoming in its way. Everybody smiles encouragingly.....the country has a language of its ownyou feel swamped with passivity and impotence' (Hitchens, 2012)

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ABSTRACT

Head and neck cancer (H&NC) and its possible treatment options are diverse and multifaceted. This thesis demonstrates these complexities and describes three studies that have used different methodological approaches to include, rather than overlook these aspects.

The first established which aspects of patients' experiences are overlooked if health care professionals rely upon health related quality of life questionnaires to represent the experience of patients.

The second identified that the multi-disciplinary team (MDT) working with the patients use humane judgement, not technical expertise, to predict patients' symptoms pre treatment.

The third, with reference to the previous two, used Q-Methodology to explore the experience of H&NC patients during and after their treatment. Five interpretations were identified:

- Meaning and attachment to illness
- Overwhelmed by the disease
- Change and recovery
- Surviving or not
- Keep control- for the greater good of others

This unique study has developed a framework through which the MDT can start to translate H&NC patients' experiences and help enable them to influence their care directly. It also suggests ways in which the framework can be applied to the clinical environment.

To Sally for her belief and support that despite all the events in life
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CONTENTS LISTINGS

TABLE OF CONTENTS

INTRODUCTION	1
STRUCTURE OF THE THESIS	5
CHAPTER 1 THE FACTS AND MANAGEMENT OF HEAD AND NECK CANCER	
INTRODUCTION	6
DEFINITION, INCIDENCE AND INITIAL PRESENTATION.....	6
CLASSIFICATION OF THE DISEASE.....	9
AETIOLOGY.....	13
MODERN-DAY MANAGEMENT AND PROGNOSIS -A UK PERSPECTIVE.....	16
THE MANAGEMENT OF THE DISEASE	
ASSESSMENT	21
TREATMENT OF HEAD AND NECK CANCER, GENERAL POINTS.....	22
CO-MORBIDITIES AND HEAD AND NECK CANCER.....	23
SURGERY	23
ONCOLOGY TREATMENT –RADIOTHERAPY.....	24
CHEMOTHERAPY.....	25
TREATMENT SIDE EFFECTS AND COMPLICATIONS.....	27
FOLLOW-UP POST DEFINITIVE TREATMENT	29
PROGNOSIS.....	30
THE MODERN CONTEXT FOR HEALTH OUTCOME MEASURES	32
SUMMARY.....	35

**CHAPTER 2
MEASURING OUTCOME**

SETTING THE CONTEXT FOR OUTCOME IN HEALTH-CARE.....	36
THE JARGON ASSOCIATED WITH OUTCOME MEASURES	37
HEALTH DOCUMENTS RELATING TO THE PATIENT ROLE WITHIN THE NHS.....	41
• THE EXPERT PATIENT: A NEW APPROACH TO CHRONIC DISEASE MANAGEMENT FOR THE 21 ST CENTURY.....	41
• CREATING A PATIENT-LED NHS.....	43
• HIGH QUALITY CARE FOR ALL.....	44
• THE NHS OUTCOMES FRAMEWORK.....	45
• IMPROVING OUTCOMES: A STRATEGY FOR CANCER.....	47
• HOLISTIC NEEDS ASSESSMENT.....	47
• NHS PATIENT EXPERIENCE FRAMEWORK.....	49
• WHAT MATTERS TO PATIENTS	51
HEALTH CARE FOR CANCER PATIENTS ENSURING PEOPLE HAVE A POSITIVE EXPERIENCE OF CARE	53
TREATING AND CARING FOR PEOPLE IN A SAFE ENVIRONMENT AND PROTECTING THEM FROM AVOIDABLE HARM.....	55
ENSURING PEOPLE HAVE A POSITIVE EXPERIENCE OF CARE	57
ENHANCING QUALITY OF LIFE FOR PEOPLE	

WITH LONG-TERM CONDITIONS	61
ENHANCING QUALITY OF LIFE FOR PEOPLE WITH LONG-TERM CONDITIONS. -OUTCOME MEASURES SPECIFIC TO HEAD AND NECK CANCER VARIABLES THAT IMPACT ON QUALITY OF LIFE SCORES.....	64
QUALITY OF LIFE AND CO-MORBIDITIES.....	67
REPEATED USE OF QUALITY OF LIFE MEASURES.....	68
QUALITY OF LIFE AND SURVIVAL-DATA.....	68
CONCLUSION.....	70

CHAPTER 3

THE OUTCOME QUALITY OF LIFE WITH PARTICULAR REFERENCE TO HEAD AND NECK CANCER

INTRODUCTION.....	73
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HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRES: ARE THEY FIT FOR PURPOSE?

• INTRODUCTION.....	75
• METHODS	
• RESEARCH DESIGN.....	81
DATA GATHERING	
• SOURCE 1:THEMATIC ANALYSIS OF HRQOL QUESTIONNAIRES.....	82
• SOURCE 2: THEMATIC REVIEW OF THE LITERATURE.....	84
• SOURCE 3: THEMATIC ANALYSIS OF PATIENTS' PERSPECTIVES.....	90
FINDINGS	
• FINDINGS FROM QUESTIONNAIRES, LITERATURE AND SEMI- STRUCTURED INTERVIEWS.....	93
• FINDINGS FROM LITERATURE AND INTERVIEWS.....	99
• FINDINGS FROM THE SEMI-STRUCTURED INTERVIEWS.....	102
• DISCUSSION.....	106
• CONCLUSION.....	109

**EFFECT OF ORAL TUMOUR SIZE ON QUALITY OF LIFE
JUDGEMENTS BY HEALTH CARE PROFESSIONALS
WORKING WITH HEAD AND NECK CANCER PATIENTS:
A PILOT STUDY.**

- ABSTRACT.....111
- INTRODUCTION.....112
- METHOD.....115
 - STUDY DESIGN.....115
 - SAMPLE.....115
 - MATERIALS.....116
 - PROCEDURE.....117
 - PILOT.....117
 - MAIN STUDY.....117
 - ETHICAL CONSIDERATIONS.....118
- RESULTS AND ANALYSIS.....118
 - PRE-ANALYSIS CHECK OF THE
QUESTIONNAIRE'S INTERNAL RELIABILITY.....119
 - T4 GROUP.....121
 - T2 GROUP.....121
- DISCUSSION.....122
- CONCLUSION.....124

CHAPTER 4

**THE ROUTE TO A METHODOLOGY -THE DECISION PROCESS DESCRIBED
WHEN CHOOSING Q-METHODOLOGY AND A DESCRIPTION OF THE
METHOD**

INTRODUCTION.....125

USING REFLECTION TOWARDS A RESEARCH QUESTION.....125

EARLY STAGES OF RESEARCH.....131

RESEARCH IN THE CLINICAL ENVIRONMENT.....137

CONSIDERING OTHER METHODS THAT ARE NOT QUANTITATIVE.....144

A DESCRIPTION OF Q-METHODOLOGY.....146

SPECIFIC Q-METHODOLOGY TERMS.....147

THE MAIN DIFFERENCES BETWEEN R METHODS
AND Q METHOD.....149

WHAT THE RESULTS LOOK LIKE AND
HOW THEY CAN BE USED.....154

THE PURPOSE AND VALUE OF THE APPROACH
TO HEALTH-CARE AND RESEARCH BY USING
Q-METHODOLOGY.....156

ADVANTAGES OF Q-METHODOLOGY.....158

DISADVANTAGES OF Q-METHODOLOGY.....	160
SUMMARY	162

CHAPTER 5

**A Q METHODOLOGY STUDY TO EXPLORE THE EXPERIENCE OF PATIENTS
DIAGNOSED AND TREATED FOR HEAD AND NECK CANCER**

INTRODUCTION	163
METHOD	
STEP 2: CREATION OF THE Q SAMPLE.....	164
STEP 3: THE Q SORT.....	168
SELECTION OF PARTICIPANTS FOR THE Q SORT.....	168
○ INCLUSION CRITERIA.....	169
○ EXCLUSION CRITERIA.....	169
○ Q SORT PROCEDURE.....	169
STEP 4 AND 5: ANALYSES OF THE RESULTS AND INTERPRETATION	172
RESULTS.....	175
FACTOR 1: MEANING AND ATTACHMENT TO ILLNESS.....	186
FACTOR 2: OVERWHELMED BY THE CANCER.....	189
FACTOR 3: CHANGE AND RECOVERY	192
FACTOR 4: SURVIVING OR NOT	195
FACTOR 5: KEEP CONTROL -GREATER GOOD OTHERS.....	198

CHAPTER 6

DISCUSSION AND CLINICAL IMPLICATIONS OF THE STUDY

DISCUSSION OF THE FACTORS.....	202
DISCUSSION OF EXTREME AND CONSENSUS SCORES.....	210
ADVANTAGES OF Q METHODOLOGY.....	214
LIMITATIONS OF Q METHODOLOGY.....	216
IMPLICATIONS OF THIS STUDY IN RELATION TO HEALTH POLICY AND CLINICAL PRACTICE.....	218

APPENDICES

APENDICES 1.1-5.4	234-297
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REFERENCE LIST

A-L.....	298-304
M-Z.....	304-312

LIST OF FIGURES

CHAPTER 1	
FIGURE 1.1 SCHEMATIC DIAGRAM OF LYMPH NODE LEVELS (SCOTISH INTERCOLLEGIATE GUIDELINES NETWORK, 2006 p77).....	11
FIGURE 1.2 OUTLINE OF THE PATHWAY OF THE CARE FOR A PATIENT WITH SUSPECTED AND THEN CONFIRMED DIAGNOSIS OF HEAD AND NECK CANCER. SCOTTISH INTERCOLEGIATE GUIDELINES (2006 p55).....	19
CHAPTER 3	
FIGURE 3.1 SIX GLOBAL THEMES REPRESENTING THE EXPERIENCE OF H&NC.....	94
FIGURE 3.2 THEMATIC NETWORK: DAY-TO-DAY PHYSICAL COMFORT.....	96
FIGURE 3.3 THEMATIC NETWORK: EMOTIONAL WELL BEING.....	96
FIGURE 3.4 THEMATIC NETWORK: PLACE IN SOCIETY.....	98
FIGURE 3.5 THEMATIC NETWORK:OWN MORTALITY.....	100
FIGURE 3.6 THEMATIC NETWORK: QUALITY OF CARE.....	101
FIGURE 3.7 THEMATIC NETWORK: REALITY.....	103
FIGURE 3.8 45 STATEMENTS REPRESENTATIVE OF THE EXPERIENCE OF H&NC.....	104
CHAPTER 4	
FIGURE 4.1 MODEL OF HOW SOCIO-DEMOGRAPHIC FACTORS (INPUTS) CAN BE MEDIATED BECOME POOR OUTCOMES (OUTPUTS) (MUNRO 2005, P.915).....	137

FIGURE 4.2	
Q-METHODOLOGY GRID –STATEMENTS	
ARE SORTED ONTO AN ALLOCATED	
SPACE ON THE GRID.....	148

CHAPTER 5

FIGURE 5.1	
45 REPRESENTATIVE STATEMENTS	
OF THE EXPERIENCE OF H&NC.....	166
FIGURE 5.2	
STAGES USED TO CREATE FIVE FACTORS.....	174
FIGURE 5.3	
DISTINGUISHING STATEMENTS FOR EACH FACTOR.....	181-182

LIST OF TABLES

CHAPTER 1	
TABLE 1.1	DESCRIPTION OF CASUES, BEHAVIOUR AND REFERENCES FOR H&NC.....13
CHAPTER 2	
TABLE 2.1	ELEMENTS OF PATIENT-LED SERVICE.....44
TABLE 2.2	OUTCOME FRAMEWORK-DOMAIN AND DESCRIPTION.....46
TABLE 2.3	SUMMARY OF MAIN POINTS FOR THREE HOLISTIC NEEDS ASSESSMENT TOOLS USED IN THE NHS.....49
TABLE 2.4	DESCRIPTION OF WHAT ELELEMENTS OF CARE MATTER TO PATIENTS.....52
CHAPTER 3	
TABLE 3.1	PAPERS REVIEWED AS A RESULT OF THE LITERATURE REVIEW.....85
TABLE 3.2	BIO-SOCIAL STATISTICS OF PARTICIPANTS n=6.....90
TABLE 3.3	TREATMENT OF COMPLICATIONS FOR PARTICIPANTS.....90
TABLE 3.4	QUESTIONS USED TO GENERATE INTERVIEWS OF THE H&NC PATIENTS92
TABLE 3.5	BIO-DETAILS OF CONVENIENCE SAMPLE HCPS TAKING PART IN THE STUDY.....119
TABLE 3.6	INDEPENDENT SAMPLES T-TEST COMPARING RESPONSES OF PARTICPANTS ACCORDING TO SIZE OF TUMOUR T2 VS T4.....120

CHAPTER 4

TABLE 4.1
LEVELS OF EVIDENCE FOR INTERVENTIONS
(SACKETT ET AL; 2000).....131

TABLE 4.2
QUALITATIVE RESEARCH APPROACHES.....145

TABLE 4.3
Q-METHODOLOGY TERMS, STAGES AND DEFINITIONS146

TABLE 4.4
THE MAIN METHODOLOGICAL DIFFERENCES
BETWEEN THE REDUCTIONIST R METHOD
APPROACH AND Q METHOD BASED ON WORK
BY WEBLER ET AL (2009a).....151

CHAPTER 5

TABLE 5.1
THE BIO-DETAILS FOR ALL THE PARTICIPANTS ...177-178

TABLE 5.2
FACTOR MATRIX.....179

TABLE 5.3
STATEMENTS FOR ALL FIVE FACTORS
ARRANGED FROM CONSENSUS
TO CONTENTION.....184-185

TABLE 5.4
DISTINGUISHING STATEMENT FOR FACTOR 1187

TABLE 5.5
DISTINGUISHING STATEMENTS FOR FACTOR 2.....191

TABLE 5.6
DISTINGUISHING STATEMENTS FOR FACTOR 3.....194

TABLE 5.7
DISTINGUISHING STATEMENTS FOR FACTOR 4.....198

TABLE 5.8
DISTINGUISHING STATEMENTS FOR FACTOR 5.....198

CHAPTER 6

TABLE 6.1
STATEMENTS THAT REPRESENTED
THE WIDEST RANGE OF SCORES

	BETWEEN Q SORT.....	210
TABLE 6.2	CONSENSUS STATEMENTS BETWEEN THE Q SORTS.....	211
TABLE 6.3	LEVELS OF HEALTH-CARE AND DESCRIPTIONS WITH REFERENCE TO THE FRAMEWORK.....	220-221
TABLE 6.4	HEALTH POLICIES RELATING TO THE EXPECTATION OF PATIENTS' ROLES	227

APPENDICES

CHAPTER 1

APPENDIX 1.1

FIGURE 1:

LATERAL SCHEMATIC DIAGRAM OF
HEAD AND NECK DETAILING MAIN AREAS
OF THE HEAD AND NECK.....234

FIGURE 2:

MAIN STRUCTURES OF THE ORAL CAVITY
DORSAL ASPECT OF TONGUE.....235

FIGURE 3:

VENTRAL ASPECT OF TONGUE.....236

APPENDIX 1.2

TUMOUR CATEGORIES FOR ORAL, ORAL PHARYNGEAL
AND HYPOHARYNGEAL CANCERS FROM UICC TNM
CLASSIFICATION OF MALIGNANT TUMOURS.....237

TUMOUR CATEGORIES FOR LARYNGEAL
CANCERS (SIGN,2006 P71).....238

NODAL AND METESTATIC CATEGORIES FOR
H&NC TUMOURS (SIGN,2006 P73).....239

CHAPTER 2

APPENDIX 2.1

HOLISTIC NEEDS ASSESSEMENTS

- DISTRESS
THERMOMETER.....240-241
- HOLISTIC NEEDS ASSESSEMENT
PEPSICOLA,AIDE MEMOIR.....242
- SHEFFIELD PROFILE FOR ASSESSMENT
AND REFERRAL TO CARE (SPARC).....243-249

CHAPTER 3

APPENDIX 3.1

THREE MOST COMMONLY USED QUALITY OF LIFE QUESTIONNAIRES

- UNIVERSITY OF WASHINGTON H&N CANCER QOL QUESTIONNAIRE UoW250-252
- FUNCTIONAL ASSESSMENT OF CANCER THERAPY (FACT).....252-255
- EUROPEAN ORGANISATION FOR THE TREATMENT OF CANCER CORE (EORTC C30)256
EORTC HEAD AND NECK CANCER SPECIFIC (H&NC 35).....257-258

APPENDIX 3.2

LITERATURE SOURCES THAT GENERATED THE SEMI-STRUCTURED INTERVIEW QUESTIONS.....259-277

APPENDIX 3.3.....

GENERATING THE THEMES FROM QoL QUESTIONNAIRES, LITERATURE AND SEMISTRUCTURED INTERVIEWS

APPENDIX 3.4.....278-279

QUESTIONNAIRE COMPLETED BY THE MDT FOR T4 CASE STUDY280-288

CHAPTER 5

APPENDIX 5.1

ORIGINAL QUOTES FOR THE GLOBAL THEME REALITY AND FINAL STATEMENTS USED289-290

APPENDIX 5.2

CONCOURSE STATEMENTS NUMBERED291-293

APPENDIX 5.3

COMPLETED EXAMPLE OF Q SORT.....294

APPENDIX 5.4

SEMI STRUCTURE INTERVIEW FOR SORT NUMBER 9.....295 -297

GLOSSARY OF TECHNICAL TERMS

Alternative method of feeding a different way of a patient being fed or hydrated that does not rely on eating or drinking such as percutaneous endoscopic gastrostomy (PEG) or naso-gastric tube (nose to stomach)

Aspiration food or drink going below the level of the vocal cords i.e. the voice box into the lungs causing an infection as a result of this penetration

Cancer centre a designated regional specialist hospital that has known experts for the treatment of cancer, who will after definitive treatment refer back to local health care

Flap surgical reconstruction using either soft tissue or bone and soft tissue (composite) examples include:

Anterior lateral thigh flap (ALT) soft tissue flap associated with the outside of thigh with blood supply of vein and artery

Radial forearm free flap (RFFF) soft tissue and vein and artery from underside of forearm as tissue replacement for lesion typically from floor of mouth or tongue

Scapula flap composite flap (containing bone and soft tissue) from shoulder used typically to replace mandible (jaw) or maxilla (roof of mouth)

Glossectomy-total removal by surgery of the tongue

Head and Neck cancer tumours classified pathologically within one of the structures of the head and neck, but excluding brain

Health related Quality of Life (HRQoL) a set of standardised questions that explores a patient's specific issues relating to their health

Laryngectomy -total removal by surgery of the larynx

National Institute of Clinical Excellence (NICE) an independent body set by the government to implement guidelines and review best treatment practice

Neck dissection removal by surgery of designated levels of lymph glands within the neck

Nodal disease relates specifically to neck nodes, which may as a result of the tumour in the head and neck develop disease extending into the lymph glands within the neck

Oesophageal speech the vibration of food-tube, oesophagus, to form an energy source

Quality of life questionnaire QoL- a set of standardised questions that explores a patient's specific issues relating to their life

Tracheostomy Breathing tube placed below level of larynx in order to provide a temporary or permanent way of breathing. Difficult to talk when one is placed due to air bypassing laryngeal area

INTRODUCTION

Cancer is a common disease affecting one in three of the United Kingdom population. Treatments have become more successful at enabling patients to survive the disease and a review of cancer data-bases indicates that three million people have survived the disease (Maddams et al., 2009). These researchers have predicted that this figure will rise by a rate of three percent per year over the next twenty-years. Whilst treatments might be judged as more effective because patients are surviving longer, longevity cannot represent outcome exclusively. Policy-makers and cancer survivors have started to describe the personal consequences of surviving cancer and quality of life (QoL) data has been seen as a way of supplementing survival statistics.

This thesis will suggest that for head and neck cancer (H&NC) patients, both survival rates and QoL measures are too basic and are poor representations of what the patients might experience. The thesis discusses the limitations of such measures, and an argument is developed that the science of QoL research is flawed because it is a false assurance to think that they represent the patients' perspective accurately. This lack of ability to reflect the real experience for patients might explain why their use has remained limited in clinical settings and is used rarely to form part of treatment plans. The possibility that there are important aspects of the patient viewpoint, up to now defined inadequately, is demonstrated by one of the participants who was part of the Q study, sort number 10:

'I never thought of myself as ill, going in or coming out I limped around couldn't open my mouth properly- all the accoutrements of illness- but without feeling particularly ill; so it's not like I have a long-term disease even though I can still visualize a fixed chunk of time as opposed to a chronic condition...some people do define themselves by their illness. This does not define me at all; my values define me and none of those include being ill.'

Sort number 10: Page 2. Line 31 to page 3 line 9 (2.31- 3.9.)

Whilst there might be patients who can identify with some or all of participant 10's sentiments, clinical and research environments have invested thought, expertise and time generating numerous disease-specific questionnaires that try to capture, in a standardised way how patients might be affected. The science has remained unchallenged around how limited it is and cannot answer satisfactorily fundamental questions such as:

- What is the experience for patients of the diagnosis and treatment of head and neck cancer?
- Why do patients with apparently similar disease classification and treatment appear to have such different reactions to the treatment?

Clinicians and researchers are in danger of reassuring themselves falsely that what they are measuring is important to patients. Porter, a medical historian, who has written on the history of hospitals, suggested the following in a commentary (Porter, 2003 p.151):

'In our times cutting-edge medicine has been practiced in purpose-built hospitals served by armies of paramedics, technicians, ancillary staff, managers, accountants, fund-raisers and other white-collar workers, all held in place by rigid professional hierarchies and codes of conduct. In the light of such massive bureaucratisation, it is small wonder that critiques have once again emerged. The hospital was no longer primarily denounced, however, as a gateway to death but as soulless, anonymous, wasteful and inefficient medical factory, performing medicine as medicine demanded it, not as the patient needed it.'

Much of the author's clinical time is spent in intense therapeutic relationships with patients, working with them in order to enable them to communicate and swallow as well as possible. It is her strong desire that the portrayal of Porter's modern-hospital-medicine should never be a reality. This thesis intends to reduce the likelihood of such a description. The following illustration of a patient's treatment can help to

illustrate how inadequate questionnaires might be, in representing a patient's real experience.

David aged 62 was diagnosed with laryngeal cancer and it was decided by his clinical team that his definitive treatment would involve surgery followed by chemo-radiotherapy. Part of his original reconstructive surgery meant that his larynx pharynx and upper-oesophagus had to be replaced. The surgical team decided to use an anterior lateral thigh flap and created a tube of free-tissue that could be joined into the major-blood vessels within the neck to replace the diseased tissue. One of the peri-operative complications of this procedure was that the flap failed, and was therefore not viable. This meant a second flap had to be harvested to replace the necrotic tissues. For this second flap part of the patient's unplanned, but necessary management was a further operation and the use of part of the patient's bowel, which could be fashioned into a tube to reconstruct the area that it needed to replace. The patient, who was unemployed and lived in, by his own description, a rocky-relationship, was in hospital for 85 days. During this time he had a permanent tracheostomy. His main way of communicating was through mouthing words with no sound produced, or by writing down, with no possible way of eating or drinking for more than three months because of the poor healing process of the first failed-flap and then the second healing one. The patient had three large scars that needed to heal: neck, lateral thigh and abdomen. Once he had recovered from this surgical treatment he had to have oncological treatment, which included both chemo and radiotherapy. This meant his total length of actual treatment, from his operation date, through to his last day of radiotherapy was 145 days. This patient consented to a semi-structured interview during which he discussed how he had been during this treatment period:

*'Once you let your defences down, that's when you start to crumble, so it's as though I'm standing on the outside of the building, but I've crumbled inside.....
.....There are times in the last few weeks I've felt, "oh hell what's the point?" I'm not bothered but I don't let on.'*

Study 1: Participant 4:16.3.-16.8

David was participant 4 in the part of the study, which helped create the concourse for the Q methodology study. It would seem most unlikely that David would have consented, or engaged with completing a questionnaire, or if he had he would have been somewhat superficial with the answers, because of not finding it possible to concede how difficult life had become. It will be suggested in this study that it is important to understand, at an individual-level, how patients are affected by both their disease and treatments in order to support them more appropriately. It cannot be suggested that another patient would react in the same way that David did, but whilst

such treatments with their complications might seem extreme, it is not unusual for many patients to have protracted periods of treatment so that their chances of returning to a pre-morbid level of function are remote.

Patients' individual needs rather than the system in which they find themselves treated should be described. The human aspect of a very personal disease should be better represented, so that the specialism is better informed. The field has to progress from the dominating outcomes of temporal and QoL descriptors towards individual patient-centred and derived data. Through this approach patients, clinicians and researchers have a more detailed understanding and can therefore influence the care of patients.

THE STRUCTURE OF THE THESIS

The work is presented in a progressive format and uses the context of the disease to develop the research. The specific layout of each chapter is as follows:

- Chapter one presents a review of the epidemiology and aetiology of the disease; the likely co-morbidities associated with it, and describes the management of the disease, treatment sequelae, complications and outcomes.
- Chapter two presents the modern aspect of outcome measures and describes how, within health-policy, patients are experts in their care, in which more holistic assessments should be carried out.
- Chapter three presents two publications by the author. The first explores why QoL measures may not be the best way of measuring patient experiences associated with head and neck cancer; the second reports on the judgements relating to QoL made by the clinicians working at the author's cancer centre with this patient group.
- Chapter four reflects upon some of the clinical and research learning the author has experienced and explains why Q-methodology was chosen for this study.
- Chapter five presents the Q-methodology study and its results.
- Chapter six discusses the results, clinical implications of the findings and suggests some of the possible post-doctoral research.

CHAPTER ONE

THE FACTS AND MANAGEMENT OF HEAD AND NECK CANCER

INTRODUCTION

This chapter will describe in detail the epidemiology, aetiology, treatment choices and management for patients who present with head and neck cancer (H&NC). The intention is to demonstrate the diversity of all of these aspects so that there is a sense, for the reader, of the diversity and complexity within the disease, which will influence the choice of methodology used in the research.

A DEFINITION, INCIDENCE AND INITIAL PRESENTATION

H&NC is a collective term for more than thirty specific anatomical sites. Convention around description has meant that the region is subdivided into three areas: oral cavity; pharynx; and larynx. The brain is not included in the classification of this cancer group. Figures 1, 2, and 3 in Appendix 1.1 represent these three regions; they describe visually their numerous structures, their three dimensional nature, as well as their relative size and locality to one another. At a global-level H&NC incidence accounts for six per cent of all cancer and five per cent of all mortalities. Every year more than 550,000 people are diagnosed with the disease, and 300,000 die (Ferlay et al., 2010). The majority, sixty percent, present with advanced disease (Parkin et al., 2005), and late-detection is the main reason for a poor survival rate with approximately half of all patients dying within five years of initial presentation. The late presentation is, in part, due to poor public-knowledge of the disease, and an inability to appreciate that the symptoms experienced are H&NC. In the UK late presentation is exacerbated by its comparative rarity, such that its incidence the fifteenth most common cancer for males and nineteenth most common cancer for

females; other cancer sites such as breast and prostate dominate. Figures from 2004 show there were 8,000 new cases of newly diagnosed H&NC cancer in the United Kingdom for that year and 2,500 deaths in 2005 (Cancer Research UK, 2009). This is in contrast to other cancer site incidences for which in 2008, breast cancer represented 48,000 cases (32 percent of all cancers diagnosed among women) and prostate cancer 37,000 (25 percent of all cancers diagnosed among men) (Cancer Research UK, 2009). The implications of these different presentation statistics are that there are likely to be ten times more patients diagnosed with breast, or prostate cancer, than H&NC. It becomes even less well identified when it is known that 'head and neck cancer' is an overarching term and the incidence for each of the three individual regions (oral, pharyngeal and laryngeal) is even more rare because these are sub sets of H&NC. UK-based research has identified poor public-awareness and gone further by reporting that the public think their symptoms are trivial and will resolve (Rogers et al., 2011b, Rogers et al., 2011a). Whilst the general population has poor insight, there is little evidence that health-care professionals have redressed the balance by being any better informed. McCann et al, (2005) reported that less than half of medical undergraduate courses included the topic in their syllabi. No specific research has looked at the identification rate of oral cancer by dentists in the UK, but research has suggested their skills are at a basic level. Whilst the majority of dentists will carry out a routine visual assessment of oral mucosa, they are not confident in their ability to identify oral lesions (Kujan et al., 2006). This taken together with the knowledge that one in five of the UK population does not have universal access to an NHS dentist, (McGrath et al., 2001) will mean that H&NC remains a disease likely to have a poor-profile in populations and professionals alike.

Late detection is only part of the problematic initial presentation. The UK government has recognised since 2000 that the access to specialist cancer centres for patients with suspected cancer is not only variable but also cumbersome. The publication of the National Cancer Plan 2000, (Department of Health, 2000), sought to re-dress this situation by introducing a two-week referral time from primary care to specialist centre for patients who were suspected of having cancer as a way of fast tracking patients. Unfortunately there is little evidence to suggest that this is the process through which the majority of cancer patients access cancer centres. The National Awareness and Early Diagnosis Initiative reported on data for patients within England from 2007 (National Cancer Intelligence Network, 2008). It reviewed how patients accessed cancer services in England prior to their diagnosis. The results indicated that only twenty-five percent of patients were diagnosed through the Two Week-Wait, whilst twenty-three percent presented as emergencies. Patients at the more extreme age limits of under twenty-five or over seventy-five, were the most likely to present as emergencies. A socio-economic gradient was also observed and this suggested that more affluent patients were less likely to present as emergencies. They also were able to conclude that the route of referral to the cancer services influenced the overall survival rate for all cancer patients, except those diagnosed with leukaemia. The National Audit Office has also reported that nearly one in four cancers are not detected until a patient is admitted via an emergency department (Department of Health, 2011). This is certainly the case for H&NC patients (Hobson et al., 2008); the minority are seen through the two-week referral route but they are not unique in this experience. The intention is that after assessment in primary care the patient is referred for more specialist investigation. The National Audit of Cancer Diagnosis in Primary Care (Royal College of General Practitioners, 2011) described a wide

variation in referral times, with unacceptable variations between trusts in the two-week-wait referral route. It is of note that since the introduction of H&NC guidelines in Scotland, Wales and England, there has not been a subsequent improvement in the ultimate clinical measure i.e. survival. However, use of the guidelines may not be the main problem for H&NC, but rather, access to the service. Patients remain unable to access the service because of poor recognition of the disease by primary care clinicians (Singh and Warnakulasuriya, 2006), exacerbated by a significant percentage being unable to access the services via the urgent two-week wait pathway (Hobson et al., 2008). It would seem, despite established protocols for referrals, the initial referral into the specialist centres is not well used. The National Cancer Patient Survey of 2010 (Department of Health, 2010c) revealed corroborative and equally less comforting data from the audit of primary care. Patients who were surveyed revealed that a quarter of them saw their GP three or more times before being referred onto a specialist service. Patients are both complex and individual in their initial presentation, and they, as well as the screening clinicians, are poor at recognising the implications of the symptoms early.

CLASSIFICATION OF THE DISEASE

Most of the tumours from the head and neck arise from the epithelial lining of the mucosa and as a consequence, approximately 90 per cent have the pathological label of squamous cell carcinoma (SCC). By convention, cancer is classified by tumour size (T), nodal spread (N) and distant metastases (M). H&NC is no exception to this. The primary tumour, if detected within the head and neck region, is classified by using a universal system of tumours' classification that is reviewed on a regular basis (Greene and Sobin, 2009). Different suffixes follow the TNM classification and

differentiate the tumours' characteristics further. These include: "is", 1, 2, 3 or 4 in which size dominates the description of the tumour such that an increasingly large number (one to four) signifies a tumour from less than 2cms to greater than 4cms. The number four however, is not only based on size of tumour, but represents any extension of the tumour into adjoining structures, such as invasion into adjacent cartilage or bone. This means that a tumour can be categorised as a T4 tumour based on its invasion into structures rather than using size as the criteria. The dimensions and extent of the tumour can be assessed clinically and described more precisely with pathology and imaging services. There are other suffixes apart from numbers used to describe the tumour. The suffix, 'is', represents tumour classification, in pathological terms, as 'in-situ' and means that the tumour presentation is either non-invasive or in-situ. At the other end of the spectrum the suffixes of "a" or "b" can follow the number 4. The former denotes that it is possible to remove the tumour, the latter that it is not because of its location to vital structures. It is unusual not to be able to visualise through imaging a tumour of the head and neck; an unknown primary tumour will exist only in 2-3 percent of cases and is denoted by the suffix "x". Whilst the tumour-size and extent is important to investigate and describe, other aspects of the cancer have to be understood at the assessment stage, so that the prognosis, and the possibility of the treatment, might be understood more completely.

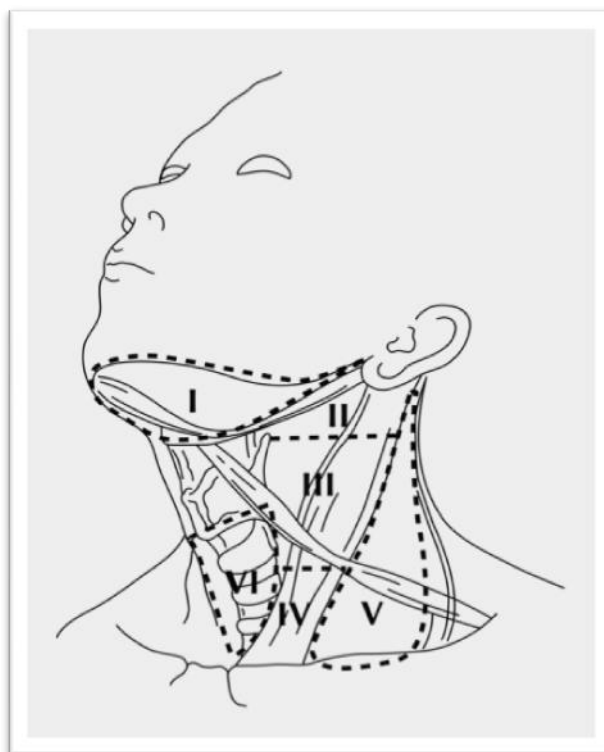
Tumours will spread typically from the head and neck into a complex and rich lymphatic drainage system within the neck. Cervical nodes may have disease, which has spread from the primary head site. If this is the case patients are much more likely to have recurrent disease (Roland, 2012). There is approximately a fifty per

cent reduction of five-year survival in patients who are diagnosed with a cervical lymph node. The descriptions of the neck disease are multiple, and establish:

- The level in the neck the node is located (I-VI);
- Laterality of the node(s), (ipse-lateral, contra-lateral unilateral or bilateral);
- Number, single or multiple,
- Size and spread beyond the node breaching the nodal-structure (extra-capsular).

Figure1.1 represents the classification of the different levels within the neck. If the disease has breached the nodal membrane the disease presentation is more aggressive and or more advanced (Roland,2012).

FIGURE 1.1 SCHEMATIC DIAGRAM OF LYMPH NODE LEVELS (Scottish Intercollegiate Guidelines Network, 2006)p77



The final part of the staging for the disease relates to more distant spread of the disease known as metastatic disease. The presence or absence of metastases is indicated by M followed by 1 or 0 respectively. It is unusual for patients, who present with H&NC as their primary disease, to have metastatic disease; it is more common

for H&NC to be a metastatic extension of other tumour sites such as breast, bowel or lung. It is for this reason that patients need to have a full assessment at presentation, to assess the likelihood of another tumour within the body (Roland, 2012).

TNM nomenclature set out in Appendix 1.2 might be viewed as being very specific in its classification of the disease. There is however, criticism that it is open to individual interpretation. For example the concept that bilateral nodes, N2, are of less pathological significance than to have a node larger than 6 centimeters -N3, is not accurate. The classification also has other shortfalls, because it:

- Overlooks prognostic information regarding the tumour's immunological status;
- Does not denote routinely the presence of extra-capsular spread, peri-neural or lympho-vascular invasion within the nodes;
- Does not denote the volume and the infiltrative nature of tumours within the tumour staging.

The above is also further complicated because it depends on clinicians identifying correctly the presence of a node and its true dimensions. It is essential that possible nodes identified clinically from neck palpation, have more objective investigation, so that it can be established whether there is neck disease, an extension of the tumour (Roland, 2012) and whether there is an indication of more extensive disease.

AETIOLOGY

The overwhelming evidence related to the causes of H&NC is that the disease is attributable to an individual's behaviour with particular reference to their use of tobacco and alcohol. Table 1.1 details the main causes of the disease; much of the

more recent changes in incidence, particularly from a female perspective, are as a result of the different environments women now work in and the increased acceptability of them using tobacco or alcohol.

TABLE 1.1 DESCRIPTION OF CAUSES, BEHAVIOUR AND REFERENCES FOR H&NC

Cause	Description/behaviour	Source of data
Tobacco	Type of tobacco smoked and style in which smoked influences site of tumour and risk of cancer.	(Johnson, 2001)
Alcohol	Alcohol intake without tobacco. Consumption of more than 3 or more drinks a day increases the risk two-fold Drinking beer and spirits has a more pronounced impact than wine	(Hashibe et al., 2007) (Purdue et al., 2009)
Tobacco and alcohol combined	Synergistic effect 35 times 2 packs of cigarettes and 4 alcohol drinks more likely to develop oral cancer than non smokers and drinkers	(Blot et al., 1988)
Human papillomavirus (HPV)	The incidence of oral sex has risen as a reaction to known sexually transmitted diseases. The development of the specific virus into oral cancer is not a direct correlation but whilst smoking rates have decreased oro-pharyngeal cancer with HPV positive pathology has increased.	(Fakhry et al., 2008)

Whilst tobacco-use has been identified as a carcinogen, alcohol-consumption is less well recognised. It would seem, however, that the latter has played a more substantial role than had been understood previously. The aetiology of other cancers can give some informative evidence towards this notion. Smoking incidence has reduced greatly in the UK and so proportionately has the incidence of lung cancer (Office for National Statistics, 2011). There has not been however a similar rate of reduction in H&NC, which suggests that other factors are influencing its cause within

the UK. These might include environmental pollutants and occupational hazards, as well as behaviours relating to alcohol. Increasing alcohol-intake has been an observed trend over the last twenty-years. Data issued on the drinking habits of the UK population from 2007, suggested that alcohol consumption continues to be at dangerous levels for 25 percent of the English population (Office for National Statistics, 2011). Furthermore the disease presentation has also been identified as showing a pathological shift and is likely to explain why, despite a reduction in the incidence of smoking, there has been an increase in the number of oral cancers identified which is set to continue to rise.

‘By 2030 it is predicted there will be 9,200 cases of oral cancer in the UK every year compared to 6,240 in 2009 and 3,030 in 1984. Rates continue to rise in both men and women and in all age groups including the under 50s with more young people developing oral cancer than ever before.’ (Cancer Research UK, 2012)

Oral cancer for men has increased by 24 per cent whilst lung and laryngeal cancers have declined by 24 per cent and 12 per cent respectively (Cancer Research UK, 2009). A review of the world literature between 1957 and 2000 suggests that oral cancer now presents in four to six per cent of patients who are under the age of 40, which is a new concept. Llewellyn et al (2001) reported that there were an increased number of patients diagnosed under the age of 40 and that the aetiology, as well as pathology of the disease, in this group of patients, was likely to be different. A third contributor, viruses, has been recognised. They may be the cause of oral and or oral-pharyngeal tumours and these tumours are tested more routinely for their human papillomata virus (HPV) status. It would seem that this part of the disease epidemiology may explain why oral cancers continue to increase in incidence for both genders, whilst lung and laryngeal cancer, a disease of a smoking population, have

declined. The literature would also suggest that there are other associated risk factors that might influence the causes of H&NC apart from alcohol and tobacco-use.

They include:

- Poor diet (Garavello et al., 2008)
- Poor oral and dental hygiene (Maier et al., 1993)
- Occupational exposure (Maier et al., 1991, Dietz et al., 2004)

Whilst behaviours seem to influence the aetiology of the disease, there is a more difficult link to be investigated in socio-economical terms. The situation is more complex and there are no strong links that could be identified specifically to suggest lower status equates to a higher risk of the disease. Smoking seems to be the major influence, Conway et al (2010) carried out a detailed patient questionnaire on a cohort of H&NC patients in the West of Scotland to define the impact of socio-economic status. They identified that those living in the most deprived communities, had the largest tumour burden, but they were unable to establish a clear relationship with socio-economic status. It seemed that a higher-level of education had a protective effect, and that a lifetime experience of unemployment was associated with a higher risk of the disease. After multivariate analysis, only smoking remained as a significant causative factor. The authors suggested that when trying to understand the complex relationship between socio-economic status and risk of developing oral cancer a lifetime socio-economic profile would be informative. Such a recommendation was made earlier by Wooley et al (2006) when they had looked at similar contextual issues. The impact of deprivation, whilst difficult to isolate from causation, may influence outcome in terms of survival and quality of life (QoL). It has been suggested that lack of community support, isolation, bereavement and withdrawal from family or other support mechanisms may affect QoL significantly and

outcome. Woolley et al (2006) suggested that deprivation becomes an important case-mix adjustment measure when reporting outcomes. Their research investigated the impact of deprivation on QoL for H&NC patients. The results suggested that patients living in the least deprived areas had better QoL scores than those in the most deprived areas. Stage of disease, and subsequent treatment was not influenced by deprivation and they suggested that the lack of an intact social network, or the ability to access it due to financial constraints, was influential. They recommended that keeping an updated deprivation index within the cancer database could help identify those patients at greatest risk of developing depression after treatment. This aspect of deprivation, a mediator of the disease presentation, will be explored more fully in chapter four through the work of Munro, a clinical-academic oncologist.

MODERN-DAY MANAGEMENT AND PROGNOSIS -A UK PERSPECTIVE

Implementing the best evidence through the use of guidelines is one of the ways that the quality of health care can be assured. Harrison et al (2010) defined them as the synthesised evidence (relating to a topic) that has been translated into specific practice-orientated recommendations. For many governments and professional organisations these guidelines are construed as a way of tackling possible variations in practice for disease that might be complex and have protracted management. They are also a direct link from local practice to national recommendations with the influence of both experts and politicians. Guidelines have been justified as a way of trying to consolidate health-care costs by streamlining services, and are set in a context of evidence-based medicine, which has sought to eliminate anecdotal or

inconsistent approaches to healthcare and improve patient outcome (Scottish Intercollegiate Guidelines Network, 2006). From a H&NC perspective both of these issues are most pertinent. The rarity of presentation, the multiple variables that need to be accounted for and the need to address individual patient needs, means that guidelines remain recommendations from which clinicians might select treatment options too. In England and Wales they have been regarded as a way of trying to diminish disparity in care that might occur, which seemed due to local variability and became known by the colloquial term of 'postcode lottery'. There was evidence published by the media that fuelled public unease that possible treatment and successful outcome was being affected by where patients lived rather than the severity or needs of their disease.

As a reaction to such circumstances guidelines have been created. The National Institute for Clinical Excellence (NICE), was set up to promote and explore high quality health-care and produced the English and Welsh H&NC guidelines (National Institute for Clinical Excellence, 2004).

These guidelines:

- Defined the recommended assessments
- Described the limits of its remit in terms of tumour type, and so stated explicitly that they did not include skin cancer, sarcomas, lymphomas or brain tumours
- Detailed the professional groups involved along with their specific roles
- Described an expectation that peer-review and regular team discussions became part of the standard and expected process of patient-care

The guidelines had key recommendations, for cancer networks, which are made up from the health service, local authorities and voluntary agencies. The

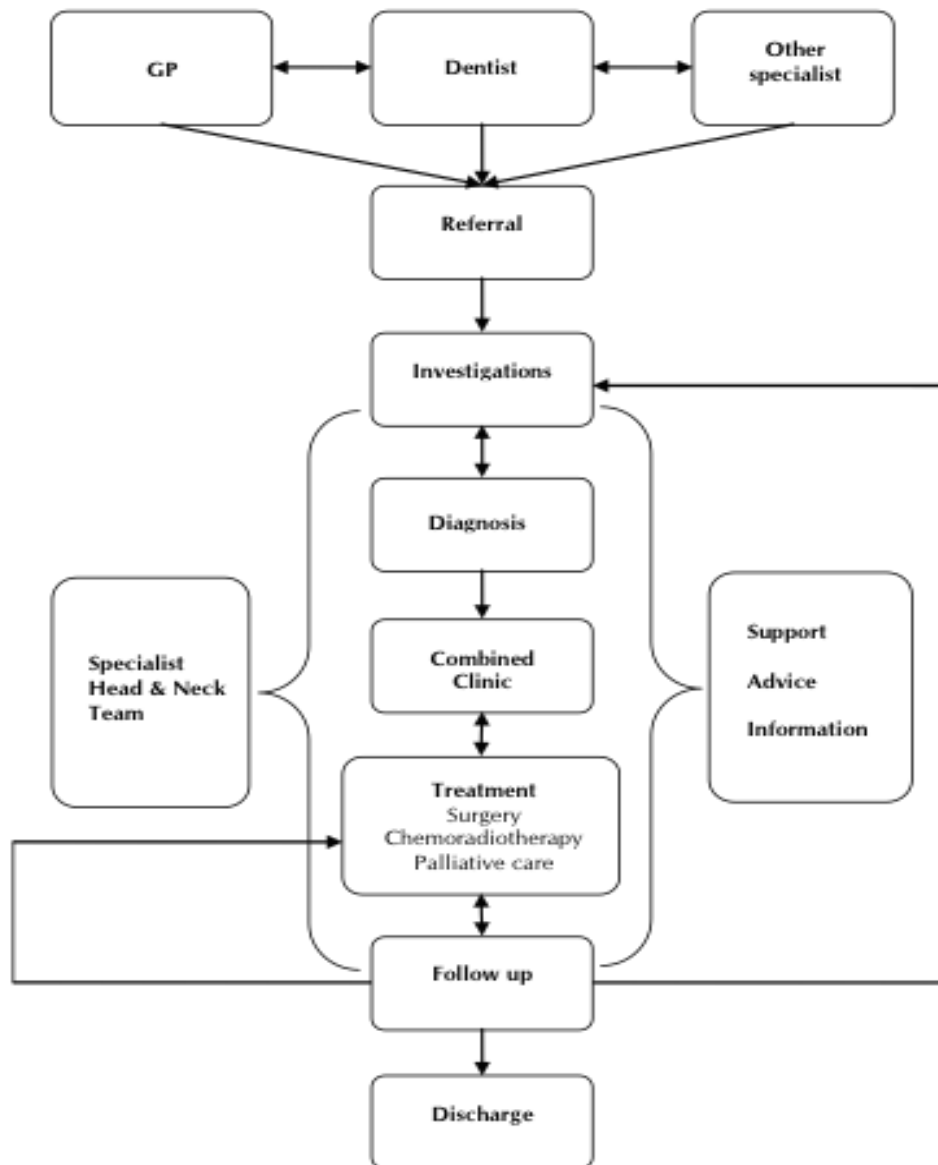
recommendations of the guidelines are listed below:

- The establishment of H&NC centres, (definition of a centre-managing at least 100 newly diagnosed patients a year, from a population base of more than a million)
- The referral process should be streamlined to reduce administrative delay

- The need to provide a wide-range of specialist support services from the pre-treatment stage that should continue until rehabilitation was complete
- The services after the acute hospital treatment should be community based
- The multi-disciplinary team MDT should collect data recording the management and outcomes of the patients treated
- An urgent need for the development and expansion of research into the effectiveness of management

A general outline of a treatment pathway has been published but the emphasis is on broad descriptors rather than intricacies of the individual patients. Scottish guidelines (2006) on H&NC and the NICE guidelines (2004) are a synthesis of the available data by experts in order to inform the public and the health service.

FIGURE 1.2 OUTLINE OF THE PATHWAY OF THE CARE FOR A PATIENT WITH SUSPECTED AND THEN CONFIRMED DIAGNOSIS OF HEAD AND NECK CANCER. (Scottish Intercollegiate Guidelines Network, 2006) p55



Decisions about treatment are complex, and must balance treatment success and subsequent survival, with possible functional impairment and QoL changes (Mehanna et al., 2010). The H&NC multi-disciplinary-team has developed because

no one professional group can manage the patient from diagnosis through treatment and follow-up. It relies upon many specialities liaising with one another, in order to formulate a possible treatment-plan. This cohesion of care and expertise based on volume has benefits to outcome, complication and cost (Westin and Stalfors, 2008). These factors are likely to be more relevant as there is further advancement or refinement in oncological and surgical treatments. Whilst it is known that teams should have the opportunity to discuss the possible treatment options prior to decision-making, it has been suggested, by identifying possible co-morbidities and having insight into patients' preferences, that the effectiveness of the decision can be improved (Blazeby et al., 2006). The purpose of such meetings is to determine the best way to control the tumour whilst maintaining survival and QoL. In terms of Sackett's classification of research quality much of the evidence associated with the disease does not exceed quality level 2a, systematic reviews of cohort studies (Sackett et al., 2000) because of the heterogeneity of the patient group. This factor is evident from a review by Conway et al (2009) which found that of the fifteen systematic-review articles that were identified, most were judged to have methodological flaws or poor statistical power.

THE MANAGEMENT OF THE DISEASE

ASSESSMENT

The sense of variety of health-care provided and broad, rather than specific guidelines will have helped establish that the disease and its management is complex. Diagnosis is very unlikely to be established by a single outpatient

appointment. It is critical to carry out investigations in a logical, sequential way. If certain procedures are performed before others there is a possibility that the information gathered could be influenced wrongly by the timing of investigations. During the assessment process, which will include clinical examination, radiological scans, and pathology scrutiny, the disease can be confirmed and classified more accurately. The original assessments have to answer two specific questions:

1. Is the disease too advanced?
2. Can the patient tolerate the recommended treatment from a physiological and emotional perspective?

Imaging, in the ideal sequence of assessment, should be carried out before any biopsies of the structures so that the scan represents the nature and spread of the disease, rather than including localised tissue-trauma from the biopsy. The imaging work-up might include plain X-ray, computerised tomography, (CT) Magnetic Resolution Imagery (MRI) or positron emission therapy (PET). All provide different, but complimentary assessment information. The main aim of these scans is to confirm, by corroboration, three aspects of the disease:

1. The suspected tumour site
2. Extent of the disease within the neck
3. The possibility of synchronous tumours not yet identified

The direct examination of the patient and tissue-sample allows for a comprehensive and detailed assessment of the patient and the possible disease that will need to be confirmed by pathology.

A possible tumour needs to have confirmation from a pathologist before treatment can be formulated. Any biopsy carried-out might require the patient to have a general anaesthetic in order to access the area and take enough tissue to be a representative sample. The decision about the use of single or dual-modality treatment is based largely on the pathological findings. It is not until this point that

the disease can be staged formally (Roland, 2012) and the need for oncological treatment established.

TREATMENT OF HEAD AND NECK CANCER, GENERAL POINTS

At the time of presentation many patients may have limited or minimal symptoms from the tumour. In broad terms there are two types of treatment that might be used solely or in combination, surgical or oncological. The order and combination selected is dependent on many aspects of the disease-presentation and the practices of the country in which the patient lives. This chapter will emphasise the UK approach to treatment but will also acknowledge the context of the differences from an international perspective. Guidelines were drawn up by NICE (2004) and SIGN (2006). Within the guidelines area framework, it is not possible to be overly prescriptive because of the numerous presentations that need to be considered. Some of the methods of treating H&NC are affected by international preferences. Over the last twenty-years, with the advent of improved surgical and oncological techniques, treatments for H&NC have become more sophisticated and intricate. It is possible however because there is little to choose between results from different ways of treating patients, that a patient might be offered chemo-radiotherapy in one country whilst receiving surgery as the primary and definitive treatment in another. Clinical decisions cannot be made purely on the basis of the patient's tumour presentation and have to take into account possible co-existing medical conditions, known as co-morbidities. Appendix 1.3 lists some of the national guidelines used for H&NC

CO-MORBIDITIES AND HEAD AND NECK CANCER

Patients with any type of cancer can present with co-occurring medical conditions, which may range in both presentation and severity. Co-morbidities have been shown to have prognostic importance within the H&NC population (Piccirillo, 1995, Singh et al., 1998, Pugliano et al., 1999), which might be more significant than the presenting head and neck disease. The prognostic impact of these co-morbidities is thought to arise from the physiological burden of the chronic co-morbidity and its ongoing treatment to the patient. It has been established that the severity of co-morbidities is high for the H&NC population, with only lung and colorectal patients presenting with a greater degree of co-morbidity burden (Piccirillo et al., 2004). H&NC patients with co-morbidities have been reported as having poorer survival, even after taking into account other important clinical factors such as age, site and stage of disease (Yung and Piccirillo, 2008). Therefore, despite a patient surviving the initial treatment for the cancer, the co-morbidity might still be the dominant variable that will affect survival.

SURGERY

Surgery in general has been able to progress because of very significant advances. These have included the ability to anaesthetise patients safely, control infection and the successful use of blood transfusions. Surgery in the head and neck region has progressed in its sophistication over the last twenty years because of micro-vascular

techniques. This means that the reconstruction might include bone as well a soft-tissue, and will try, as far as possible, to mimic the pre-morbid shape that it replaces. The use of micro-vascular free-flaps has enabled structures to be preserved in part, whilst removing the tumour, and enough of a surrounding margin of tissue. Failure of the flap to survive is a rare occurrence and has been reported in the UK to have an incidence of approximately five percent (Novakovic et al., 2009). There are many papers that compare the relative merits and surgical techniques in order to harvest and relocate the flaps (Genden et al., 2009, de Bree and Leemans, 2010, Wehage and Fansa, 2011).

Surgical intervention, as well as attempted excision of the tumour, will also include management of the patient's neck, which as described within the assessment may, or may not, at the time of presentation, have confirmed nodal disease. A predictable pattern of possible nodal involvement has been known about since the mid-nineteen-sixties (Fisch and Sigel, 1964) and early seventies (Lindberg, 1972). From such work, clinicians are able to perform neck dissections that allow for the preservation of some of the anatomical structures within the neck and similarly limit the impact on physical function. The benefit to the patient is that there is disease clearance whilst poor range of movement to both the shoulder and neck are minimised.

ONCOLOGY TREATMENT - RADIOTHERAPY

Radiotherapy has also shown advances from a technical perspective. There has been the more universal use of Intensity Modulated Radio-Therapy (IMRT), which enables the radiation dose to be delivered in a three-dimensional way. The main advantage of this technique within the head and neck region is that the structures,

which might be sensitive to radiotherapy, can be spared by receiving a much lower dose than the ultimate dose delivered to the tumour. The sources of the radiotherapy build up and focus on the epicentre of the disease and they might therefore allow the salivary glands to be spared. It has been reported that the main influence on tumour control for such a treatment is tumour and nodal volume (Chao et al., 2002). IMRT has been used clinically within Britain since 2001 (Webb, 2005). However as Webb (ibid) discussed there are three reasons why the benefits of the technique are unclear and the real impact of the advancement will never be truly reported:

- The technique was used in the States where there is generally a broader acceptance of the use of technology;
- The long-term effects cannot be known because the technique has not been used for long enough.
- Central to the rationale is the preservation of normal tissue from late radiation effects, which makes it difficult to recommend randomised controlled trials.

CHEMOTHERAPY

The increasing complexity of surgical management has been replicated within the field of oncology. Chemotherapy is a relatively new treatment for patients and concurrent chemo-radiotherapy (simultaneous) or induction (prior to radio-therapy) chemotherapy has, for patients with no adverse co-morbidities, almost replaced radiotherapy alone (Merlano, 2006, Benasso et al., 1997, Vermorken et al., 2007) because of the reported increased survival rates. Concomitant chemo-radiotherapy has also been seen as a viable alternative to surgery and post-operative radiotherapy, (Posner, 2005, Posner and Vermorken, 2008). Induction (prior to treatment) chemotherapy, followed by chemo-radiotherapy, has been presented as a combination treatment in which the chemotherapy prior to the chemo-radiotherapy treats the distant metastatic disease, whilst the more traditional use of the chemo-

radiotherapy achieves loco-regional control (Posner and Vermorken, 2008, Bhide et al., 2008, Vokes, 2010).

The decision as to which combination of treatment is going to be used, and in which order, is likely to remain controversial and unanswered. Seiwert and Cohen, (2005) have discussed that a randomised controlled trial is unlikely to be used as a way of establishing the answer, because of the inherent bias in patient selection, and the difficulty in staging patients in a similar way. As they further comment, there is a place for both approaches, which can and do co-exist. There are, therefore, for the first time, the possibility of two treatment methods available for consideration, with the intention to cure: surgery and radiotherapy or chemo-radiotherapy. It is of note that no randomised controlled trial to compare the regimes used across countries has been undertaken. This is due to a belief, by different health organisations, that the way they are treating the disease is most appropriate.

The situation is made more complex from the oncological aspect because there are many variables within the speciality evident across countries. This might include total dose of treatment delivered, as well as different combinations of chemotherapy drugs used. The difficulty in comparison is compounded because the new combined modality therapies often change more than one variable at a time, such as the dosage type of chemo-radiotherapy (Choong and Vokes, 2008) as well as how the drug-integration is fitted within the radiotherapy regimes (Maluf et al., 2007). In many of these studies the results focus on the survival rate and there is very little input from a patient perspective in terms of QoL and any symptoms as a result of the treatment. This issue is developed more fully within chapter two. Outcomes remain focused on

the statistical presentation of survival and loco-regional recurrence, grade of mucositis and adherence to complete the treatment. Choong and Vokes (2008) wonder if, after further analysis of results, induction chemotherapy may provide minimal survival-benefits. Chemotherapy is used much more routinely as an important treatment option for advanced H&NC. However, phase three clinical trials and meta-analyses cannot find any specific and favourable outcomes with reference to either loco-regional control or survival (Adelstein, 1998, Adelstein, 1999, Pignon et al., 2000, Cohen et al., 2004). The difficulty seems to lie in the heterogenic nature of the disease presentation, such that H&NC sites behave differently in terms of lymphatic drainage and propensity for distant metastases in each of the main site areas of categorisation -oral cavity, oro-pharynx, larynx and hypo-pharynx (Adelstein, 2008). Adjuvant chemotherapy as opposed to radiotherapy only, has been shown to improve loco-regional control and, in some cases, survival (Forastiere, 2004, Bernier et al., 2006). However, it is important to note again that these studies did not review such issues as swallowing function and patient related symptoms, which are detailed in the next section.

TREATMENT SIDE EFFECTS AND COMPLICATIONS

By this point in the chapter the potential impact that this disease might have on some of the most basic and personal functions for patients should be evident. There is likelihood that vital structures are likely to be impaired and will, as a consequence, compromise patients with far-reaching disease and treatment side-effects. These

delicate, complex, coordinated structures, should they be subjected to any treatments, are at risk of having their function impaired. There is every possibility that a patient will never have appreciated what the effect will be until functions such as eating, breathing and communicating are altered, perhaps irrevocably.

The identification of co-morbidities as discussed earlier will, prior to the start of treatment, enable the team to be both proactive and vigilant. An understanding by the team of the repercussions is also important so that the patient and their relatives are informed about the possible side effects of the treatment. The intention would be to reduce the incidence of treatment complications, which might be equally as life threatening as the untreated disease. The possible complications can be categorised broadly into those that are as a result of co-morbidities (hypertension, respiratory disease) and those that are as a result of the actual treatments (infection, fibrosis, dry mouth, poor taste, reduced range of movement). This may mean that a patient's function might be affected as a direct result of the treatment sequelae or because of their existing co-morbidities.

There is a need to incorporate the patient qualities within the possible outcome of the treatment. From the research it would seem that there are some patient behaviours that are better at dealing with symptoms (Scharloo et al., 2005). Their work detailed the types of patients who were likely to feel that they had worse quality of life. These patients tended to focus on symptoms, believed they were at high risk of recurrence, had a high score for self-blame and had poor scores relating to the emotional domain of QoL questionnaires. The impact of patient characteristics was also in work carried out by de Leeuw et al (2001). Reliance on alcohol, denial and fatalism were

the patient profiles of people less likely to improve from their symptoms. The symptoms might also be more complex because they are multi-factorial. Examples might include change in body image, communication, ability to socialise, reduction in mood and activities. There has been research to suggest that an impact on speech and eating is likely to have the most impact on a patient's well being (Duffy et al., 2008). Again there is a real need to measure these aspects more carefully.

Research has suggested that to have a prolonged method of alternative method of feeding is likely to predict a poor QoL, (Ronis et al., 2008). Perhaps what should be included is detail on the ability to eat, and be integrated socially rather than merely the presence or absence of alternative methods of feeding. Merrick and Farrell's study (2012) investigated, in detail, patients' attitudes to alternative methods of feeding. Three perspectives to gastrostomy tube-feeding were evident from the research: some patients adapted in a constructive way to feeding tube, some were ambivalent to the situation and the final group showed much more negative reaction to it and were, as a consequence of the procedure, anxious and fearful of the treatment used. The recommendation of this study was that there is a real necessity to provide patients who are tube-fed whilst receiving HNC treatment with individualised patient centred nutritional care.

FOLLOW-UP POST DEFINITIVE TREATMENT

Recurrence or late-stage complications such as tissue or bone necrosis can be monitored and managed at this stage. Outpatient review for patients with H&NC after the initial and acute healing-time is focused principally on surveillance (Vaamonde et al., 2003). There may be a role for re-imaging a patient should there be suspicion of

a recurrent tumour, but as documented by Hermans (2008) there is a difficulty in differentiating change in tissue from recurrence when using this assessment technique. Davidson states that one of the highest predictors of tumour recurrence is previous H&NC (Davidson, 2001). Patients with cancer of the oral cavity and pharynx have been described as particularly susceptible to the development of new cancers because of the rich blood and lymphatic system.

There is much less success in achieving curative status in patients who present with a second primary tumour in the head and neck (Kyrgidis et al., 2010). If a patient has already had radiotherapy for a tumour treated previously it will not be possible to offer further radiotherapy because the soft tissues will not be able to withstand another radiation treatment without being destroyed. If further treatment cannot be offered, the surveillance team will need to manage the progressive and additional symptom-burden that follows. This is most likely to include referral onto specialist community palliative care teams to support the patient and their families as the disease progresses.

PROGNOSIS

The complexity of the disease presentation and combination of possible treatments should have established that advising patients about their prognosis is difficult. It would seem very reasonable that patients can discuss with their team the likelihood of recurrence and the expected impact of the treatment on their everyday lives; but it

maybe that the answer remains vague and that much of the detail is judged to be too individual to be predictive or useful. The heterogeneity of both the patient and disease presentation means that definitive prognostic information is difficult and might at an individual level be meaningless. The variation of tumour site, size, and pathological classification, diversity of treatment options, the presence of co morbidities, and the precise interpretation of these at a unit level, make discussion difficult. Predictions about treatment success are not amenable to percentage answers. There are, however, some broad principles that can be used. One and two-year survival is better in patients who present with smaller volume tumours and in tumours situated in the larynx rather than oral cavity or pharynx (Cancer Research UK, 2012). Such a statistic is in part related to how easily cancers are identified at initial presentation, and persistent hoarseness, a feature of laryngeal cord cancer, is amenable to early detection.

Prognosis is variable and depends on a number of factors. The presence and stage of neck disease has already been discussed. There appears to be a better outlook for patients diagnosed with oral cancer that is HPV 16 positive (Fakhry et al., 2008). These tumours are more susceptible to induction chemotherapy compared to tumours that are HPV negative. There is also better long-term survival because there appears to be less likelihood of recurrence from tumours fitting into this pathological classification. Survival for H&NC patients is hampered by a high incidence of distant metastasis, second primary tumours, and co-morbidities (Gleich et al., 2003). Gavilan et al (1992) suggested that predictors of recurrence after surgical resection, from a pathological perspective, included: involved margins at the

time of the first resection and the presence of neck nodes, which may exhibit extra-capsular spread.

Although clinical features of the tumour are pivotal in disease-free survival, there are other factors such as socio-economical status that have been linked to prognosis. Level of deprivation has been shown to impact on survival within the UK. Patients who are classified as having greater wealth have, over time, been shown to have an increasing chance of survival. Five-year survival rates have, for more affluent patients, increased from 43-55 per cent between 1971-1975 and 1986-90, compared with a corresponding small change from 42-44 percent for more deprived patients over the same time intervals (Conway et al., 2007). Perhaps this has been the real impact of population education.

THE MODERN CONTEXT FOR HEALTH OUTCOME MEASURES

Chapter two will describe the context and possible outcome measures that might be used in health-care. However, there is a need to explore this briefly within the management of the disease. Darzi stated in the document 'High Quality of Care for All' (Dept. of Health, 2008) that a quality outcome should include safe, effective care, but should also encompass the broader experience of treatment and care provided to both patients and their carers.

It is by no means easy to measure what is useful and meaningful for patients in terms of results or outcome post-treatment. It becomes the job of health professionals and researchers alike, to define with patients what the toll might be. As the introduction to

this study stated, until recently the way of measuring the personal and service costs of cancer in Britain has focussed on the routine measurement of length of survival and the achievement of process-driven targets such as:

- Referral to first appointment
- Assessment work-up to diagnosis and agreed treatment plan
- Length of hospital stay
- Re-admission-rate

Such measures have been viewed as too minimal and as having little relevance to patients in terms of the quality of the care they receive. In an attempt to address this particular issue for cancer services, the coalition government brought out a document in January 2011 aimed specifically at discussing outcome measures for cancer patients, *'Improving outcomes: A Strategy for Cancer'* (Dept of Health, 2011). This paper described ways in which it was hoped to deliver world-leading health outcomes. It was noted that whilst temporal targets, length of stay and survival intervals, are part of the quality measurements they are not the only way that health care outcomes should be measured. Three underpinning ideologies were stipulated, which placed patients in the centre or of the issues relating to care:

- Patients are at the heart of the public services through the principle of 'no decision about me without me'
- The NHS was re-orientated towards delivering the improvements in outcomes, which matter – rather than measuring processes, which do not
- Local organisations and professionals were encouraged to be innovative (Dept of Health, 2011)

These statements may be seen as real intentions of care being delivered to the highest possible standard and to be moving away from meeting targets that are process driven, towards ones that are meaningful to individual patients (Kennedy, 2003). The difficulty still remains however around how patients will know whether the quality of care they are receiving is good, or even exceptional, rather than just the

care they would want. Outcome measures should be orientated towards patient needs rather than absolutes of either survival or process. They are also set within a context where more patients are less well but demand either directly, or indirectly, more emotional or physical support because of increasing expectations of health-care.

There is a need to draw a distinction between what might be a service outcome, or an outcome relating to a treatment and what the personal impact might be upon a patient. From a swallowing perspective this can be demonstrated by thinking through an outcome such as being fed by alternative non-oral methods. The presence or absence of a feeding-tube does not take into account the aspects of swallowing at either an individual or detailed level. There is no understanding as to whether patients have adapted by a change in what they eat, how they eat, how long it takes and whether they are in pain or have reduced appetite and taste. Similarly there might be many reasons why a patient does not eat, such as: low-mood, fatigue, poor appetite as well as the more predictable reasons of physical limitations from poor soft-tissue function. All of these aspects are explanations as to why alternative methods of feeding are used but give little substantial explanation as to why there is such an effect. The lack of true clinical detail can be illustrated further by a paper by Salama et al, (2008), that reviewed the use of chemo-radiotherapy. Patients should be aware that there is a strong possibility that their swallow will be affected. They reported that sixty per cent of patients had a worse swallow after the treatment; twenty per cent had no measurable change and twenty per cent had an improved swallow. They also noted that older people were more likely to have a detrimental swallow post-treatment. There remains the clinical gap, therefore, between survival

success and impaired function. It would seem really important as survival improves, that a review of function and the impact on patients are reported routinely so that patients are informed more fully and are able to deal with the impact of the possible treatment side effects. At the moment these issues are not reflected within the literature in great detail. There is, as yet, a gap between the outcome measures reported, and the specific impact on patients. In its extreme, this might be seen as a conflict between the minimal data set and the rich unspecified patient experience.

SUMMARY

This opening chapter has detailed the diversity of the disease in terms of its aetiology and incidence and given some of the main ways in which H&NC is treated, should it be considered curative, by progressive and numerous assessments. It is to be hoped that, whilst the exact detail of disease and treatments cannot be retained, there is an overall sense that the disease is complex, multifaceted and that patients present in many diverse ways. There is, unfortunately, despite a real effort to manage patients through an efficient process, delay in diagnosis because of poor recognition of the disease by both the population and health-care-professionals. In England and Wales a political intention exists that would suggest that once patients are in a specialist environment, the outcome measures used are at a meaningful level rather than measuring what is easy to collect.

CHAPTER 2

MEASURING OUTCOME

SETTING THE CONTEXT FOR OUTCOME IN HEALTH-CARE

The opening chapter has discussed some of the evident variation that might exist for H&NC patients, and stated that the outcome measures of survival intervals and time-to-treat targets have dominated, despite being both minimal and basic in the information that they give. This chapter gives the context of the management of H&NC within the government documents that have been produced since 2000. The chapter is not a critique of the policy documents but helps inform the reader as to why and how the methodology chosen for this study was decided. It emphasises the government's intention to broaden care and outcome beyond numerical descriptors and involve patients directly in the planning of their care.

There has been, over the last decade, increasing political and health-care resources spent on producing information gathered directly from patients, which has moved the emphasis away from process-driven targets (Department of Health, 2001, Dept of Health, 2010, Department of Health, 2011). Many of the documents produced have sought to increase the role of patients, seeing them as important sources of meaningful information. The central theme for this chapter is the exploration of key health-service documents that discuss and recommend a change in emphasis relating to outcome. Longevity without quality is of limited acceptability and the latter needs to be considered rigorously. Part of this change in emphasis has meant that the experience of care for a patient has become more central. Patients' statistics

therefore, which are beyond survival measures have been viewed as important sources of data because they depict, the outcome of disease and treatments in more detailed ways; they are known generically as Patient Related Outcome Measures (PROMS).

THE JARGON ASSOCIATED WITH OUTCOME MEASURES

The vocabulary that exists and is specific to outcome within the context of health-care should be commented upon. It is easy to find that vocabulary is used in ways that might sanitize the real meaning behind the care of patients; the phrases used can make aspects of care abstract and removed from their source, the patients, when they should be personal as possible. Sir Ian Kennedy, an influential member of the judiciary, is direct with his criticism of the terminology used (Kennedy, 2004):

“We meet ‘patient safety’, ‘patient consent’, ‘patient focus’ and ‘the patient experience’... The centrality of concern for patients is undermined. It is replaced by a managerial concept: something to be included on an agenda and ticked. It allows the object and the objective of the expression, the patient, to be marginalised. It is no longer about patients; it is about some abstract notion. Change the language, not only to accommodate the principles of grammar but also to stress what is important and you have: ‘the experience of patients’, ‘a focus on patients’, ‘the safety of patients’. The discourse is completely changed. We are now talking about patients as people, whose experiences and safety are what we are concerned with.”

Kennedy urges health-care professionals to re-focus on the personal aspect of patients’ care, but is well aware that the terms used are in danger of side-lining the patient despite the intention to keep them central rather than marginalised, or abstract. The language used sanitizes the terms, makes them harder to understand and leads to health care jargon:

- The experience of patients is termed patient experience
- The satisfaction of patients is termed patient satisfaction
- Outcome measures reported directly by patients about themselves is termed patient reported outcome measure;

Despite such health-care vocabulary, holistic needs-assessment, patient-centred care, patient-related outcome measures and patient experience are all methods and measures used to represent patients directly, which could inform the future quality of care and outcomes. The experience of patients in relation to their care has been acknowledged as highly relevant and important and should not be excluded from results (Goodrich and Cornwell, 2008). In the context of the treatment and management of patients a resetting of the way the outcomes of care are reported needs to be achieved. The difficulty is that in a culture when results need to be understood quickly and represented simply, any that require more than a headline explanation are judged as complicated to present or explain. To move beyond the superficial message a deeper, more considered familiarity and understanding has to be acquired by both health-care professionals and policy-makers.

Sir Ian Kennedy has spoken and written extensively on the issue of patient-centred care and suggested more than thirty-years ago (BBC, 1980)

“The power now is with the professional. Only when it is realised that health is too important to be left to doctors, that it is a matter for all of us, will conditions be created for the necessary redirection of effort and resources. Only then will any real movement towards health be achieved”.

Kennedy was used as an objective outsider when he chaired The Bristol Royal Infirmary Cardiac Surgery Enquiry in 2000, which can be seen as the genesis of clinical governance. He had questioned, within the report, the clinical and cultural

practice of what had been believed to be an expert-unit respected nationally (Kennedy, 2001). The mortality rate was above average and the enquiry made seventy recommendations. In an essay that reflected upon what had been learnt from the enquiry, Kennedy, a decade later (2010), was not reassuring on any progress made since the enquiry's report. Whilst recognising 'generalised failings within the NHS' he observed that much of health-care has been 'atomised by health care workers and managers, with a tendency to describe patients in terms of body-parts, appointments, or cases-to-treat.' He noted that, in reality, each professional had either labeled the patient as 'an objective set of things', or a 'set of episodes' to be managed. The patient has become a form of currency, not a person to be understood and cared for. Kennedy warned that 'It is not possible to assure oneself that there has been much discernible progress in the last thirty years'.

Kennedy's assertions are not unique to the NHS. The American health care community, via the Picker and Plane Tree Institutes, in their introduction to 'Patient Centred Care Improvement Guide' (Plane Tree and Picker Institute, Accessed April 2012) observe similar issues to Kennedy's 2010 commentary:

'.....health care convention has been such that providers are the experts, families are visitors, and patients are body parts to be fixed. Indeed, for decades, the provision of consumer-focused health care information, opportunities for loved ones' involvement in patient care, a healing physical environment, food, spirituality, and so forth have largely been considered expendable when compared to the critical and far more pressing demands of quality and patient safety-not to mention maintaining a healthy operating margin.'

All of this literature has observed the fractioning of the complex person, which is to the detriment of their care, instigated in order to make the systems in which they experience care easier to work with, rather than for the benefit of individual patients'

health. It has also been a system used to allow targets around the processes of care to be achieved and monitored, which, whilst important, remain at a basic-level in terms of the information that it might offer towards the quality of a patient's care. Quality that can be measured and patient safety have dominated understanding and caring for the patient has been overlooked. The terms used within health care and highlighted by (Kennedy, 2004) are an indication of this. However, perhaps a change of emphasis is emerging.

The next section presents some of the influential documents published since 2000 that have started to describe and advise the change in health-policy towards data that is drawn from the patient directly and is therefore more patient-orientated. The documents reviewed have a particular relevance to H&NC patients and intend to increase an awareness of the current health-care context in which H&NC patients are being treated so that the detail and specifics of what might be relevant to their care can be considered.

HEALTH DOCUMENTS RELATING TO THE PATIENT ROLE WITHIN THE NHS

THE EXPERT PATIENT: A NEW APPROACH TO CHRONIC DISEASE

MANAGEMENT FOR THE 21ST CENTURY (Department of Health, 2001).

The term 'expert patient' was seen as a patient-centred approach, which was described as a way of patients driving-up improvements in health-care systems, reducing costs by patients doing some of their care and influencing the health-budget. Patients were seen as having a legal and moral right to autonomy and self-determination. They were recommended to have knowledge and information that should support them and facilitate their independence from health-care systems. In a commentary Donaldson (2003), the chief medical officer at the time, set high expectations for the term and described the term 'expert patient' as a concept that would be:

“.....ushering in a new era of opportunity for the NHS.The patient as expert and partner in care is an idea whose time has come and has the potential to create a new generation of patients who are empowered to take action to improve their health in an unprecedented way”.

The notion meant that if people can be engaged in their own care, and taught skills to adjust their behaviour, they have the possibility of controlling their own health outcome. The role of the clinician, as a result of this change in emphasis, was believed to be shifting, from professional-expert to guide, which would mean that giving support and advice whilst navigating the patient through the health-care system would be expected. Conventional self-management might fail; it was suggested for four reasons:

1. Lack of awareness and engagement among patients
2. Failure by staff to consider low health-literacy or cultural norms
3. Lack of attention to family and social support
4. A fragmented approach to health and social care

Self-management might bring order into a patient's life, if there is the possibility that both the patient and the health care team start to recognise and monitor the patient's personal boundaries. It had the potential to lead to personal growth. The reality of such expert patient programmes within the cancer-field is hard to approve universally. There are perhaps some assumptions made about patients that need to be checked rather than seen as omnipresent. In a critique of the literature Wilson (2008), suggested various clinical practicalities were being overlooked:

- The patients who might attend such programmes might not be typical of the patient population
- Recruitment can be difficult
- Clinicians are reticent towards the concept
- The material used within the programmes is not flexible enough to meet the patients' needs

To truly have patient-led care from a patient who becomes an expert in their own condition, with an assessment of both the mental and physical aspects, is a significant clinical practicality to engage with for health-care workers as well as patients. Greenhalgh (2009) urges support for clinicians to engage in the unique challenges that all patients might face in trying to maintain their lives, despite chronic-illness. She recognised however, in an extension of the role of expert patient, that self-management programmes, (the most utilised mechanism of the idea) needed to be extended so that whole systems of change can be incorporated, she saw this as particularly important where health-inequalities with complex social-determinants had been identified. There is a real need to investigate this as a valid or possible concept with patients diagnosed with H&NC, particularly with patients who might find it more difficult to engage with the health care system they find themselves in. The reality is that they find themselves in a situation in which

they have little knowledge of what to expect and little resource, physical, emotional or financial to invest in the process, which may include different phases of treatment, possibly over many months.

CREATING A PATIENT-LED NHS (Department Of Health, 2005).

This document emphasised that patients should have good clinical care and a good experience of that care. It consolidated much of the work discussed in the expert patient document. The introduction of the report acknowledged that whilst the NHS was more able to cope with some of the capacity issues, which had prevented it providing a prompt service, it had also to address, in more detail, some of the quality aspects of care. It stated that the main way of achieving this would be through a patient-led service, which would facilitate care to respond to patients' needs and wishes.

'to move from a service that does things to and for its patients to one which is patient-led, where the service works with patients to support them with their health needs.' (P3)

'Patients who are treated considerately, who are not left to endure anxiety and worry, who are treated attentively, who are given full and prompt information, who understand what they are being told and who are given the opportunity to ask questions, are more likely to have better clinical outcomes. A good patient experience goes with good clinical care – and patients need both.' (P8)

The vision of a truly patient-led service described within the document has eight aspects of care identified, which are summarised in table 2.1.

TABLE 2.1 ELEMENTS OF A PATIENT-LED SERVICE

	Elements of a patient-led service
1	Respecting patients for their knowledge and understanding of their own experience, their own clinical condition, their experience of the illness and how it impacts on their life
2	Providing people with the information and choices that allow them to feel in control
3	Ensuring everyone receives not just high quality clinical care but care with consideration for their needs at all times
4	Treating people as human beings and as individuals, not just people to be processed
5	Ensuring people always feel valued by the health service and are treated with respect, dignity and compassion
6	Understanding that the best judge of their experience is the individual
7	Ensuring that the way clinical care is booked, communicated and delivered is as trouble free as possible for the patient and minimises the disruption to their life
8	Explaining what happened if and when things go wrong and why, and agree the way forward

CREATING A PATIENT-LED NHS (Department Of Health, 2005).

These elements of a patient-led service seem to echo Kennedy’s description of a service that is much more focused around the needs of the whole patient and attributes high importance to them rather than deferring to the convenience of medical processes.

HIGH QUALITY CARE FOR ALL (Dept. of Health, 2008)

This document described the expectation of care for patients and introduced the idea that a quality outcome should, as well as including safe, effective care, encompass

the broader experience of treatment and care provided to both patients and their carers. Darzi emphasised the role of the practicing clinician and recognised that the modern health care system has challenges which include:

1. Relating to rising public expectations
2. Increasing demand driven by demographics, (an ageing population with co-morbidities)
3. The continuing development of an 'information society'
4. Advances in treatments
5. The changing nature of disease
6. The changing expectations of the health-workplace

The inference of this document was that information gathered directly from a patient would re-dress the balance so that patients are more fully represented, echoing the theme from the 2000 document and that there is data gathered beyond the effectiveness and safety of clinical interventions. This document emphasised that the experience of care was vital for patients and should be seen as equally relevant as the other two aspects of safety and quality.

THE NHS OUTCOMES FRAMEWORK. (Dept of Health, 2010)

This document described what are seen as the key-outcomes and indicators in the NHS for the health service. The Outcomes Framework has been created with the intention of capturing the range of activities that the NHS is responsible for delivering. Where appropriate, they are not condition-specific. Instead, they are generic and seek to capture those outcomes at an individual level, beyond any specific condition. Each domain and a brief description is presented in the table 2.2. This document

builds on previous ones and in particular refers to themes from the High Quality of Care for All document (2008)

TABLE 2.2 OUTCOME FRAMEWORK-DOMAIN AND DESCRIPTION

Domain	Description
1 Preventing people from dying prematurely	Capture how successfully the NHS is playing its part in reducing the number of avoidable deaths,not all deaths can be prevented through healthcare; the major impact on reducing mortality will be by preventing people becoming ill in the first place.
2 Enhancing quality of life for people with long-term conditions	Allow people to live as normal a life as possible. The overarching indicator 'health-related quality of life' was the most valued by people with long term conditions: (i)Feeling supported to manage their condition - look after themselves and handle the consequences of their conditions (ii) Being able to return to employment.
3 Helping people to recover from episodes of ill-health or following injury	Two complementary objectives: (i)Preventing conditions from becoming serious requiring emergency admission (ii)Helping people to recover effectively.
4 Ensuring that people have a positive experience of care	Ask people to provide direct feedback on the quality of their experience, treatment and care.
5 Treating and caring for people in a safe environment and protecting them from avoidable harm	Patient safety is of paramount importance along with (i)quality of care (ii)delivering better health outcomes. The pace of change is too slow and 'cultural barriers' that prevent patients being as safe as possible.

IMPROVING OUTCOMES: A STRATEGY FOR CANCER (Department of Health, 2011).

This report emphasised the holistic nature of the patient experience. It recognised and detailed that as well as the physical aspects of patients' health there are also financial and emotional aspects to be accounted for. It stated that there was a real intention of the government's health-care-system to facilitate as much independence as possible for a patient from both the health-care-system and their informal support-networks. Specific aims were set out within the report, one of which was that there should be a decrease in the proportion of people who report unmet physical and psychological needs post-cancer treatment. The report expressed the view that both disease and treatment symptoms needed to be described in a more representative way and that this was best done by work being delivered by government, local organisations, patients and professional groups.

HOLISTIC NEEDS ASSESSMENT (National Cancer Action Team, 2011)

This document was complimentary to the Improving Outcomes Strategy (2011) and was a way of describing how holistic needs assessment could be carried out. The document commented that a cultural-shift was needed and detailed the process. The publication suggested that if the holistic needs of patients could be identified, patients would be more likely to be engaged with their care. This would facilitate the location of possible resources, or services available during the latter stages of treatment. The holistic needs assessment (HNA) of patients was set out as a way of trying to achieve this goal through the thorough and meaningful assessment of patients. In

the introduction to the document, the description included how the HNA can enable patients to engage fully with their care, offering choices over the course of their management. It is set in the context of ongoing processes that start prior to discussion about treatment options, and extend into survivorship or end-of-life care pathways. Again this paper builds upon the previous ideas set out within the Expert-Patient (2001) and Patient-Led Care (2005) documents.

This is not the first time that the government has stressed the need for holistic care and the HNA document is a practical application of the earlier recommendations presented within the Cancer Reform Strategy (Department Of Health, 2007) and the organisation the National Cancer Survivorship Initiative (NCSI) (Department of Health et al., 2010). These initiatives all emphasise the need to assess the patient so that the interconnected aspects of physical, social, psychological and spiritual status are identified. The absolute intention is not merely to describe *if* patients are affected, but *how*, so that their concerns are considered and supported, rather than assumed, overlooked or recorded and never acted upon. There is also awareness, and perhaps frustration within the HNA that despite the recommendations made within the reform-strategy there is limited implementation of the approach at a clinical level.

The HNA cites the importance of assessment in improving the experience of patients' care. It suggests that patients should be helped to identify their concerns and to raise these so that practical help can be routinely accessed and planned for (National Cancer Action Team, 2011). The HNA paper suggested that there are three structured tools that might make the identification of patient distress easier to identify and classify more accurately - Table 2.3 details the tools.

TABLE 2.3

SUMMARY OF MAIN POINTS FOR THREE HNA TOOLS USED IN THE NHS

Assessment	Domains	Format
Distress Thermometer	Concerns with: Practical aspects; Family; Emotional; Spiritual; Physical	Tick box one side of A4 paper rate level of distress 0-10 concerns are ranked with a description in free text and an action plan
Sheffield Profile for Assessment and Referral to Care - SPARC	Communication and information issues Physical symptoms Psychological symptoms Spiritual issues Independence and activity Family and social issues Treatment issues Personal issues Free text for other issues to bring up Able to have space to write questions to ask team	Yes/no response and 4 point Likert scale ranging from not at all to very much; free text box
Holistic needs assessment PEPSI COLA	Physical Emotional Personal Social support Information/communication; Control Out of hours Living with your illness After care	Each domain is in a grid and the health care professional is asked to consider with the patient issues relating to each area and the possible resources available or professionals to transfer on to.

The full version of these assessments is provided in Appendix 2.1. It should be commented upon that these documents have been seen by policy makers as a way of challenging health care professionals to enquire directly from patients details relating to the symptoms they experience from both their disease and treatment. They are however, somewhat superficial and are in danger of cataloguing patients' symptoms rather than actually improving the quality of the interaction between patients and health care professionals.

NHS PATIENT EXPERIENCE FRAMEWORK (Insitute for innovation and improvement, 2012).

In 2012 the NHS National Quality Board (NQB) published the NHS Patient Experience Framework (Insitute for innovation and improvement, 2012). The main points of the framework can be summarised:

- Respect of patient-centred values, preferences, and expressed needs including: patients' cultural issues; dignity, privacy and independence
- An awareness of quality-of-life issues; and shared decision-making
- Coordination and integration of care across health and social-care systems
- Information, communication, and education on clinical status, progress, prognosis, and processes of care to create autonomy, self-care and health promotion
- Physical-comfort including pain management, help with activities of daily living, and clean, comfortable surroundings
- Emotional support and alleviation of fear and anxiety about issues as clinical status, prognosis, and the impact of illness on patients, families and their finances
- Welcoming the involvement of family and friends, in decision-making and demonstrating awareness and accommodation of their needs as care givers
- Transition and continuity as regards information that will help patients care for themselves away from a clinical setting, and coordination, planning, and support to ease transitions

- Access to care with attention for example, to time spent waiting for admission or time between admission and placement in a room in an in-patient setting, and waiting times for an outpatient appointment

The framework outlines elements critical to patients' experience of care from the NHS. The National Quality Board sees the elements as fundamental ways of addressing patients' experience.

WHAT MATTERS TO PATIENTS (King's College London & King's Fund, 2012)

This document, published in the same year as the patient experience framework, was a collaborative piece of work between the King's Fund and King's University. It stated that national measures of patient experience should be designed to achieve four purposes, which were acknowledged as being derived from the Outcomes Framework (2010):

1. Accountability (reporting upwards)
2. Transparency (reporting out to patients and the public, which means that the measures reported are understood by the public)
3. Improvement in services
4. Convince clinical staff, especially doctors, and encourage clinical leadership to engage with patient experience

The report had triangulated results from patients, carers and organisations; it highlighted that providing a good patient experience should be multi-dimensional, consisting of two aspects:

1. The systems and factual aspects of care, (Functional care)
2. The interaction of the health-care professionals with patients, (Relational care)

The results of the triangulated sources are presented in table 2.4. It is of note that communication, a relational aspect of the experience, whilst seen as vital by patients,

is poorly represented as a reported outcome. Clinical effectiveness or the safety of patients continues to dominate reports.

TABLE 2.4 DESCRIPTION OF WHAT ELEMENTS OF CARE MATTER TO PATIENTS

Experience described as being important to the patient	Category
Good information provision written, oral and time to ask questions	Functional Relational
Having confidence in health professionals	Relational
Awareness and understanding of specific health conditions by the HCP	Functional Relational
Right treatment/right staff/right time, knowing limitations, demonstrating working cohesively	Functional Relational
Continuity of care	Functional Relational
Caring, dedicated ,respectful staff, treated as a person	Relational
Being in partnership with professionals	Relational
Friendly, kind staff, who listen and spend time with patients	Relational
Efficient processes	Functional

All of these documents are capable of adding greater detail to the outcome measures that are gathered routinely and traditionally. Independently or jointly they can be used to describe the experience of care, and give a more complete view of patients' function physically, emotionally and socially. The patient's input to this aspect of outcome has been seen as essential and can enable the patient experience to be represented.

The documents presented so far in this chapter highlight the need for individual experience, whilst identifying the patient as a whole, not segmenting them, or their

care, for ease of a process. The rest of this chapter describes the aspects of health-care for cancer patients and H&NC patients, set within the outcomes domain framework, because of its evident influence on the future way that the NHS will describe outcome using the five domain definitions used within the outcomes framework document (2010).

HEALTH-CARE FOR CANCER PATIENTS: ENSURING PEOPLE HAVE A POSITIVE EXPERIENCE OF CARE

The government has started to emphasise the role that health-care-professionals and the care-system can have on the experience of patients and is aware that this will impact on patient's outcome. Measuring the experience of patients is seen as a way of improving their care and safety; what to measure and how to transfer this back into real change in the patient care remains a challenge. It is not unreasonable for any prospective patient to ask two key questions:

- Will the care that I am given be responsive to my psychological needs as well as my physical ones?
- Will my experience and perspective influence the health-care of other patients treated in the future?

The inference is that there is a danger that health-care will ignore the person attached to the disease and remain ignorant, month after month, and year after year, to any experiences that might be seen as ways of reflecting and changing current care. Kennedy's warning of abstracting the person from the care would then become a reality.

There is a need for health care professionals to move away from a didactic and paternalistic role with patients; instead, they should try to elicit patient preferences in order that the quality of care that patients receive can be seen to be truly improving by being patient-centred. There is, however, evidence from the National Cancer Patient Experience Survey (Department of Health, 2010b) that a coherent approach is not being achieved. One hundred thousand questionnaires were sent to cancer patients treated by the NHS, between January and March 2010. Sixty-seven thousand responded. This document indicated that multi-disciplinary teams still have a lot of improvements to make in terms of regarding patients in a holistic way. The return rate for the questionnaires was good, with around 80% of these patients responding with a good or excellent rating, but the number of respondents not agreeing with this description, or not replying, means that the response might more properly be considered to be either mediocre or unknown for 46,000 patients. This figure represents nearly half of all the patients sent the survey.

From a H&NC perspective, being able to discuss the care that patients have had and reviewing how much they understand, in the context of their own care, is important. Having the patient at the centre of their care and able to ask timely and repeated questions about complex intricate care and is essential. It is very likely that the treatment that patients have will not be well understood prior to the treatment. It is not likely that the patient, their carers or primary care teams will have had much, if any, experience of the treatment and recovery of H&NC. From a health-service point of view, patients should be treated by cancer-centres in which there are specialist teams who have regular dialogue with the primary care staff so that the patient can be supported with any of the ongoing issues that are experienced.

TREATING AND CARING FOR PEOPLE IN A SAFE ENVIRONMENT AND PROTECTING THEM FROM AVOIDABLE HARM

In chapter one it has been suggested that outcome measures in H&NC remain fixed firmly with survival statistics and quality of life measures. In England and Wales, part of the way of detailing outcome measures for H&NC patients is through the clinical biometrics for H&NC patients, which are uploaded to the British Association of Head and Neck Oncologists (BAHNO) database. The information includes both biomedical and psychosocial parameters. The outcome measures are limited to tick-box categories and intervals of time-to-treat, time to assess and survival information rather than more descriptive information. They are, however, an attempt at a more complex level of statistics to describe the management of H&NC patients. The database for head and neck oncology (DAHNO) published an audit based on patients identified with H&NC between January 2004 and November 2005 (British Association of Head and Neck Oncologists). In this 18-month period, just over a quarter of all patients with H&NC were included. Of this minority only two-thirds were discussed within the recommended format of a multi-disciplinary-team meeting. This would suggest that domain five, from the outcomes domain framework, (described in table 2.2 page 47), treating and caring for people in a safe environment and protecting them from avoidable harm, is not assured by a quality process.

Examination of this process reveals there is as yet no facility to describe in detail how the team might meet and discuss cases, to explore whether the decision-making is a collective, considered decision or merely a rudimentary rubber-stamping of patients treated in a centre. In part this is why there is the recommendation within the specialty-specific guidelines, Improving Outcomes Guidelines (2004) that MDTs should discuss all of the presenting H&NC cases together in order to promote best

and current practice. The intention is that each clinician can be supported and seen to be carrying out a treatment that has been sanctioned by colleagues, rather than becoming a lone operator who is not having their cases reviewed regularly.

However, it is salutatory to note that even basic quality of discussion, stipulated in the guidelines, cannot be demonstrated to take place routinely. The actual evidence to identify the effectiveness of an MDT discussion is scant. Patkar et al (2011) in a review of the MDT commented that the empirical evidence to support the use of MDTs is weak. The major problem with trying to study the effect of such a practice is the extensive number of confounding variables, which make the establishment of causal links very difficult. What they did conclude however is that it is important to recognise that the lack of good-quality evidence does not mean there is evidence to suggest the meetings are ineffectual for patient-care. They were aware that the use of randomised controlled trials for such complex interventions were likely to be impossible, and concluded that it was both intuitive and obvious that MDT meetings improved information exchange. They also urged regular communication-flow, which could only be seen as being supportive of the care of patients in a way that is accountable, transparent and reliable. This is an essential governance role carried out by MDTs that is in part a legacy from Kennedy's work that stipulated the need for joint and transparent decision-making following the Bristol cardiac-unit enquiry.

This chapter has so far described the last decades' shift by policy-makers and writers on health-care from the physical aspects towards the emotional ones too. It would be a limiting concept to suggest that H&NC has no influence on the patients' emotions. It would also be too simplistic to suggest that patients do not draw upon previous life events in order to help them manage the current diagnosis. From these viewpoints alone there is value in exploring how patients recover from the disease

and treatment. NICE estimates that fifty percent of all patients experience anxiety, or depression at some point during their cancer assessment treatment and recovery (National Institute for Clinical Excellence, 2004). If the subjective aspect is left out in an attempt to follow a quantitative protocol, the relevance of the results will remain, from the clinical perspective, poor representations of the patients. If the research depicts poorly the clinical caseload, the danger is that clinicians may fail to perceive a link between making clinical decisions and the research. This particular aspect is discussed in greater detail in chapter four through the works of Munro and Salander.

ENSURING PEOPLE HAVE A POSITIVE EXPERIENCE OF CARE

One such subjective aspect is distress, a significant element featured in holistic needs assessments, has been defined by the National Comprehensive Cancer Network (NCCN, 2012) as:

‘A multi- factorial unpleasant emotional experience of a psychological, social, and spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment’ (p2).

Distress has been identified in as many as seventy percent of cancer patients (Holland and Bultz, 2007). Bultz et al (2011) reviewed the Canadian perspective and has suggested that distress should be seen as the sixth vital sign because it should be monitored as routinely and overtly as the more traditional physiological signs of life. They suggested that the ‘people part’ of cancer care is fundamental and has ethical, emotional and economical sense. There would seem to be the need to use a formal tool as a way of identifying and grading distress, because there is no evidence to suggest clinicians recognise and grade it accurately. This is perhaps even more

essential when it is recognised in the definition, that the very features of distress might prevent patients from being able to be expert patients as expected in the document of an NHS patient-led service (2005). If clinicians are unable to identify this aspect it might impede patients' abilities to make informed choices.

There is limited evidence to suggest health-care professionals are able to recognise distress. A study that directly reviewed clinicians' ability to do this reported their performance as only "modest" (Mitchell et al., 2008). Some studies have reported that certain styles of communication can help professionals detect distress more readily. In a review of more than fifty articles published since 1980, accessed from a data base, to include the search terms of: physician-communication, non-verbal communication, doctor-patient communication, cues, detection of distress, Ryan et al (2005) concluded that active listening, open questions, emotional rather than factual terms and a patient-centred approach would be more able to identify distress. It is relevant at this point to state that health-care professionals, when assessed in the clinical setting, are not able to demonstrate their ability to judge, with any degree of accuracy, either the physical or emotional aspects of oncological disease. It has also been reported that fewer than fifteen percent of cancer professionals use screening questionnaires, such as the distress thermometer in clinical practice, preferring instead to rely upon their clinical judgment. Unfortunately, their abilities appear to be neither specific nor attuned enough to recognise the level of distress being experienced by the patients (Mitchell et al., 2008, Davis et al., 2006). This work has further support from an earlier paper which investigated the ability of oncologists to recognise appropriately which patients within a general oncology case-mix were distressed in an outpatient setting (Sollner et al., 2001). The results suggested that even when distress had been screened as severe, it was only noted within a third of

the patients by the oncologists, and they tended to be least good at identifying the existence of distress in patients with head and neck and lung cancer. Distress, from their medical perspective, was correlated much more with the advanced nature of the disease and the level of denial behaviours used by the patients. It might be concluded therefore that health-care professionals are likely to over-predict the physical aspects of the disease, based on the classification of the disease, from early to advanced and under-estimate the psychological impact of the disease and treatment. It would seem imperative from such research that assumptions are not made on behalf of patients about what the personal impact has been on them and in particular that no assumption is made related to the staging of the disease from a pathological perspective because this is unlikely to be accurate.

The situation is further complicated because patients may deny or avoid exploration of their emotional aspect from their experience so that they do not engage in the reality of the disease and avoid examining their fears (Madden, 2006). This specific facet has been demonstrated within the H&NC population in which results have suggested that patients are likely to under report their experiences because of fears related to how they might cope with the additional losses that H&NC has already imposed upon them (Moore et al., 2004). There is evidence too, that the impact might be long-term. Recent work, relating to cancer patients as a group, has suggested that whilst anxiety, pain and distress are transient during the first year of treatment, these features may remain in a third of patients a year post-diagnosis (Carlson et al., 2011). From a UK perspective this prediction conjoined with Madden's review of the UK cancer registries, suggests there will be a growing

number of cancer patients who have not been able to express the psychological distress that they might be experiencing as cancer survivors.

It would seem, therefore, that it is not enough to allow clinicians to gauge accurately the presence and degrees of distress without recourse to a specific framework through which they can review routinely and systematically the individual's situation. The HNA, detailed earlier in this chapter, would conclude that the identification of such qualities is only part of the role; something has to be done beyond the identification. Their management needs should move from a mere portrayal to action. It is for this reason that there has been the recommendation that health-care-professionals should acknowledge emotional distress as a core-indicator of a patient's health and well-being (Bultz and Johansen, 2011). Yet the focus remains on the easier to measure bio-medical and clinical-process (Carlson and Bultz, 2003) despite the importance of going beyond the superficial-level of the disease and treatment so that the patient's needs can be represented more holistically (Salander, 2011b).

The problem of identification is compounded by the knowledge that the research suggests patients place a low-priority on their desire for psychological support (Tuinman et al., 2008). The research demonstrated of five-hundred patients with a diagnosis of cancer only ten percent wanted a referral to be made for psychological-support. For patients who were identified, as being distressed, eighty-two percent had no wish to be referred. This would suggest that the patients are not able to contemplate referral onto other agencies. There is perhaps a misconception that distress is a negative reaction, rather than being accepted as part of a normal

process that patients might be expected to go through; to seek support implies it is an unnatural reaction and classifies it as morbidity (Bultz et al., 2011).

ENHANCING QUALITY OF LIFE FOR PEOPLE WITH LONG-TERM CONDITIONS

Quality of Life (QoL) has started to occupy a central-position in health-care generally and more specifically in H&NC care. The World Health Organisation defined this ubiquitous and somewhat over-used term as:

‘A state of complete physical, mental and social well being not merely the absence of disease’. (WHO., 1997)

In the context of disease, it is described in terms of health-related QoL (HRQoL) the subjective experience of the impact of health status on QoL for the patient (Curtis, 1997;). The single most difficult feature to overcome in the collection and representation of QoL information, is the inevitable impact of imposing an objective, numerical score on a subjective, phenomenological position (Rapley, 2003).

Questionnaire design is a flawed science, and while rigorous psychometric principles are used in the development of QoL scales, the accuracy of their measurement and the validity of their focus may well be subject to debate (Sprangers and Schwartz, 1999). They might, at first inspection, be thought to be patient-centred but many of the measures fail to capture this uniqueness to individuals, because the moment a standardised questionnaire is used, the domains thought relevant to the patient-group have been pre-determined, becoming measures of health-status rather than an individual’s QoL (Carr and Higginson, 2001).

Despite such a specific and undeniable limitation, the most common way of collecting QoL information is via a questionnaire. The number and diversity of questionnaires relating to QoL is vast, whether seen in general or disease-specific terms. QoL

questionnaires measure different aspects of a patient's QoL. Consensus has been reached, which recommends that a number of QoL components should be measured, irrespective of disease, and include symptom-status, (physical, emotional, role), and social-functioning (Moinpour, 1994). Whilst a global, overall subjective measurement may give an indication of the impact, the more detailed components of the questionnaire enable better insight into the influence of the disease and treatment on the patient. Coons et al (2000) reviewed seven of the most commonly used generic cancer HRQoL questionnaires and suggested that it is necessary for researchers to choose a questionnaire based on the characteristics that are most relevant to a particular HRQoL measurement. It has been recommended that the optimal combination of questionnaires used would include both a general and disease specific questionnaire, so that small, but significant changes to a patient's health can be identified (O'Boyle, 1997). A review by Bottomley (2002) of HRQoL questionnaires used with cancer patients showed that there were three generic HRQoL tools that are most commonly used in the oncology field: the Medical Outcomes Study Short-Form Health Survey (SF-36), Sickness Impact Profile (SIP), and Quality of Well-Being (QWB) scale. The review suggested all of the questionnaires have inherent bias because:

- The language and presentation of questions does not allow for patients to describe QoL in relation to the general population
- The focus is on the degree of disease symptoms

The latter point-of-view was made by Cummins et al (2004). The questionnaires do not recognise personal growth or secondary gain. Operationally, many of the instruments measure HRQoL, physical, social and emotional status that might be described generically as 'performance'. Such a model cannot be judged as patient-

centred. They are, instead, a way of representing what health-professionals and society believe are the constituents to healthy lives (Carr and Higginson, 2001). The overall scores however, make it difficult to distinguish these concepts so that the headline-score may subsume the impact of a particular difficulty. The intricacies of these sub-scales may also alter over time, whilst the sum-total does not. This would suggest that a method of weighting results would make them more meaningful. However, the use of weighting, by ranking item-importance, suggests that patients are able to judge which is more important to them (e.g. relationships with their family versus their ability to work, versus lack of control). Similarly, it is hard to argue that symptoms or patient-care are of equal value, and much of that diversity will be because patients have different and personal values surrounding the situation. The result of not capturing an individual's QoL is that the measures are unlikely to be responsive to change and even if they are, they do not measure what is important to the patient, with the likelihood that different scores might be obtained after the same intervention in the same population. The implications of this are far-reaching and leave four fundamental questions with no satisfactory answers:

1. How can the effectiveness of interventions be truly determined?
2. Can the real quality of the service a patient has had be assured?
3. Does much of the patient-response depend on the relationship built with the MDT?
4. Are resources being used efficiently?

All of these questions are set in the context of growing patient needs and expectations, whilst budgets diminish in real-terms, a point acknowledged within the document High Quality of Care for All (2008). Chapter three expands these particular issues of QoL with reference to both the patient and health-care

professionals who care for them, by describing research carried out by the author that investigates the limitations of HRQoL questionnaires.

ENHANCING QUALITY OF LIFE FOR PEOPLE WITH LONG-TERM CONDITIONS. -OUTCOME MEASURES SPECIFIC TO HEAD AND NECK CANCER VARIABLES THAT IMPACT ON QUALITY OF LIFE SCORES

HRQoL data, when it is patient-derived, may be a medium through which clinicians, patients, policy-makers and researchers are informed about the effect disease and treatment can have on patients. It might be that such patient perspectives can offset the temporal target-driven health-care and system description that is controlled by clinicians and policy makers. The National Cancer Survivorship Initiative (Department of Health et al., 2010) an organisation that is a partnership between the NHS, charities and the Department of Health, has published recommendations that they envisaged could improve care and the support of cancer survivors. They suggested that the quality of the survival, as well as the more easily measured survival statistics or treatment target measures, should be within domain one, preventing people from dying prematurely, the NHS Outcomes framework (Dept of Health.,2010). They described specifically a greater focus on recovery and health and well being after cancer treatment; a shift from description towards information provision and personalised care-planning. The intention is that patients have their management based on individual needs, with the appropriate clinical assessment, support and treatment. This would mean a change in practice from a single model of clinical follow-up to one of tailored-support that enables early recognition of, and preparation for, the consequences of treatment as well as early recognition of signs and symptoms of further disease. They also described a move towards measuring experience and outcomes for cancer survivors through the routine use of Patient

Reported Outcome Measures (PROMs) in aftercare services. Such recommendations may be achieved by using QoL measures. Despite the aforementioned short-falls of such measures, they are derived directly from patients. From a H&NC specific point of view, although many studies report on survival and recurrence-free survival (Kovacs et al., 2002) other studies report on the variables that might impact on QoL. Gurney et al (2008) reported that predictors of worse QoL for this patient-group included advanced stage, the presence of a gastrostomy-tube and dependence on it and the presence of a complication, or recurrence. More recently there has been research that might suggest that QoL assessments may act as a way of screening at-risk patients, such that patients with a poor measure on particular parts of a QoL questionnaire were more likely to be at risk of recurrence (Karvonen-Gutierrez et al., 2008). In the same year Ronis et al (2008) reported that smoking behaviours, depression, gastrostomy placement and treatment modality all impacted on QoL factors with physical domains tending to worsen and emotional domains improve. They recommended that health-professionals should support patients with accurate information about the effect the treatment is likely to have on them. The same research group (Duffy et al., 2008) also published information on patients at a year post-treatment and suggested that health-behaviours after treatment (drinking, smoking), and the symptoms of lack of sleep and depression are interrelated. They impact on QoL and should therefore be treated together.

Functional information has been published on patients undergoing multi-modality treatment (Skoner et al., 2003). Although the patient-populations were small, (less than twenty), some of the significant information clinically can be reported upon, such as number of days in hospital, number of days taken for removal of tracheostomy and number of days to achieve oral intake. Researchers have also reported on

wound complication (Teknos et al., 2001) or donor-site flap-morbidity from a patient perspective (de Witt et al., 2007). Even when investigating the literature with reference to a very specific outcome, such as the use and complications of free-tissue-flaps, there is a need for consensus surrounding the results collected. The specific variability can be illustrated by examining the research-papers that discuss the outcome measures used when detailing radial forearm free-flaps (RFFF). Some of the research has focused on the survival of the flap (Santamaria et al., 2000), others the function, (Chen et al., 2005). Such an example is a very narrow part of the whole treatment process; if the definition of outcome is broadened to include the factors that impact upon speech and swallowing, there is even less work published (Zuydam et al., 2005, Pauloski et al., 2004, Pauloski et al., 1998, Colangelo et al., 1996). The variables remain obvious and many. Patient populations are not the same, the treatment regimes are many, and the access to full specialist-rehabilitation-teams has many permutations. It remains difficult to reach conclusions, because of the hidden, or unknown variables that might be influencing scores, it is difficult to compare results or understand with certainty why they may differ. What may be concluded from such studies are generalities, which may include:

- The relationship between the structures involved
- The size of the lesion to be treated and the resulting functional impairment
- The impact of combined modality treatment

Anecdotally, however, there are still patients who might appear to be at odds with such research outcomes. Those with small tumours and single treatment modality, might be unable to carry out their routine activities, return to work and seek support from either formal or informal sources, whilst patients who have had combined treatment for larger disease return to near pre-morbid function.

Health-care professionals are likely to be inaccurate, just as they have been demonstrated to be, with the identification and degree of distress. They have been found to over-estimate the physical symptoms, under estimate the subjective impact (Maher and Jefferis, 1990) and not account for tumour size (Reid et al., 2009).

QUALITY OF LIFE AND CO-MORBIDITIES

It seems logical that patients who have co-morbidities at the time of their treatment might be different from those patients who do not. However, the relationship between co-morbidity and HRQoL has produced conflicting results. Post-treatment, Pourel et al (2002) found no significant association between co-morbidity and HRQoL. However, Terrell et al (2004) reported that patients with two or more co-morbid conditions had reduced QoL scores relating to the physical domains, and increased evidence of pain post-treatment. Pre-treatment, similar conflicting results have been reported, in that pre-treatment co-morbidities have been reported as impacting on HRQoL (Piccirillo and Vlahiotis, 2006), whilst an earlier study by Gourin et al (2005), reported no such relationship. The disparity in results might be a reflection of the heterogeneity of the patient groups, the varied assessments used to grade co-morbidity and the time-interval at which the data was collected. It might also be that because the domains being measured are pre-determined they cannot be said to be measuring an individual's QoL (Carr and Higginson, 2001).

REPEATED USE OF QUALITY OF LIFE MEASURES

Over time, the scores within categories, or sub-categories for HRQoL, might vary without an apparent change to the overall score, or the possibility that if scores do change they are often in relation to the patient's emotional response to a life-changing event, and not as a consequence of a shift in physical symptoms. It is therefore very possible that scores are more a reflection of people's adjustment to their change of circumstances rather than a measure of their physical or emotional state. This notion has been demonstrated by a study by Logemann et al (2001) in which the impact of dry mouth on H&NC patients' function and perception of their swallow was investigated post-radiotherapy. Logemann et al concluded that dry mouth did impact on sensory and comfort issues of swallowing but not on the actual function of the swallow. Subjects' functional abilities to swallow were correlated with their *perceived* lack of oral secretions rather than the *actual* saliva they produced. This would suggest that the patients are moderating, or adjusting to the experience and that, whilst objective measures are important, there is value in collecting the diverse, subjective aspects because this will influence patients' score to physical aspects of the disease or treatment.

QUALITY OF LIFE AND SURVIVAL-DATA

In the context of accepting that outcomes have been measured in terms of survival and temporal and process targets it is little wonder QoL measures are not used in the clinical setting. Until recently it would be implicit that there would be little point in collecting QoL information unless it could act as a prospective, prognostic measure.

There has been no true link established between QoL scores and survival for H&NC patients. A review of the literature concluded that the evidence was neither strong nor proven (Mehanna et al., 2008). Such failure to answer research questions definitively has meant that the outcome is viewed as vague, complex and not particularly useful. A review of the QoL literature relating to H&NC and survival by Montazeri (2009) identified only eight papers that investigated a possible link between QoL and survival, the ultimate measure of outcome. Whilst four of the papers were not conclusive, a further four did show a clear relationship in this area and are presented in table 2.3.

Table 2.3 Relationship between Quality of life Domains and Survival

Primary author and date of study	Quality of life Questionnaire used	Quality of life domain associated with survival
(de Graeff et al., 2001)	EORTC QLQ-C30 + QLQ-H&N35 + CES-D	Cognitive functioning was predictor of survival while physical functioning; mood and global QOL were not.
Fang et al., 2004	EORTC QLQ-C30 + EORTC QLQ-H&N35	Pre-treatment fatigue
Nordgren et al. 2006	EORTC QLQ-C30	Physical functioning was significant predictor of survival
Karvonen-Gutierrez et al., 2008	SF-36, HNQOL	The SF-36 physical component summary score and three domains of the HNQOL (pain, eating and speech) were associated with survival.

Montazeri concluded that in order to really identify other variables, future studies should use more methodological and statistical rigor. This recommendation is a recurring conclusion and perpetuates the concept that quantitative research is an

adequate way of investigating the clinical complexity evident within the specialty H&NC. Such an approach holds with the belief that if homogeneity can be achieved between patient groups, eventually statistically significant variables can be identified. Perhaps this is an unrealistic goal with the instruments available and explains why different studies might appear to contradict one another. It is, therefore, possible that the actual variables impacting on outcome as measured by QoL remain both multiple, illusive and uncertain.

CONCLUSION

This chapter has detailed, through reference to key-policy documents for England and Wales since 2000, how other aspects might compliment survival and temporal outcome measures. There has been no attempt to critique these policies but there has been the intention to describe the key papers that have influenced health care providers working with patients who have cancer. It has also been demonstrated that bio-clinical data, whilst more amenable to measurement and easier to summarise, may conceal from researchers and clinicians a plethora of useful data. The system looks for physical measures and does not routinely, or in a structured way, review distress. Policy documents continue to recommend a more holistic approach that examines the patients' experience as well as the evidence-base and safety of procedure. However, clinical practice is as likely to rely on natural intuition, which has been demonstrated to be poor, when assessing patients who do not divulge their emotions to their health- care teams. Patient experience of H&NC can continue to be described by tumour detail, survival and QoL scores, but this ignores important

aspects of the whole and does not allow patient-data derived directly from them to be represented. A detailed review of the topic shows that many aspects of both patient and disease characteristics may influence the outcome of treatment. The modifiers of outcome are interactive and should be included rather than controlled. Chapter four will develop this aspect further.

The care that patients receive and the experience surrounding an episode of care will impact on their judgment of care. However, there remains the significant challenge of how best to represent this and then influence clinical practice. It is essential to assure leading commentators, such as Kennedy, that patient care is not fragmented or atomised, and that the patient is not seen only in terms of a currency.

Patients will differ in their reaction to the diagnosis and the treatment, but it would appear unlikely that many patients will contemplate being open and honest about their feelings because of their limited physical resources as a consequence of the treatment. It would seem, therefore, that there are two influences that might recommend more qualitative methodologies for the ongoing investigation of H&NC patients:

1. The lack of clear and consistent QoL results because of an inability to truly represent patients at an individual level
2. A political and professional expectation, which encourages a meaningful description of care at an individual level, which can enable patient views to be intertwined with those who treat them.

There have been objective and well-constructed criticisms of health-care systems, which it is hoped will galvanise researchers and clinicians alike to work on understanding the real outcome for patients. There is evidence from the patient experience surveys conducted in England that there is a failure of clinical staff to

provide information to patients at critical points in their treatment and that health-care professionals persist with a culture that is not truly patient-centred (Dept of Health 2010a). The intention of this chapter has been to review in more detail the cognate aspects of outcome measure scales and particularly QoL scales. It is evident that they do not cover the whole scope of the experience. This means opportunities to engage H&NC patients with their own care and treatment is frequently missed. There is the perpetuation of a paternalistic style. Much work is still to be done.

CHAPTER 3

THE OUTCOME QUALITY OF LIFE WITH PARTICULAR REFERENCE TO HEAD AND NECK CANCER

INTRODUCTION

Chapter two has described some of the limitations surrounding QoL data. Despite these drawbacks, in the last twenty-five years there has been an exponential growth in the number of papers that use QoL measures with H&NC patients because they are seen as a way of describing patients at either the pre or post treatment stage (Rogers et al., 2007). There is evidence that might help formulate reasonably accurate predictions about how patients' tumour size and site will impact on their physical and psychosocial functioning. Yet policy documents and complex modern treatments may pre-occupy teams to such a degree that acknowledgement and inclusion of the patients' function and reaction post-treatment is overlooked at the expense of measuring aspects that are more quantifiable and more easily represented. 'Overlooked' in this context is not only left out but also poorly understood.

The complexities in the specialism of H&NC are all pervasive. Chapters one and two have described these intricacies and also the policy documents in health since 2000 with particular reference to cancer that have sought to make the care of patients more individual. The multiplicity of disease factors means there is no absolute baseline therefore the clinician and or researcher have to prepare for complex results, which may or may not corroborate with previous findings from other research groups. It would appear that patients with similar symptoms, or that have undergone similar treatments may present with different QoL scores and that this is a result of

the ability of the individual to adapt or mediate the symptoms that are highly significant (Llewellyn et al., 2005, Scharloo et al., 2005).

This chapter presents two published pieces of work by the author that investigates two specific issues in relation to QoL:

1. How useful are QoL questionnaires at measuring the patient experience of the disease?
2. Are clinicians, if presented with the parameters associated with QoL, accurate in their assessment of the particular QoL issues for patients?

The first question investigates the limitations of QoL data, and suggests that they are not able to cover the scope of an individual's health-experience. The second, carries out research involving the multi-disciplinary team at the author's cancer centre. It demonstrates the limited understanding health care workers have of the possible symptoms H&NC patients may have with reference to the extent and range of symptoms they might experience. Both are presented in their entirety with the same content as published within a book as a chapter (Reid et al., 2012a) and a peer review journal (Reid et al., 2009). Appendix 3.1 reproduces the three QoL measures referenced in the first study.

This section of the thesis has been published as:

HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRES:

ARE THEY FIT FOR PURPOSE?

(Reid et al., 2012b)

INTRODUCTION

Patients frequently ask two poignant questions during their management: 'How will I be after my treatment' and 'Am I cured?' Focused or absolute answers are generally frustratingly absent and the multidisciplinary team are likely to be guarded in their response because at presentation the site of the tumour and the stage of the disease will influence treatment possibilities and outcome. Outcome from the varying treatment modalities have been reported in terms of survival interval and more recently the patients' quality of life (QoL). The latter outcome is a multifaceted and dynamic concept which the World Health Organisation defined as a:

'Broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence and their relationships to salient features of their environment'
(WHOQOL group, 1993).

More specifically, such data in the context of disease is described in terms of health-related QOL (HRQoL), the subjective experience of the impact of health status on QoL for the patient (Curtis, 1997;) it can, in relation to H&NC patients be described as a patient's physical, emotional and social function at the pre and post-treatment stage(Hammerlid et al., 2001, Hammerlid and Taft, 2001).

The number of studies that routinely report on HRQoL has increased substantially over the last twenty years. In the literature it has been recommended that HRQoL tools should not only be used within the research arena but also within the clinical-

setting (Velikova et al 2010). However, the recommendation has not been put into practice and its use within the clinical setting remains limited. This is despite patients reporting them both as a useful way of structuring their thoughts during outpatient appointments as well as a way of building a rapport with the teams involved in their care (Mehanna and Morton, 2006a, Velikova et al., 2010).

Researchers have investigated why clinicians do not use QoL measures routinely within the clinical environment (Mehanna and Morton, 2006b, Kanatas et al., 2009).

The results have suggested that clinicians do not view the findings as relevant to the clinical setting and that the logistical burden in the resultant collection and analysis of the data is too great. The volume of QoL questionnaires to choose from, further complicates the situation. In a review of the head and neck cancer (H&NC) literature Kanatas and Rogers (2008) identified five broad categories of patient completed QoL questionnaires and as many as thirteen disease-specific questionnaires. Their conclusion was similar to a previous review by Ringash and Bezjak (2001) in which it was acknowledged that choice of questionnaire should be governed by the research questions being considered and the resources available.

The use of QoL data acknowledges that the patient aspect should be represented and that this information should be collected from the patient rather than from other sources such as health care professionals or carers. The former are likely to over estimate the physical symptoms (Reid et al., 2009) the latter under estimate the emotional aspects of the disease (Sollner et al., 2001). Complexity exists in all aspects of the field from the choice of questionnaire available to the possible influences on the results. Many and diverse variables would appear to impact on QoL scores and these include psycho-social factors: tumour characteristics, (Hammerlid et al., 2001) physical symptoms, (Campbell et al., 2004) and treatments

undergone,(Department of Health, 2011, Ronis et al., 2008) as well as psycho-social aspects of patients(Llewellyn et al., 2005, Howren et al., 2010).

The multi-dimensional and subjective nature of QoL makes it difficult to fit into the bio-medical model throughout the treatment management process. The link between QoL scores and survival for this group of patients has been noted to be neither strong nor proven (Mehanna et al., 2008) Over time the scores within categories or sub-categories might vary without an apparent change to the overall score, or the possibility that if scores do change they are often in relation to the patient's emotional response to a life-changing event and not as a consequence of a shift in physical symptoms. It is, therefore, very possible that scores are more a reflection of people's adjustment to their change of circumstances rather than a measure of their physical or emotional state. This notion has been demonstrated by a study by Logemann et al (2001) in which the impact of dry mouth on H&NC patients' function and perception of their swallow was investigated post radiotherapy. Logemann et al concluded that dry mouth did impact on sensory and comfort issues of swallowing but not on the actual function of the swallow. This would suggest that the patients are moderating or adjusting to the experience and that whilst objective measures are important there is value in collecting the diverse subjective aspects because this will influence patients' score to physical aspects of the disease or treatment. A systematic review of the HRQoL, for H&NC patients diagnosed and treated with reference to psychosocial variables Llewellyn et al (Llewellyn et al., 2005) suggested that personality, depressive symptoms, social support, satisfaction with consultation and information, consumption of alcohol and tobacco all influenced HRQoL scores. In the same year a study carried out by Scharloo et al (2005) described how illness perceptions by patients' attention to symptoms, believing in a greater likelihood of

recurrence, engaging in self-blame, and a strong emotional reaction to the illness- all contributed to lower QoL scores. There are, therefore, indications that the impact of the disease and treatment is moderated by subjective patient characteristics.

A review of QoL within the field of H&NC by Montazeri (2009) identified eight papers that reviewed QoL and survival. Whilst four of the papers were not conclusive in their findings about the effect of QoL on survival a further four did show a clear relationship in areas such as cognitive function, (de Graeff et al., 2001) pain, appetite and eating scores (Karvonen-Gutierrez et al., 2008) and pre-treatment fatigue (Karvonen-Gutierrez et al., 2008, Fang et al., 2004) were reported as being linked to survival. The conclusion of the review paper was that in order to really identify other variables more methodological and statistical rigor should be used in future studies. This recommendation is a recurring conclusion and perpetuates the concept that quantitative research is an adequate way of investigating the clinical complexity evident within the specialty H&NC. Such an approach holds with the belief that if homogeneity can be achieved between patient groups eventually the methodology will enable significant variables to be identified statistically. Perhaps this is currently an unrealistic goal with the QoL instruments available and explains why different research findings might appear to contradict one another. It is, therefore, possible that the actual variables that truly impact on outcome as measured by QoL remain both multiple, illusive and therefore uncertain.

It would be a limiting concept to suggest that H&NC impacts on the physical aspects of a patient with no influence on the emotional aspect. It would also be too simplistic to suggest that patients do not draw upon previous life events in order to help them

manage the current diagnosis. From these two premises there is value in exploring the experience of H&NC at an individual level. The National Institute for Clinical Excellence estimates that 50% of all patients experience anxiety or depression at some point during their cancer assessment treatment and recovery (National Institute for Clinical Excellence, 2004). If the subjective aspect is left out in an attempt to follow a quantitative approach to study design, the relevance of the results will remain, from the clinical perspective, poor representations of the patients. This will mean that clinicians fail to perceive a link between making clinical decisions and the research because it poorly depicts their caseload.

Being able to describe in a more representative way the disease and treatment is the preliminary stage of patient management. A United Kingdom government report has set out the outcomes which it would like to see developed and used within cancer care in England (Department of Health, 2011). The Department of Health cited research by Maddams within this document, which predicted that by 2030 there will be more than three million people who will have been treated for cancer and survived, of which a third will be of a working age. The report emphasised the holistic nature of the patient experience, acknowledging the financial and emotional aspect as well as the more frequently cited physical aspects. It is a real intention of the government's health care system that patients should achieve as much independence as possible from both the health care system as well as their own support network. Specific aims are set out within the report, one of which is that there should be a decrease in the proportion of people who report unmet physical and psychological needs post-cancer treatment. This is a significant challenge when considered in the context of a 2010 report that detailed patient experience and reported fewer cancer patients than in previous reports had understood the

information they were given even at the point of diagnosis (Department of Health, 2010a). Specifically within Britain therefore, despite more adherences to time-targets, a cultural shift needs to be achieved from a process-driven system towards a more personalised one. Part of this process has seen the development of Holistic Needs Assessment (HNA) for people with cancer (National Cancer Action Team, 2011). The publication suggested that if the holistic needs of patients were identified patients would be more likely to be engaged with their care, and identify the possible resources or services available during later stages of their treatment. Another government publication published in the same year, Improving Outcomes-A strategy for Cancer Care (Department of Health, 2011) has also recommended outcomes derived directly from patients should form the basis of outcome measures. It would seem therefore that there are two influences that might recommend more qualitative methodologies for the ongoing care of H&NC patients (i) the lack of clear and consistent QoL results (ii) a political expectation, which encourages the description of care at an individual level. It is within this context that the current study was devised. The purpose of this was to establish whether H&NC QoL measures adequately reflect a) the literature on patient experience b) the reported experience of H&NC patients undergoing curative treatment.

METHODS

RESEARCH DESIGN

A qualitative methodology was used in order to identify the themes associated with the experience of H&NC. Three different sources of information were systematically explored using a previously described method of analysing information (Attride-Stirling, 2001). The sources were:

- 1) The three most commonly used HRQoL questionnaires in the H&NC literature. These had been identified by previous research carried out by Rogers et al (Rogers et al., 2007) who had reviewed a five year period (2000-2005) and reported on the range and most frequently used questionnaires. These are reproduced in appendix 3.1
- 2) A review of the literature that describes the H&NC patient's experience of the condition, its treatment and sequelae
- 3) Semi-structured interviews recorded and transcribed from six H&NC patients. The interview questions were informed by the themes developed from the literature, in source 2

For each of the three sources the themes were derived using a thematic analysis protocol as described by Attride-Stirling (2001). The application of thematic networks is a way of organising qualitative data in a systematic way. It involves reviewing the material collected and establishing a network of themes, which are hierarchically developed from basic through organising to global themes. The process allows for the researcher to classify all the material into the basic themes, which can then be categorised to higher levels. The themes were generated independently for the HRQoL questionnaires; but the literature review was used as a way of forming the semi-structured interview structure. This meant the process was sequential and relied upon the literature generating the initial interview structure. In effect the third source was dependent on the themes described in the second. Following categorisation, basic themes that evolved from each source were grouped, re-read and re-framed. The intention was to identify underlying patterns that might not be apparent on reading each in isolation. Finally, a review process took place in order to decide which organising themes were discrete or broad enough, to represent a group of ideas. The themes that were identified were organised in relation to one another such that they could be classified as either super-ordinate, or sub-ordinate to one another. Using the Attride-Stirling (2001) thematic analysis this meant that the themes were classified as basic, organising or global thematic networks. Independent assessment was provided to confirm the validity of the themes.

Diagrams, which represent and summarise visually the global themes between each of the three sources are presented within the section marked findings.

DATA GATHERING

SOURCE 1:THEMATIC ANALYSIS OF HRQOL QUESTIONNAIRES

At the time of reviewing the H&NC QoL literature (2008) a paper by Rogers et al (2007) acted as a source of information. The paper had reviewed the literature relating to H&NC and QoL presenting the range and frequency of QoL questionnaires used in the literature over a five year period, The review had identified the three most commonly used ones as:

- The University of Washington (Hassan and Weymuller, 1993);
- The EORTC C30 and H&N C35 (Bjordal et al., 1994, Bjordal and Kaasa, 1992); which are used in conjunction to one another
- The Functional Assessment of Cancer Treatment –Head and Neck Subscale FACT (List et al., 1990).

These questionnaires are presented as Appendix 3.1. Thematic analysis using the method described by Attride-Stirling (2001) was carried out on these questionnaires. The areas represented by each questionnaire require patients to describe in the past week which statement is most representative of their current situation. The University of Washington (UoW) reviews: pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder function, taste, saliva, mood and anxiety. Patients also represent these aspects of their health or function by one of five statements, which grade their abilities from 'no' to 'severe change' in function. Patients also have to identify three domains that are most affected, rate their health

to prior to the cancer diagnosis, during the past week and their overall quality of life during the past week from outstanding through to very poor. The Functional Assessment of Cancer Treatment –Head and Neck Subscale (FACT H&N) has a five point scale ranging from a description of “not at all” to “very much” examining specific areas and which include: seven questions re physical well being, seven questions regarding social well being six questions regarding emotional well being and seven questions regarding functional well being one of these questions asks the patient to rate their current satisfaction with their QoL. There are also twelve H&NC specific questions that investigate eating, communication, appearance, smoking, and drinking behaviours and pain. The EORTC reviews via a four-point likert scale with descriptors ranging from “very much” to “not at all” the presence of the quality a range of issues. The general questionnaire EORTC C30 is composed of 30 multi-item scales and single items assessing areas of functioning (physical, role, emotional, cognitive, and social), as well as general symptoms -fatigue, pain, emesis, dyspnoea, insomnia, appetite loss, constipation, and diarrhoea. The patients are also asked to rate on a seven-point scale their attitude to their own health and quality of life status over the past week. The disease specific module EORTC H&N35 consists of 35 questions including seven symptom scales: pain, swallowing, senses, speech, social eating, social contact, and sexuality. There are 11 additional, single items covering problems with teeth, mouth-opening, dry mouth, sticky saliva, cough, feeling ill, weight loss, weight gain, use of nutritional supplements, feeding tubes, and painkillers. The patient can complete all three questionnaires independently.

SOURCE 2: THEMATIC REVIEW OF THE LITERATURE

A literature search was carried out in July 2009 using MEDLINE, EMBASE, the Science Citation Index (ISI), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the PsycINFO, the Allied and Complementary Medicine (AMED) and Global Health databases to review the literature surrounding H&NC patients' experience and or coping with the disease. The search terms used were 'head and neck cancer' and 'experience'; and 'head and neck cancer' and 'coping'. There was also a manual review of topic areas specific to experience and H&NC. The references are presented in Table 3.1 Reading the literature associated with the experience of H&NC and care generated the questions for the semi-structured interviews. A summary of the literature conclusions which then generated the questions for the semi-structured interviews are presented in Appendix 3.2.

Table 3.1 Papers Reviewed as a Result of The Literature Review

Aarstad AK, Aarstad HJ, Bru E, Olofsson J

Psychological coping style versus disease extent, tumour treatment and quality of life in successfully treated head and neck squamous cell carcinoma patients. *Clinical Otolaryngology*, December 2005, vol./is. 30/6(530-8), 1749-4478

Aarstad AK, Aarstad HJ, Olofsson J

Personality and choice of coping predict quality of life in head and neck cancer patients during follow-up.

Acta Oncologica, 2008, vol./is. 47/5(879-90), 1651-226X

Baker, C., 1992.

Factors associated with rehabilitation in head and neck cancer. *Cancer Nursing*. 15(6), pp. 395-400.

Bjordal K, Freng A, Thorvik J, Kaasa S

Patient self-reported and clinician-rated quality of life in head and neck cancer patients: a cross-sectional study.

European Journal of Cancer. Part B, Oral Oncology, July 1995, vol./is. 31B/4(235-41),

Cady J

Nutritional support during radiotherapy for head and neck cancer: the role of prophylactic feeding tube placement.

Clinical Journal of Oncology Nursing, December 2007, vol./is. 11/6(875-80),

Chaturvedi SK, Shenoy A, Prasad KM, Senthilnathan SM, Premlatha BS

Concerns, coping and quality of life in head and neck cancer patients.

Supportive Care in Cancer, May 1996, vol./is. 4/3(186-90),

De Leeuw, JR.J. et al.,. Prediction of depressive symptomatology after treatment of head and neck cancer: The influence of pre-treatment physical and depressive symptoms, coping, and social support. *Head & Neck* 2000. 22, pp. 799-2000.

Dropkin MJ

Coping with disfigurement/dysfunction and length of hospital stay after head and neck cancer surgery.

ORL-Head & Neck Nursing, 01 January 1997, vol./is. 15/1(22-26),

Dropkin MJ

Body image and quality of life after head and neck cancer surgery.
Cancer Practice, 01 November 1999, vol./is. 7/6(309-313),

Edmonds MF, McGuire DB

Treatment adherence in head and neck cancer patients undergoing radiation therapy: challenges for nursing.
Journal of Radiology Nursing, 01 September 2007, vol./is. 26/3(87-92),

Fox LE, Rau MT

Augmentative and alternative communication for adults following glossectomy and laryngectomy surgery.
AAC: Augmentative & Alternative Communication, 01 September 2001, vol./is. 17/3(161-166)

Gamble K

Communication and information: the experience of radiotherapy patients.
European Journal of Cancer Care, September 1998, vol./is. 7/3(153-61)

Happ MB, Roesch T, Kagan SH

Communication needs, methods, and perceived voice quality following head and neck surgery: a literature review.
Cancer Nursing, 01 January 2004, vol./is. 27/1(1-9)

Harrington S, McGurk M, Llewellyn CD

Positive consequences of head and neck cancer: key correlates of finding benefit.
Journal of Psychosocial Oncology, 01 September 2008, vol./is. 26/3(43-62),

Hassanein KA, Musgrove BT, Bradbury E

Psychological outcome of patients following treatment of oral cancer and its relation with functional status and coping mechanisms.
Journal of Cranio-Maxillo-Facial Surgery, December 2005, vol./is. 33/6(404-9),

Humphris, G.M., 2003. Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients.
Oral & Maxillofacial Surgery. 32, pp.486-491.

Humphris GM

The missing member of the head and neck multidisciplinary team: the psychologist. Why we need them.
Current Opinion in Otolaryngology & Head & Neck Surgery, 01 April 2008, vol./is. 16/2(108-112),

Katsura K, Sasai K, Sato K, Saito M, Hoshina H, Hayashi T

Relationship between oral health status and development of osteoradionecrosis of the mandible: a retrospective longitudinal study.
Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology & Endodontology, 01 June 2008, vol./is. 105/6(731-738),

Koliha CA

Obstructive sleep apnea in head and neck cancer patients post treatment... something to consider?
Head & Neck Nursing, 01 January 2003, vol./is. 21/1(10-14)

Kugaya A, Akechi T, Okamura H, Mikami I, Uchitomi Y

Correlates of depressed mood in ambulatory head and neck cancer patients.
Psycho-Oncology, November 1999, vol./is. 8/6(494-9),

Larsson, M., Hedelin, B., Athlin, E., 2003. Lived experiences of eating problems for patients with head and neck cancer during radiotherapy. *Journal of Clinical Nursing*. 12, pp.562-570.

List MA, Lee Rutherford J, Stracks J, Haraf D, Kies MS, Vokes EE

An exploration of the pre-treatment coping strategies of patients with carcinoma of the head and neck.
Cancer, July 2002, vol./is. 95/1(98-104), 0008-543X

Llewellyn CD, McGurk M, Weinman J

Striking the right balance: a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer. *Psychology, Health & Medicine*, 01 May 2005, vol./is. 10/2(180-193), 13548506

McGoldrick P

Reflections on coping with head and neck cancer
British Journal of Oral & Maxillofacial Surgery, October 2001, vol./is. 39/5(347), 0266-4356

McLane L, Jones K, Lydiatt W, Lydiatt D, Richards A

Taking away the fear: a grounded theory study of cooperative care in the treatment of head and neck cancer.

Psycho-Oncology, July 2003, vol./is. 12/5(474-90), 1057-9249

Moore R.J., Chamberlain R.M., Khuri F.R., 2004. Communicating suffering in primary stage head and neck cancer.

European Journal of Cancer Care, 13(1), pp.53-64.

Newell, R., Ziegler, L., Stafford, N., Lewin, R., 2004. The information needs of head and neck cancer patients prior to surgery.

Annals of the Royal College of Surgeons of England. 86, pp. 407-410.

Pourel N, Peiffert D, Lartigau E, Desandes E, Luporsi E, Conroy T

Quality of life in long-term survivors of oropharynx carcinoma.

International Journal of Radiation Oncology, Biology, Physics, November 2002, vol./is. 54/3(742-51), 0360-3016

Rodriguez CS

Pain measurement in elderly head and neck cancer patients with communication impairments. 01 January 2003, vol./is. /(0-131),

Rodriguez CS, VanCott ML

Speech impairment in the postoperative head and neck cancer patient: nurses' and patients' perceptions.

Qualitative Health Research, 01 September 2005, vol./is. 15/7(897-911),

Sadler GR, Stoudt A, Fullerton JT, Oberle-Edwards LK, Nguyen Q, Epstein JB

Managing the oral sequelae of cancer therapy.

MEDSURG Nursing, 01 February 2003, vol./is. 12/1(28-36),

Semple CJ, Dunwoody L, Kernohan WG, McCaughan E, Sullivan K

Changes and challenges to patients' lifestyle patterns following treatment for head and neck cancer.

Journal of Advanced Nursing, 01 July 2008, vol./is. 63/1(85-93), 03092402

Sherman, A.C., et al., 2000.

Coping with head and neck cancer during different phases of treatment. *Head & Neck*. 22, pp.787-793.

Tromp DM, Brouha XD, De Leeuw JR, Hordijk GJ, Winnubst JA
Psychological factors and patient delay in patients with head and neck cancer.
European Journal of Cancer, July 2004, vol./is. 40/10(1509-16),

Wells, M., 1998.

The hidden experience of radiotherapy to the head and neck: a qualitative study of patients after completion of treatment.
Journal of Advanced Nursing, 28(4), pp.840-848.

Whale, Z., Lyne, P., Papanikolaou., 2001. Pain experience following radical treatment for head and neck cancer.
European Journal of Oncology Nursing. 5(2), pp.112-120.

SOURCE 3: THEMATIC ANALYSIS OF PATIENTS' PERSPECTIVES

A purposive sample of six H&NC patients was recruited for the study from a UK cancer centre. The bio-clinical details and treatment undergone for each participant are presented in Table 3.1 and Table 3.2.

TABLE 3.2 BIO-SOCIAL STATISTICS OF PARTICIPANTS n=6

n	Sex	Age	Smoker	*Alcohol	Job	Tumour site	**Pathology
1	f	68	X	none	Secretary	Mandibular alveolus	PT4N0
2	m	45	√	≤ 21	Craftsman	Floor of mouth	PT2NO
3	m	68	ex	≤7	Health wk	Laryngeal	PT1N0
4	m	62	√	≤ 21	Hairdresser	Laryngeal	PT4N1
5	m	66	√	≤ 21	Accountant	Laryngeal	PT4N2b
6	f	82	ex	≤7	Linguist	Buccal	PT4N1

*number of units of alcohol consumed in a week

**pathological classification UICC 6th edition

TABLE 3.3 TREATMENT AND COMPLICATIONS FOR PARTICIPANTS

n	Surgey	Neck dissection	RT	chemo	Complications
1	Scapula flap failed Pec major	Uni lateral	√	x	Flap failure salvage surgery pec major
2	Radial fore arm flap	Bilateral	x	x	Paralysed tongue due to neuro praxis
3	Laser Excision	None	x	x	None
4	Pharyngolaryngolaryngectomy free flap (ALT) Tracheal oesophageal puncture	Bilateral	x	√	Infected skin donor site
5	Pharyngolaryngolaryngectomy Tracheal oesophageal puncture	Bilateral	x	√	Trachy at time of biopsy
6	Fibula flap	Unilateral	√	x	None

The participants were eligible if it was a year since the definitive treatment date of a squamous cell carcinoma, were judged to be cognitively intact and able to speak English. Thirty questions acted as the structure of the interview and are reproduced in Table 3.4. A year post-treatment was judged an appropriate time interval so that participants would have recovered from the acute phase of treatment and not be overwhelmed by some of the pervasive physical symptoms that have been well documented (Rogers, 2010). Each interview was digitally recorded and independently transcribed before being analysed by the primary researcher. The length of interview ranged from 40-70 minutes.

TABLE 3.4 QUESTIONS USED TO GENERATE INTERVIEWS OF THE H&NC PATIENTS

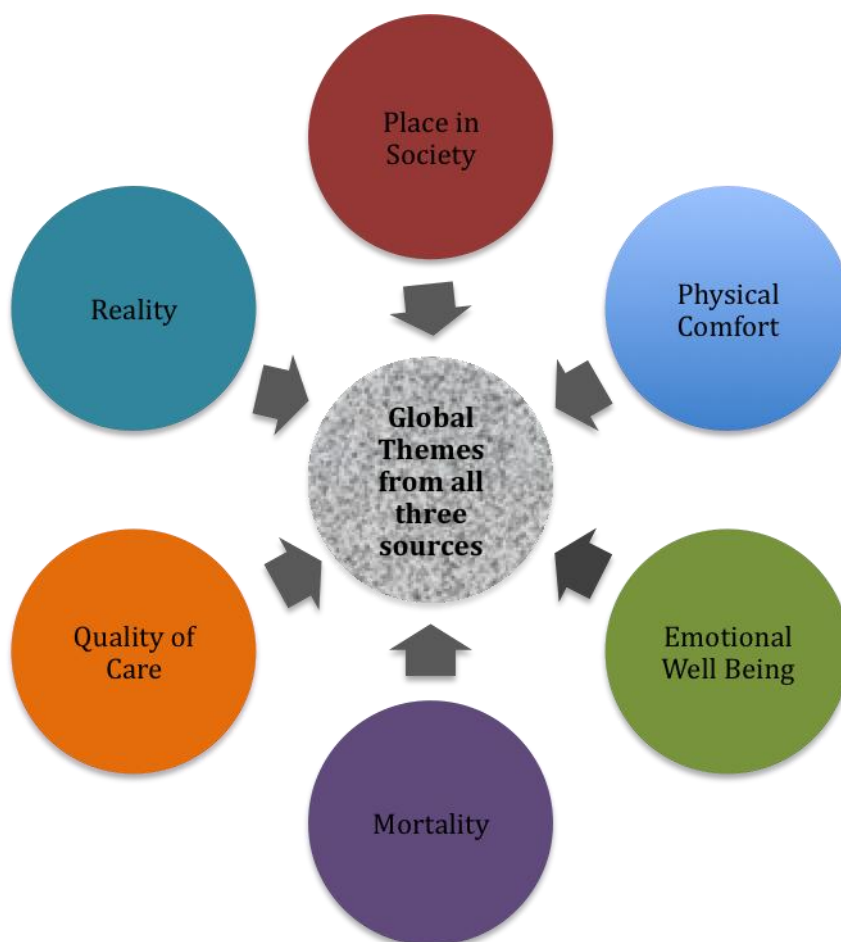
<p>Pre diagnosis</p> <p>What made you go to the doctor in the first place? Did you suspect you had cancer when you first went to your doctor? If so, what made you suspect this?</p>
<p>At the time of diagnosis</p> <p>How do you feel about the care you've been given? How do you feel about all the people that you have had to meet directly so your care could take place? How did having a diagnosis of H&NC impact on your life before you were treated? How do you feel about the information you've been given? Can you explain the effect the amount of information had on you? What has been the best thing about the information? Can you explain how the information written or verbal impacted on your ability to cope with the situation? Who did you feel the key people were? What helped you to cope with the pre treatment phase?</p>
<p>Post-treatment</p> <p>What are your main concerns now? Has the H&NC affected the way you see yourself? What was the lowest point for you over the past year? Has anything been particularly difficult to cope with? Are there particular symptoms that you continue to experience? How comfortable have you felt when discussing your situation with the team and why? What has been the most difficult time or thing to deal with? Are you still smoking or drinking -why? Is there anything particular that the team can do to help you cope? What enables you to cope with all that has happened? How do you feel about being reviewed in outpatients? Do you think that the team managing you have any idea how the treatment and disease has impacted on you? Do you feel the team understands your problems and concerns? Is there anything you wish you could tell the team that would make a difference to your care or others? What have been your feelings about undergoing the treatment? Since the treatment how do you think the disease and the treatment has impacted upon you psychologically? What were the expectations you had of the disease and treatment and how did the reality compare? How has your disease and treatment impacted on those around you at home and socially?</p>

FINDINGS FROM QUESTIONNAIRES, LITERATURE AND SEMI-STRUCTURED INTERVIEWS

The Attride-Stirling (2001) thematic analysis was used to analyse the data from all three sources. A network of themes, which are hierarchically developed from basic through organising to global themes, is constructed. The process allows for the researcher to classify all the material into the basic themes, which structured into more overarching terms by the organising and finally global themes. The data and the way it was coded is presented for each source in appendix 3.3

Six global themes were evident; day to day physical comfort; emotional well being; place in society; own mortality; quality of care; and reality. Figure 3.1 presents the global themes diagrammatically. Not all of the global themes were represented by all of the sources. Day to day physical comfort, emotional well being, place in society and reality were evident from all three sources; quality of care from the questionnaires and the semi-structured interviews and reality from the semi-structure interviews.

**Figure 3.1 Six global themes evident from a review of all sources:
QoL questionnaires, literature review; semi-structured interviews.**



The global themes that were evident from all three sources however differ in the detail covered. The questionnaires were at a basic theme level and remained at the identification and quantification of symptoms function and role. The literature and semi-structured interviews revealed a wider range of physical and emotional symptoms and demonstrated increased subtleties. This meant that there was more explanation into how participants coped with physical and emotional symptoms, as well as place in society.

Participant 1: *"We have an away day in October. I said I don't think I can go because I think it would bother me. They said "oh no we would ask for something special for you at mealtimes" I said "no I don't want to eat around a table with people, if I could*

just bring my drinks and be somewhere separate where no one would bother me or say "come and eat with us" then I'll come"

Participant 2: "People don't know how much you rely on your tongue. There are a lot of things I can't do. I can't touch the top of my lip. If I get a piece of meat stuck in the back of my tooth, before I'd use my tongue..... But now I can't. I have to use the toothbrush to get it out..... There's no point in getting irritated because I can't change it. I might do it one day but I just get on with it."

Participant 3: You try not to let it get to you, how bad you are and the pain you're in (pointing at anterior lateral thigh donor site) so you cope with it more because if you're not showing it you can cope."

All three of the above semi-structured interview excerpts describe symptoms and function - eating in public, reduced tongue mobility and the ongoing issue of pain- but also describe what strategies the participants use to overcome them.

Whilst as a basic theme identification of primary risk behaviours such as tobacco and alcohol use were evident within one of the three questionnaires-the FACT (I smoke Cigarettes; I drink alcohol); the semi-structured interviews were able to develop the theme into a personal appraisal of such behaviours being renewed.

Participant 2: "I was diagnosed on the Wednesday, I went outside and lit up; I had half a cigarette and went home, had a cup of tea and a sandwich and smoked half a cigarette. About five o'clock, I lit up another cigarette up and had half. I finished the other half about eight o'clock and I said when I go to bed tonight I'll have a cigarette in the morning. I woke up and never touched one. I used to smoke thirty or forty per day. I don't know how I just stopped and I'd been trying to pack up for ten years as my New Year resolution"

Participant: 3 More than ever, I still crave a cigarette I've actually banned it from the house now. If it's raining I'll let them smoke in the kitchen with the door closed and the windows open but it's not for me"

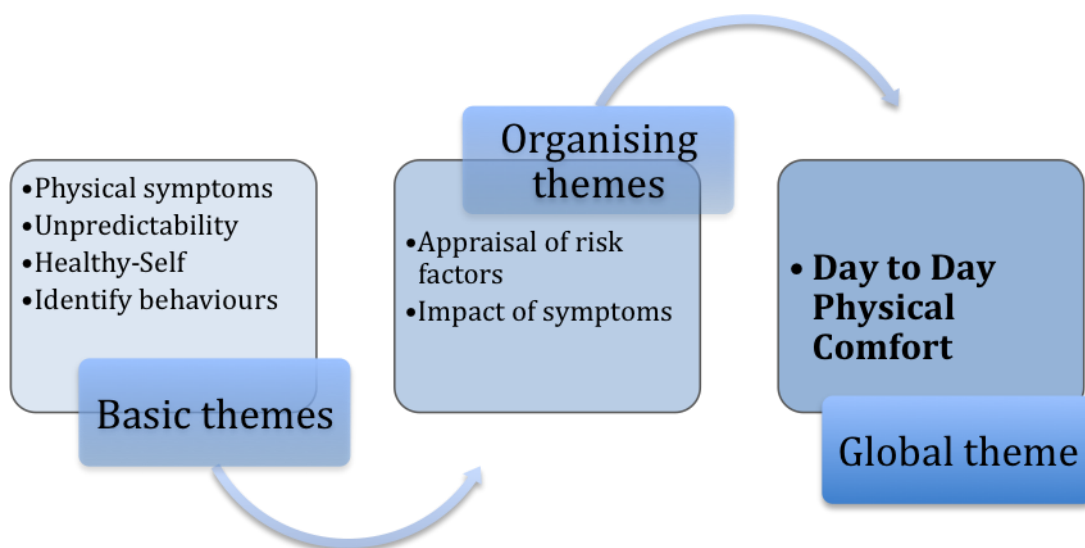


Figure 3.2 Thematic Network Day-to-Day Physical Comfort

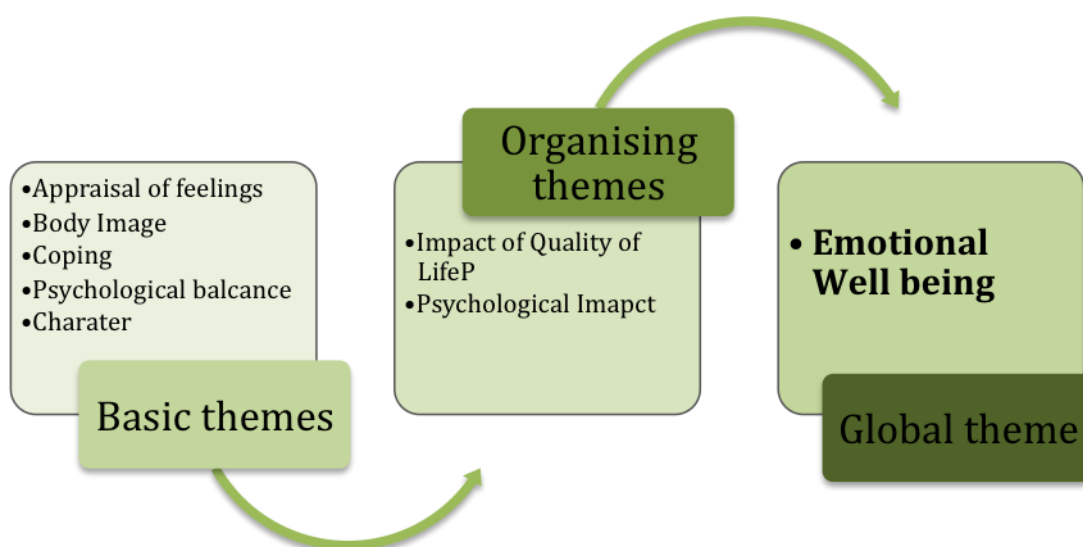


Figure 3.3 Thematic Network Emotional Well Being

Within the global theme place in society the HRQoL questionnaires revealed the basic theme of personal roles identified at work, -“my work is fulfilling” and within social and family circles “ I get emotional support from my family”, “ I feel close to my partner” (FACT H&N). Within the interviews the global theme was expressed more in

terms of the alienation from society and the purpose of some roles that participants had. Participants were very specific and actively chose who would or would not know about the diagnosis and the treatment, a way of maintaining a particular role but which within the FACT might still be labelled as having family support and so overlook certain choices made to protect other members of the family.

Participant 1: *"I couldn't tell my brother and sister, or my children. One of my sons had a first child on the way and he was born three days after I left the hospital so I couldn't possibly worry him.My younger son had had a terrible accident when he was ten months old, he poured a kettle over himself, so knowing that I had mouth cancer, I didn't even want him to come and see me, I thought it would bring it all back to him, so I shut them out of life whilst I was in the hospital."*

The semi-structured interviews also revealed the detail of explicit secondary gain that predominantly focussed around enhanced relationships. This included the adjustment of values and priorities such that more time was spent with family members. Situations were also reappraised in the context of health and survival.

Participant 3: *"I allow a lot of trivialities to go out the window, which I wouldn't have done before.....domestic situations at home, I'll break something it would have bothered me before, and I would have fixed it quickly but it can wait. I'll get it done when I feel like it when it's convenient..... I can't wait to see my grandkids. It makes you more appreciative of your family."*

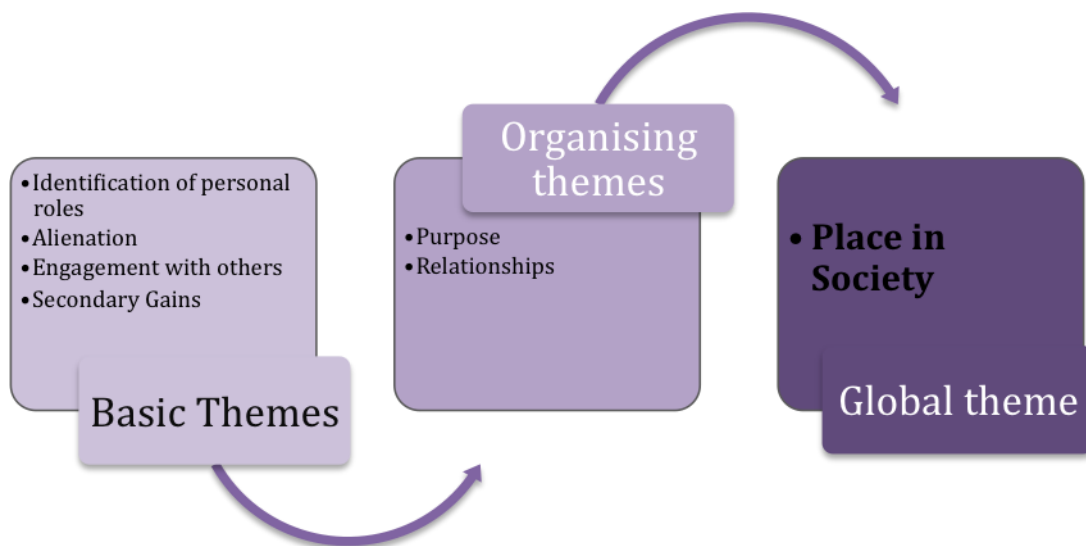


Figure 3.4 Thematic Network Place in Society

The final common theme between all three sources “Own Mortality” was again explored to different depths by each source. Within the HRQoL questionnaires it was evident with the FACT questionnaire “I worry about dying” In the literature it was explored through the theme of disease recurrence- a substantial part of the H&NC survivor literature (Llewellyn et al., 2008, Humphris et al., 2003) and an acceptance that death is a possibility (Chaturvedi et al., 1996). Fear of recurrence within the semi-structured interviews was openly expressed.

Participant 5 *“Now and then I worry it might come back”*

Participant 1 *“Now and then the worry comes over you. I don’t worry if it will come back; I wonder if I would have the courage to meet new people with that diagnosis again, I’m ok where I am.”*

There was acknowledgement that participants had actively prepared for the possibility of dying soon after treatment. Five of the six participants had made personal preparations in the event of not recovering enough to adequately deal with personal effects.

Participant 1: *“All day for a couple of weeks I didn’t think I would survive the operation and I knew the house would have to be cleared so I just spent day after day clearing books. One day I had eight bags for the charity shop”*

Two participants within the global theme of mortality expressed regret at having the treatment. There was a sense of reappraisal in the context of having the treatment and an admission that the current existence was hard to reconcile because of the change in function.

Participant 3: *“I wish to God now that I had not had it done and I would have just carried on for twelve months with a bottle in one hand, well not for twelve months I most probably would have had three. I’m not used to being ill for longer than a couple of weeks.”*

One of the participants commented on the difference for them between the questionnaires and an interview discussion.

Participant 4 : *“if you do the normal surveys when you’ve come round and asked me questions, I tick and cross the response but I don’t think I give out that much information,..... but some people like me when you start talking never stop and then you find out so much in twenty minutes, -all in one go.”*

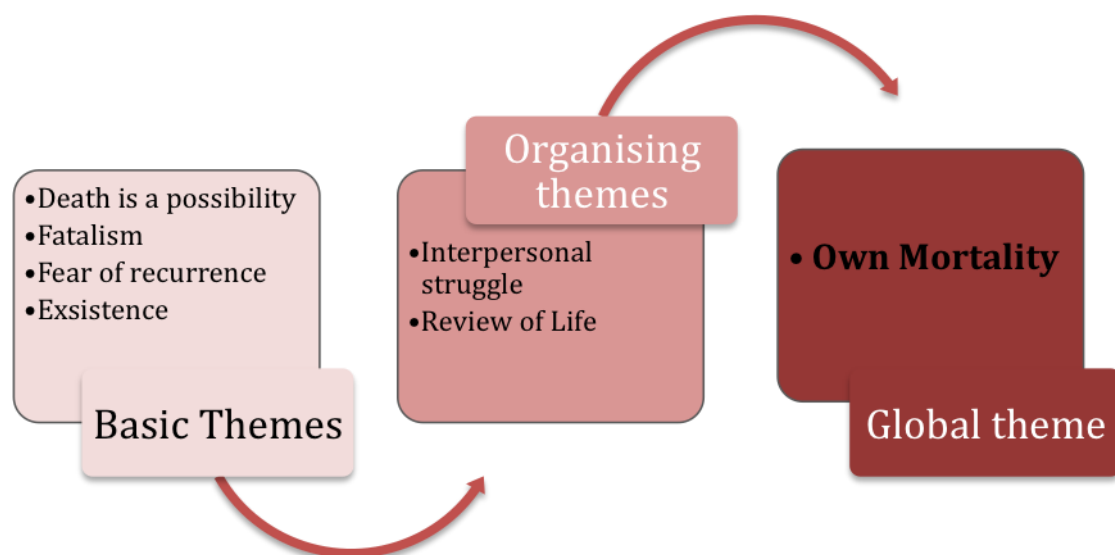


Figure 3.5 Thematic Network Own Mortality

FINDINGS FROM LITERATURE AND INTERVIEWS

The literature and interviews added a further global theme: quality of care.

The quality of care theme was able to illustrate patient vulnerabilities and assumptions that might be present during the treatment process. There was a sense from participants interviewed that it was not possible to really appreciate how long it would take to begin to recover from the treatment. The semi-structured interviews gave evidence of the difficulty participants had in the assimilation of written and verbal information, and more specifically the implications of not understanding information. One participant explicitly described how it was difficult to appreciate what the real meaning was of a neck dissection until it had happened, relating it then to physical changes.

Participant 2: "The surgeon was saying what he was going to do, he said he would cut me from here to here and he would take my glands out. I understood but I suppose I didn't understand the extent of what the operation involved. Does that make sense? They are alien words; when you say you are going to make a line from here to here and take away glands I don't really know what that means. I didn't know the glands were as big as they were. It was obvious what was happening but I didn't understand what it would mean."

Another described how despite needing three operations within the space of three weeks it was not possible to be prepared any more comprehensively because of it being so difficult to predict the course of recovery. Research has concluded that the timeliness, individuality and amount of written and verbal information given to patients are vital if trying to reduce evident mismatch between patient expectations and experiences (Llewellyn et al., 2008, Llewellyn et al., 2006).

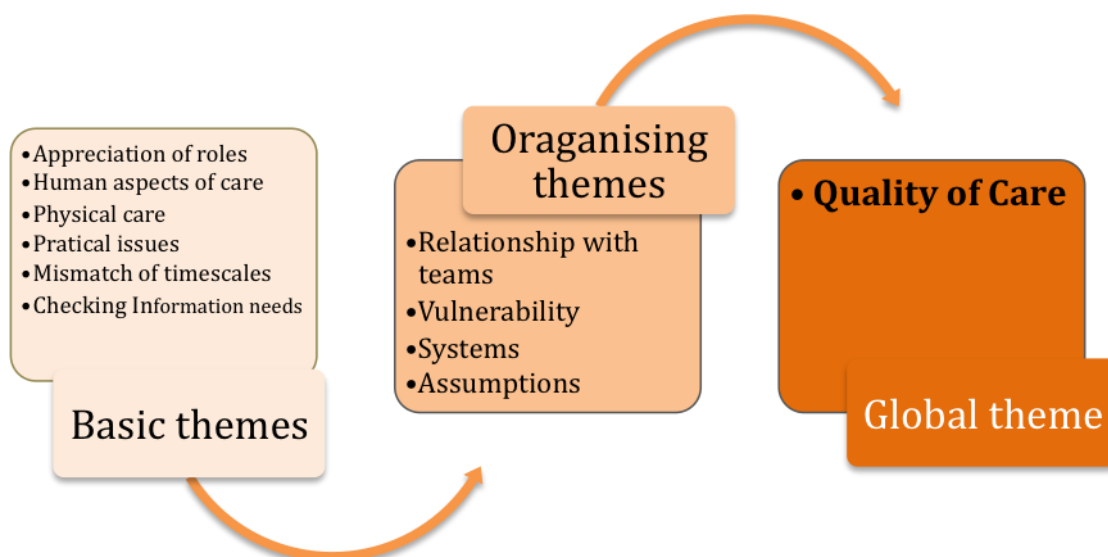


Figure 3.6 Thematic Network Quality of Care

A substantial organising theme was the relationship with the team. Examples were given within the literature of individual and patient orientated care and although the teams judged this as time consuming, (McLane et al., 2003) it was seen to have value and focus to the team and patient interactions. H&NC patients undergoing treatment have been described as resilient and resistant to offers of help (Wells, 1998), an issue echoed within the semi-structured interviews when a participant described not wanting to bother busy ward staff unless there was a real need. For example it might also be that there is some difficulty in patient compliance and adherence to treatment programmes that needs to be identified and addressed (Edmonds and MaGuire, 2007). Specific to the semi-structured interviews there was evidence of institution organisation difficulties. These included logistical and practical issues relating to appointments. Both the literature and semi-structured interviews disclosed information relating to the humane judgments in patient care. There was evidence to suggest that it was expected that there would be good advanced communication

skills used, which would result in a consistent and understood message from the teams (Moore et al., 2004, Llewellyn et al., 2006). Specifically the semi-structured interviews highlighted the utter trust, vulnerability and belief in key members of the clinical team that the participants had.

Participant 1 *“Well you couldn’t be in better hands anywhere in the world, from first meeting my surgeon I had no fear and trusted him. I always felt better when I left the appointment he was just so down to earth and gave me so much confidence”*

Participant 2 *“And the surgeon’s reputation is important, because you’re thinking if you are going to do this to me, and you are telling me its going to work, I have to believe you are the best to do it, because if I don’t then you are completely lost...They don’t make you feel like a number. If I’ve got a problem I can raise it with somebody. It’s not as though you go to the bottom of the pile and have to repeat it all the next time you visit they remember the conversation and what was on your mind at the last appointment.”*

FINDINGS FROM THE SEMI-STRUCTURED INTERVIEWS

The semi-structured interviews revealed a specific global theme, reality that reflects some of the stoical aspects of the participants in dealing with the situation. In this context participants described unremitting symptoms, the acceptance of being reactive rather than in control, the need for an inner strength and the stark choices that had been faced during the assessment and treatment phase of their disease. Participants did not perceive choice at the time of treatment because in reality little choice existed in deciding whether to have treatment.

Participant 5: *You’ve got no option, it’s that or nothing, so you have to have it done you don’t have to think about it at all-there is no choice.”*

The perceived choice by others was not in reality available to the participants. This aspect of stark choices linked to the basic theme of alienation that participants felt in the global theme “place in society”. The inner strength that became an organising

theme was made up of examples of physical and emotional loneliness and a sense of if the participants did not deal with the issues then no one else would.

Participant 3 *“I just worried that I’m not going to feel much better and I’m finding it difficult to cope”*

Participant 5 *“The days pass and you go to sleep and you relax and you don’t think about it even with the tube in your neck (tracheostomy) you have to learn to switch off and let the nurses do the worrying”*

There was also evidence of unremitting symptoms, both physical and emotional that were continually present and difficult to ignore. This in part explained the reactive state that participants expressed in which they were not able to take control of certain symptoms. There was a sense of needing to wait to heal; knowing that to be too active would lead to frustration, fatigue and deterioration in function.

Participant 6: *“For me it is a very ongoing thing and also to the point where you can have what are called one of my ‘good days’ and you think this is great only to feel the next two days are horrid and you think I’m back to where I was. I count my good days and enjoy and do what I can You have to let time pass, you can’t hurry (the recovery) and you have to let it go at it’s own pace.”*

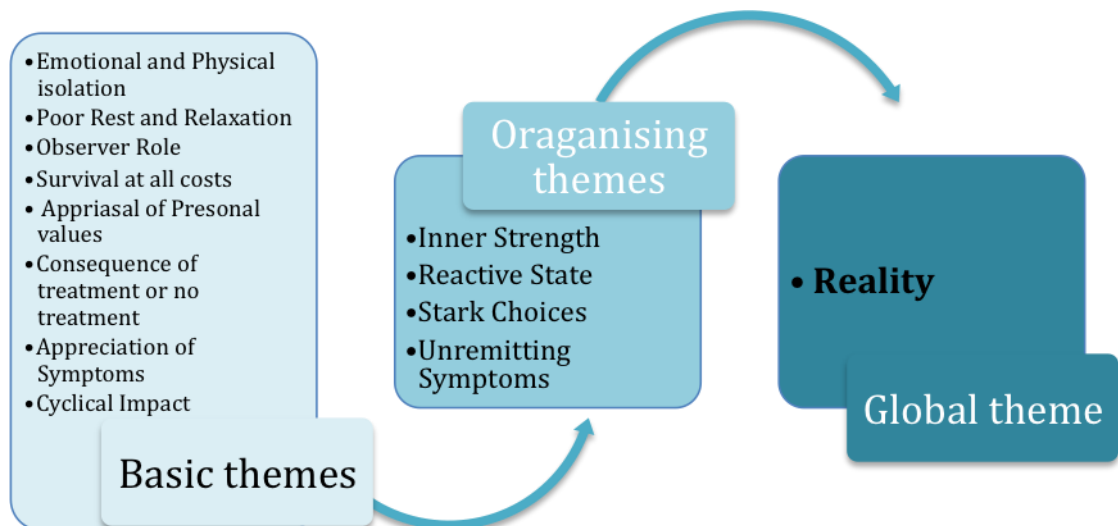


Figure 3.7 Thematic Network:Reality

The evident stoicism and depiction that participants presented that they were emotionally coping hid the reality of the gruelling impact that participants dealt with.

Participant 4 “Once you let your defences down that’s when you start to crumble, so it’s as though I’m standing on the outside of the building, but I’ve crumbled inside,there are times in the last few weeks I’ve felt ‘oh hell what’s the point, I’m not bothered but I don’t let on”

From the semi-structured interviews it was possible to represent the global themes from statements made by the patients such that statements could be categorised under the global themes and perhaps give some real salience to the experience of the disease and treatment of H&NC. Figure 3.8 present the phrases that have as their sources the semi-structured interviews and which represent the six global themes.

Figure 3.8

45 REPRESENTATIVE STATEMENTS OF THE EXPERIENCE OF H&NC

1. Physical symptoms: day-to-day comfort (8)

1. I recovered much slower physically than I expected
2. I am still in pain
3. It’s hard to remember things you’re told
4. I felt physically very isolated
5. When I talk it doesn’t feel like me anymore
6. I always think that people are staring at me
7. Any symptom I get I always think the cancer might be back
8. Day-to-day existence is physically exhausting

2. Emotional well-being (10)

1. I worried a lot how others would cope
2. When I was told I had the cancer I knew I had to face it.
3. I wish I’d never been treated
4. My appearance was much better than I expected
5. I am much more irritable than I used to be
6. I cannot do things on the spur of the moment.
7. It really affected my confidence
8. It’s amazing how much you can adjust to all the physical changes
9. Life will never be the same again
10. I never appreciated how long it would take to get better

3. Place In Society (7)

1. I felt very alone
2. I didn't want people to know what had happened to me
3. Everyone around me was so upset
4. I still don't think anyone can really understand what has happened to me
5. I cannot have a good argument now
6. I never think of myself as ill
7. I do things but on my terms

4. Own mortality (7)

1. Being cured of the cancer is still the most important thing
2. It's just as well you don't know what's going to happen or you would never cope
3. It's very hard to think about your own possible death
4. You never think it could happen to you
5. Once I knew they could do something about it that's all I needed to know
6. You just become really grateful for different things
7. Life is hard you just have to get on with it

5. Quality of care (8)

1. I didn't understand what was meant by the treatment until I experienced it
2. I felt very vulnerable when I was in hospital
3. Little things like the car park or appointments being cancelled really irritate me
4. I never felt like a number I was always treated as an individual
5. I was most frightened when I came out of hospital
6. I wanted the team always to be honest with me
7. I never read the written information I was given.
8. No two patients are the same

6. Reality (5)

1. You should never have to face this sort of thing on your own
2. If you didn't want to die there was no choice but to have the treatment
3. It's so hard waiting to heal
4. I have to be careful to not upset people
5. I'll talk about things that I wouldn't have done before my diagnosis

DISCUSSION

Three sources of information relating to the experience of H&NC have been thematically analysed using a previously described approach (Attride-Stirling 2001). HRQoL questionnaires focus on symptoms and function, which mean they remain at the level of basic themes. They do not allow the influences or the connections between scores to be understood so that patient adjustment and reappraisal when undergoing treatment is poorly represented. Whilst there might be changes identified by HRQoL questionnaires when they are repeated, there is limited explanation as to how the patient might have achieved this or the relevance of the symptom or change in function for the patient. This perspective is verified further in the context of the literature which has suggested that H&NC patients will under-report symptoms, due in part to a sense of hopelessness and loss of meaning to life following treatment for the disease (Moore et al., 2004). It might be, therefore, that the use of HRQoL questionnaires under-represents patients' real experience both in terms of intensity and scope. This investigation of the experience of H&NC enables one to conclude that there are perhaps complex and interactive patient characteristics that will impact on the H&NC patients' QoL scores. The semi-structured interviews identify in participants a reappraisal of values, numerous coping strategies, and adaptation. It might therefore be that HRQoL questionnaires are measuring other effects, that modify patients' scores which are not directly related to the treatment and disease and which might, if better understood, give insight to the patient, carers and health care team which might secure a more successful management of the patient. A specific example of this can be seen within health behaviours. If a patient is still smoking or drinking alcohol the behaviour should not only be identified but have a patient

specific commentary so that the health care professional might become more informed of the context for the continuing behaviour. If this could happen cessation programmes if appropriate might be more successful. Assessment of the existence of risky behaviours is only evident within one of the three most regularly used HRQoL questionnaires the FACT. It would seem therefore discussion of health behaviours is poorly represented within HRQoL questionnaires.

The current study demonstrates that the focus of HRQoL questionnaires is narrow and that it is important to build a context in which the HRQoL variables are a part rather than the whole. Whilst physical, emotional symptoms and personal relationships are a substantial part of a patient's description of their well being they are not the complete picture. In order to achieve this, patients' needs and possible current limitations, quality of care and the reality of the situation for them as individuals should be discussed. If this aspect of the whole person can be better understood then personalised care can be described and care plans created which meets UK government policy (National Cancer Action Team, 2011). It might also be that the process of semi-structured discussion allows a patient to review their concerns and have them recognised as important aspects of their care. Through this method of investigation the health care team might begin to truly understand, in the context of the patient's own previous life-experiences why they might have reacted in a particular way during their treatment and recovery. Such understanding and reflection might allow patients to recognise at an earlier stage their needs, which might avert a crisis; a further intention of the Holistic Needs Assessment set out by the National Cancer Action Team (2011). It might also mean that patients are able to discuss and understand dissatisfactions in life without having feelings labelled as either anxiety or depression.

It has been suggested by Salander (2011b) that the added burden of the cancer diagnosis and treatment prompts patients to seek support in order to lessen the total psychological burden. He went on to suggest that whilst patients need medical input to cure them of the cancer they are capable of lessening some of the emotions associated with the situation. As part of this process they may respond well to the opportunity to reappraise their life. Within a treatment paradigm patient data should not only act as a descriptor but also as a way of formulating a treatment plan. If this could be achieved, studies would move beyond recognising the presence of the impact, towards aiming to describe more specifically how treatment has affected patients. Discussion via semi-structured interview enables much more explanation of the patient's situation and allows for the true context of the symptom or feeling to be described. This approach is more holistic and might allow for the medical team to make judgements with the patients, which relate to their tolerance of the situation. This method of enquiry is less likely to be open to misinterpretation and might add more satisfactorily detail so that care-plans might be formulated. It might be that HRQoL questionnaires can act as a screen of needs assessment for some of the more obvious physical and emotional impacts of the disease and treatment, but they should not take the place of detailed discussion between the team and patient, and in no way can they be said to be representative of the whole experience.

CONCLUSION

Outcome should be represented in more meaningful terms than length of survival or clinical process targets. HRQoL measures might identify some of the more

superficial aspects of outcome but a more rounded understanding of the covert aspects may positively support both the patient and their carers through such life-changing experiences. HRQoL questionnaires cannot be said to adequately reflect either the available literature on patient experience or the reported experiences of H&NC patients themselves. Review of all three sources would suggest that when used HRQoL questionnaires are used there is a narrow, symptoms biased collection of information. The questionnaires cannot capture the wealth of the data that is potentially available or offer an explanation to some of the measures that are taken.

Health care teams, patients and their families should understand the impact of H&NC and its management from a holistic perspective so that the care can be achieved successfully for each individual. HRQoL measures by necessity have a narrow focus on symptom and function and these can be mistakenly seen as representing a patient's QoL rather than as some of the constituent parts. Within a clinical setting it would seem valuable to routinely invite patients who have undergone treatment to discuss, in a semi-structured way, the individual impact of the disease and the treatment. The purpose of this would be to facilitate a deeper understanding through explanation of the individual experience and to enable specialist teams to support patients more appropriately in outpatient settings. If this were to happen it would enable teams to move away from the quantifying process, in which a change in score has limited real meaning, towards more a detailed explanation. Moving towards a more holistic needs assessment should enable patients to explain what has happened to them and to appreciate a more complete picture of the impact. If this could be achieved one might expect that a patient is less dependent on others for their well-being and that they could seek help earlier.

There should be a recognition that patients' minds are intrinsically linked to their physical status and are not well represented because they are hard to describe in a meaningful way.

This study only examined the experience of six H&NC patients' experience of their treatment within a UK cancer centre. The statements gathered from them can be used in a more formal way to investigate the experiences of other H&NC patients. A future study will use the list of statements generated from the six identified themes with other H&NC patients and invite them to rank them according to how like or unlike their experience of the disease the statements are. The current study has therefore acted as a way of creating a set of statements from three sources, and is part of the a method called Q Methodology, which has been described as a way of looking for patterns in the way people think (Webler et al., 2009a). There is perhaps a role for more qualitative methodologies to be used alongside quantitative methods in order to discover what factors affect people who survive the disease, which to date has been poorly identified. This may allow a structured approach that is replicable with more groups of patients and this might be said to be an influential method of gathering key factors that are important for patients at an individual level. The ultimate goal will remain to collect information that can inform the management of patients who live with the consequences of a life changing event so that they can live as independently as possible from health care systems and carers.

This section of the thesis has been published as:

EFFECT OF ORAL TUMOUR SIZE ON QUALITY OF LIFE JUDGEMENTS BY HEALTH CARE PROFESSIONALS WORKING WITH HEAD AND NECK CANCER PATIENTS: A PILOT STUDY.

(Reid et al., 2009)

ABSTRACT

AIM To investigate whether information about the size of oral tumour influences the multi-disciplinary team's judgements about the quality of life (QOL) of Head and Neck Cancer (H&NC) patients.

METHOD Using a between-group design, two groups of Health Care Professionals (HCPs) rated a hypothetical patient on 20 outcome variables. Patient description was identical for both groups, except for tumour size.

RESULTS Comparisons of ratings for variables revealed only 3 significant differences between the groups' predictions and no consistency within conditions, suggesting that the participants held few common assumptions about the impact of tumour size on a range of patient experiences.

CONCLUSION The lack of agreement amongst the HCPs in the study suggests that where humane judgements are used in treatment decisions for H&NC patients, then these may be random and inconsistent. Consequently, patients should have a direct input into treatment decisions, using formalised QoL data.

Key words:

Head and Neck Cancer, Decision Making, Quality of Life.

INTRODUCTION

Randomised Control Trials (RCT) are the gold standard of medical research, because they enable the prediction of outcomes for given interventions. However RCT methodology may be less relevant to some patient groups because of what has been termed 'diffuse technology' (Ferguson et al., 2001) - an acknowledgement that some treatments are not easy to prescribe in experimental terms. One example of this is the management of Head and Neck Cancer (H&NC) patients. The complexity and heterogeneity of their condition, and the impact of both the disease and treatment, mean that RCT investigations of cognate interventions may be neither appropriate, nor possible to conduct satisfactorily. H&NC patients' treatments, therefore, may be best managed not through rigid adherence to clinical protocol, but instead, through incorporating into clinical decision-making, a wide range of patient centred factors.

This position is supported by the research on clinical judgement. The bedrock of treatment decision making, is defined as the fusion of technical judgement, (encompassing the scientific and evidence based information) and humane judgement, (relying on the Health Care Professional's interpretation and insight into the patient and symptoms) (Downie and Macnauhgton, 2000). It is clear from this definition that clinicians need to use, and interpret, a constellation of objective, empirical data, as well subjective, experiential and interpersonal data. Traditionally, the technical aspect of clinical judgement has relied on research that for H&NC patients has focussed almost solely on survival and loco-regional recurrence rates as the outcome measures (Norris et al., 1993, Bernier et al., 2004). However, this takes little account of the comprehensive impact H&NC and its treatment may have on the quality of all aspects of the patient's life, which, given the complex and

diverse nature of the condition, should be central to the humane judgements made about treatment options. Acknowledgment of this has more recently resulted in an exponential growth in the research relating to Quality of Life (QoL) in relation to H&NC (Rogers et al., 2007). The typically poor prognosis, the wide variation in reported problems and the highly individual response to the condition and its management mean that treatment decisions must be predicated on both technical and humane aspects of clinical judgement. However, if humane judgements are being used in the management of this patient group, it is important to establish whether the health care professionals (HCPs) involved in treatment decisions, share an understanding of the physical and psycho-social implications of the condition for the patient. Without a common understanding of what is relevant and why, clinical judgements may be ill-conceived and randomly applied, rather than informed and systematic (Brown et al., 2001). HCPs therefore need to be aware of, and responsive to, a range of subtle and often immeasurable psycho-social cues and patient concerns, and be able to interpret this information in a way that enhances treatment decisions. Although this clearly challenges the evidence based health-care culture, it may, nonetheless, be highly relevant in the management of a condition that, because of its diversity does not readily lend itself to randomised control scrutiny.

Research evidence suggests that the site and size of the tumour in H&NC may enable some reasonably reliable predictions to be made about a range of outcomes, which would mean that the research can inform technical judgement, and aid clinical decision-making. For example, the site of the tumour has been reported to influence the type and severity of swallowing difficulties pre-treatment;(Stenson et al., 2000) and site and the stage of tumour has been

demonstrated to have the strongest impact on Health Related Quality of Life, (HRQOL) (Hammerlid et al., 2001). Similarly, at pre-treatment, a relationship between tumour-burden, speech and swallowing for oral and oral-pharyngeal cancer patients has been demonstrated, concluding that the percentage of oral tongue affected significantly reduced articulation and swallowing efficiency (Colangelo et al., 2000). From this objective clinical evidence it may be possible to formulate reasonably accurate predictions about how patients will report their condition and how it impacts on their functioning and QoL. To this end, reported psychosocial/QOL information may be highly relevant to the management of the individual patient's condition (Funk et al., 2004). The crucial role of the multi-disciplinary teams (MDTs) in improving both treatment decisions and the coordination of cancer care, means that their interpretation of the totality of the patient's condition will be pivotal (Tattersall, 2006). Consequently, the way in which MDTs use patient data to interpret the patient's condition and to make humane judgements may be worthy of investigation.

Therefore, the aim of this study was to investigate whether the MDT is influenced pre-treatment by the size of the tumour when making judgements that relate to QOL issues. The research question was:

Do HCPs use their knowledge of the patient's condition (tumour size) consistently, to inform their humane judgements about the patient's QOL?

METHOD

STUDY DESIGN

An experimental between-subject design to compare the responses of two separate groups of HCPs was used. The aim was to establish whether tumour size (independent variable - IV) affected the HCPs' assumptions about the patient's QOL and other psycho-social issues (Dependent variable - DV). The study used a variant of Asch's Central Trait Theory, with tumour-size operating as a central trait (Asch). Asch's original study demonstrated that by interchanging one adjective from two otherwise identical descriptive lists, participants would form a different impression of a person. His findings were interpreted as suggesting that past experiences become organised as outstanding frames of reference and therefore affect current judgements. The theory also suggested that in making a judgement about a person, the participant will eliminate any incompatible perspectives, since rarely are attitudes half-formed or absent. Evidence for Central Trait Theory exists within healthcare (Darbyshire, 1986). Based on this research, this pilot study used the key descriptors of tumour size to see whether manipulation of this variable impacted on HCPs' assumptions about other aspects of the patient's condition.

SAMPLE

A convenience sample of HCPs were invited to participate. All worked in a MDT, within a large H&NC centre, which is involved with the management of patients with an oral tumour. Subjects were selected if they were known to have regularly worked with H&NC patients. Seventy-nine subjects were approached from a range of professional backgrounds – see Table 3.4.

MATERIALS

The materials consisted of a questionnaire specifically designed for the purpose.

The questionnaire was split into three parts. The first part focused on basic biographical details of the respondent. The second part provided a description of a fictitious H&NC patient, giving clinical and social information that would be typical of a patient presenting to the unit. The information about the fictitious patient was in the style and content routinely used within the MDT weekly meetings and in language used on the unit to describe patients, both in discussion and in written reports sent out to referring agents. It was the researchers' deliberate intention not to be gender-specific with the hypothetical patient, and for the patient to be assigned a job that might be seen as one that would require a degree of communication on a daily basis. A carcinoma of the tongue was chosen as the site so that the location of the tumour was clear and unambiguous. The description of the patient was identical for each group, with the exception of tumour size. To ensure clarity and lack of ambiguity in the respondents' understanding of the presenting clinical problem, the labels T2 (larger than 2cms but smaller than 4cms) or T4 (larger than 4cms and invading adjacent structures) were used, one for each condition.

The third part of the questionnaire required the participants to rate 20 statements relating to a range of clinical and psycho-social outcomes that the patient described in part 2 may typically experience. These outcomes were derived from a thematic analysis of the cognate research, including work involving the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire C30 (Aaronson et al., 1993) which, and the EORTC Head and Neck

specific questionnaire (Bjordal et al., 1994); both are validated and intended for use with H&NC patients (Bjordal et al., 2000, Sherman et al., 2000).

The 20 domains that were subsequently distilled from the research included tension, energy, sleep, appetite, memory, depression, limitations on work, oral pain, choking, worry, oral communication, sexual enjoyment, swallowing diet, social eating, saliva consistency, use of supplements, sore mouth, dry mouth. The participants were required to score the 20 statements on a 10cms visual analogue scale (VAS) which has been demonstrated to have good reliability and validity as a measure of subjective experiences (McCormack et al., 1988).

PROCEDURE

PILOT

The study was piloted on 3 people to see if the form and the procedure had any specific problems, which had not been identified by the investigators. No difficulties were identified.

MAIN STUDY

Questionnaires were distributed by hand, to each participant. They were asked to complete the form on their own and without discussion with anyone else. (The questionnaire is presented in Appendix 3.4). Of the 79 participants, 39 were randomly given questionnaires that contained the variable T2 and the remaining, 40 participants were given the questionnaire with the variable T4. In all other respects the questionnaire and procedure were identical.

The allocation to condition followed a stratified random sampling to ensure that there was equal distribution of the questionnaire between professional groups. This

procedure involved making a pre-requisite number of envelopes with the HCP role and then randomly allocating slips of paper to each envelope marked T2 or T4. The envelopes were then shuffled and distributed to the appropriate type of HCP. All the questionnaires were completed anonymously. The data gathered were inputted into SPSS for windows version 14, and analysed using techniques of descriptive and inferential statistics.

ETHICAL CONSIDERATIONS

The study is part of a much larger study approved by the ethics committee of South Birmingham. Participants were able to discuss with the investigator any queries they had relating to the questionnaire before completing it and were able to withdraw without giving any reason.

RESULTS AND ANALYSIS

Seventy-two out of the seventy-nine participants completed the questionnaire according to the instructions, of which thirty-six completed the T2 version and thirty-six completed the T4 version of the questionnaire.

Table 3.4 reports on the details of the participants with reference to their profession, and years working with H&NC patients.

TABLE 3.5 BIO-DETAILS OF CONVENIENCE SAMPLE HCPS TAKING PART IN THE STUDY

Profession	T2 group	T4 group
Nurse	17	18
Senior Nurse	3	3
Junior Doctor	7	7
Consultant surgeon	4	3
Consultant Other	2	2
Therapist	3	3
Number of years working with h&nc		
Less than 5 years	18	17
More than 5 years	6	5
More than 10 years	10	14

PRE-ANALYSIS CHECK OF THE QUESTIONNAIRE'S INTERNAL RELIABILITY

To test the internal reliability of the questionnaire, respondents' answers on those variables that were either clinically or psychologically similar were analysed using a Pearson's product-moment correlation. Correlations coefficients were calculated between social eating and difficulty eating solids; tension and worry; and HRQOL and QOL. All showed significant positive correlations at <0.005 level (1- tailed), thereby suggesting that the instrument has some internal reliability.

To test the main hypothesis, independent t-tests were used to compare the responses from the T2 and T4 groups on each of the 20 variables in section 3 of the questionnaire. Independent t-tests were used here because the focus of interest was the difference in ratings provided by the two separate groups (T2 and T4); the rating data was obtained from Visual Analogue Scales and could therefore be treated as interval/ratio measures. The comparison of two different Subject groups and the use of interval/ratio data therefore required analysis by the parametric independent t-test. The results are presented in Table 3.5.

TABLE 3.6 INDEPENDENT SAMPLES T-TEST COMPARING RESPONSES OF PARTICIPANTS ACCORDING TO SIZE OF TUMOUR T2 VS T4

Symptom dependent variable	t-test	Df	Sig. (1-tailed)	T2 mean score	T4 mean score
Tense	1.805	68	0.0375*	7.8676	7.4222
Lack of energy	.425	68	0.336	6.3794	6.2083
Lack of sleep	.750	66	0.228	7.5152	7.3029
Poor appetite	1.341	68	0.092	7.0735	6.5639
Poor memory	-.279	68	0.3905	6.0176	6.1222
Depressed	-.510	68	0.306	6.594	6.825
Work ltd	.507	68	0.307	6.038	5.800
Pain	-.629	67	0.2655	5.1206	5.5333
Choked	-1.356	67	0.09	4.674	5.536
Worry	.213	67	0.416	7.597	7.776
Difficulty on 'Phone	-.189	66	0.4255	5.376	5.789
Sex	-1.215	67	0.1145	6.276	7.017
Swallowing diet	-1.703	67	0.0465*	5.726	6.625
Saliva	-.960	67	0.17	4.724	5.300
Social eating	-1.983	67	0.026*	5.529	6.472
Supplements	.194	67	0.4235	4.721	4.756
Sore	-.208	67	0.4175	6.403	6.675
Dry	-.659	67	0.256	4.182	4.642
HRQOL	.698	67	0.2435	3.509	3.331
GQOL	1.184	67	0.12	3.012	2.736

*Significant at ≤ 0.05 level

The effect sizes for the significant results are as follows: tension = 0.041 (small – moderate effect) the ability to swallow diet = 0.04 (small to moderate effect) and social eating = 0.053 (small to moderate effect) (Cohen, 1988). These three domains were acknowledged by the HCPs to be significantly more difficult for the T4 group than for the T2 group. The remaining 17 factors showed no significant differences between the groups.

To establish whether there was agreement within each group, Kendall Coefficients of Concordance were calculated. This statistical test permits assessment of the level of agreement between judges. Here, the judges were the participants in either the T2 or T4 group and the items to be judged were the 20 variables. The Kendall

Coefficient of Concordance provided a measure of the extent to which the judges in each group agreed with regard to their assessment of how far each variable applied to their allocated hypothetical patient. The results for each group are presented separately.

T4 GROUP

Using a Kendall's coefficient of concordance on the data ($S=337553.71$ $W=0.39167, n=36$ $N=20$; $X^2 = 26.791$ $df=19$) the results were not found to be significant. This means that there is a no significant agreement among HCPs as to which of the symptoms is most likely to be present in the patient described with a T4 tumour.

T2 GROUP

Using a Kendall's coefficient of concordance on the data ($S=262729.80$ $W=0.3858$, $n=32$ $N=20$; $X^2 = 23.457$ $df=19$) the results were not found to be significant. This means that there is no significant agreement among HCPs as which of the symptoms is most likely to be present in the patient described with a T2 tumour. These results suggest that there is no agreement within either group regarding the psycho-social and physical concomitants of tumour size.

DISCUSSION

In so far as the participants were able to complete the task, it would seem that HCPs do associate an oral tumour with a wide range of emotional, cognitive and physical difficulties. However, these associations were not consistent within tumour size. Moreover, there were no significant differences between the groups regarding

their assumptions about 17 of the 20 associated patient problems. It can be concluded that for this group of experienced HCPs, tumour size has not been demonstrated to be a reliable central trait. Only three variables produced any significant differences, viz: that eating socially, swallowing diet and tension were considered to be worse for the T4 (larger tumour) condition. Overall, these results do not accord with the available research that suggests there is a consistent relationship between tumour size and a range of symptoms (Stenson et al., 2000, Hammerlid et al., 2001, Colangelo et al., 2000). It is also worth noting that there was no consistency either between professional group or number of years' clinical experience with H&NC. There are several possible explanations for these results. Firstly, it is conceivable that tumour size is not pivotal for the HCPs in the prediction of symptoms, and that other factors (such as a range of psycho-social factors and the nature of the patient) may be more influential in determining the impact of the disease on QOL. Secondly, and related to this, tumour size may be more variable in its clinical manifestations than the available research literature would suggest. The inherent heterogeneity of H&NC patients means that the implications of tumour size would be confounded by a range of individual variations in psychological or medical response, and in the personal/social circumstances of the patient. Thirdly, the lack of consistency among the HCPs studied may be a genuine reflection of their attempt not to stereotype, but rather to treat patients on an individual basis. Finally, the HCPs samples may simply be unaware of the research evidence relating to the impact of tumour-size.

Taking the first two, inter-related explanations, it is conceivable that HCPs consider H&NC to be so inconsistent, subjective and unpredictable, that there is little real clinical use in relying on just the clinical evidence about the tumour size to make

predictions about the impact of the disease. Certainly, anecdotal evidence from within the unit suggests that within a six-month period it is unlikely that there will be even two patients who present with similar objective clinical criteria (age, gender, site, size, pathology). Such variability will not only mean that consistent clinical pictures are scarce, but also means that HCPs may not be able to build up a critical mass of experience on which to base their technical and humane judgement. Exposure to such diversity may also spawn a philosophy, much in favour with the trend towards patient-centred care, that each case should be managed individually, rather than imposing a condition driven protocol irrespective of the patient's real needs and problems. The uniqueness of the presenting problem would then preclude the generation of stereotyped assumptions on which to base treatment-decisions. While this may be laudable in its objective, the lack of consensus within the groups about the clinical and QOL implications for the hypothetical patient may mean that where treatment decisions are influenced by the humane judgements of the HCPs, arbitrary management may result. Such a situation would compromise target driven outcomes.

The final possible explanation suggests that the HCPs may simply not be aware of the relevant research. While oncology research has, over the last 20 years, started to acknowledge QOL information as an important outcome that needs to be incorporated in treatment decisions, and one which needs time and experience to assimilate, synthesise and subsequently integrated (Frost and Sloan, 2002), it is nonetheless conceivable that the HCPs simply lack knowledge of the cognate literature. This contention is reinforced by the fact that there is a concerning under-use of QOL questionnaires in clinical practice nationally (Kanas and Rogers, 2004), despite the number of available instruments and the demonstrable value of

the information they provide. As the unit participating in the current study does not routinely collect QOL data, the contextual research may simply be unknown. Allied to this is the lack of research that investigates patients' pre-treatment QOL symptoms – the focus of the current study (Stenson et al., 2000, Hammerlid et al., 2001, Scharloo et al., 2005). This may explain in part the typical focus on the measurable end points such as length of time to treat, length of stay, morbidity, and disease free survival. A recent paper suggested that a government pre-occupation with health care reforms means that the practical and mundane tasks necessary to improve quality and outcome of complex services will always be secondary (Haward, 2006).

In absolute terms, the respondents in both conditions tended to attribute high degrees of worry, anxiety and allied problems to the hypothetical patient, irrespective of the severity of the presenting tumour. This statement may be supported by a review of HCPs' perceptions of caring for cancer patients generally (Lampic and Sjoden, 2000), which suggested that HCPs tended to ascribe high levels of anxiety and distress to all patients with a cancer diagnosis, and to overestimate patient distress and under-estimate QOL. In practice this may mean that patients are receiving care from HCPs who have a more negative interpretation of their disease than the patients themselves. The interpersonal dynamics of the HCP/patient relationship may act as a conduit for these negative suppositions, which in turn, may adversely impact on the patient's psychological state pre-treatment. Clearly, it would be desirable for the emotional interaction of the carer and patient to be realistically represented rather than assumptions being made by HCPs based on their previous experiences of managing patients.

CONCLUSION

This study has demonstrated, for a small convenience sample at least, that there is very little shared understanding of the physical and psycho-social implications of different oral tumour-sizes, despite the available evidence. While there may be many reasons for this, such variation in views may adversely impact on the humane judgements used to inform the management of this complex and diverse disease. In consequence, it might be expected that such lack of agreement as to what is relevant may result in inconsistent decision-making unless the patient is more actively involved in the process, especially via the systematic routine use of psychometrically sound QOL measures as a means by which the patient-voice and experience can be incorporated into care-plans

CHAPTER 4

THE ROUTE TO A METHODOLOGY -THE DECISION PROCESS DESCRIBED WHEN CHOOSING Q METHODOLOGY AND A DESCRIPTION OF THE METHOD

INTRODUCTION

The research route has helped the author to describe in detail the experience of the disease and treatment for H&NC, which would not have been possible via the clinical route alone. This chapter provides a narrative to some of the author's decisions made when exploring how to investigate the experience of H&NC. It describes the stages that have accompanied the process of deciding on the best method for the study. In answering the research questions posed in the introduction to the study, the chapter refers to some of the writers who influenced the author in choosing the methodology. The last section of this chapter details the main features of Q methodology, which was chosen for this research.

USING REFLECTION TOWARDS A RESEARCH QUESTION

The author has worked with H&NC patients since 1991. This is several years before the publication of two influential national reports that described how it was envisaged cancer patients might be treated in general and in disease-specific terms (The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales, 1995, National Institute for Clinical Excellence, 2004). The clinical introduction occurred after a maxillofacial consultant asked for help with the management of a H&NC patient's swallowing during his post-operative recovery.

Oral surgery was not a typical clinical area of practice for speech therapists in the early 1990's. They were trained in the theory and practical application of patients with neurological disorders but any treatment of H&NC patients would have been restricted to patients who had undergone a laryngectomy. The focus of intervention with this patient group was on the production of oesophageal speech. It was not recognised that these patients might have swallowing difficulties or that there was the possibility of further surgery in which the patient is given a small surgical hole. This latter surgical intervention connects the oesophagus and trachea allowing lung air to drive a vibratory source and produce a sound from the oesophagus, by a valve being fitted. The author advised on the management of the patient's swallow and continued to work with this patient group as the surgeon operated on more patients. There were several factors that meant the clinical skills within the emerging MDT would flourish:

- The personal support and enthusiasm of the surgeon towards MDT working
- The mutual recognition by the team of how patients' function could be enhanced by involving different members of the team
- The inquisitiveness of the team to work with a patient-group who had been given free-flap reconstructive surgery to replace diseased tissue within the head and neck region
- Clinical practice, developing in an organic, exploratory fashion, rather than from a business-case model

At an individual level the author, with a typical neurological background, applied these learnt principles to patients who had undergone reconstructive surgery.

There was a sense that the evidenced based practice techniques, learnt from the neurological specialism, could be transferred by practice-based-learning to this patient group. There was, for the author, a reassurance in working with the patient-group that many of the principles from the neurological background could be translated so that the perceived gap in expertise was not as large as it might have

been supposed. There were very few resources available to increase the theoretical knowledge for the management of H&NC patients. Most examples of learning involved shadowing and discussion with profession-specific self-appointed experts. In 1997 Manchester Metropolitan University had established a module designed to increase therapists' expert management of H&NC patients. The lecture notes detailed reviews of papers relating to swallowing, which might be considered in the clinical environment. It is of note that very few of the speakers on the course acknowledged the use in their clinical practice of Quality of Life (QoL) questionnaires. Instead they discussed possible treatments and judged them by the mortality rates, numbers of days in hospital and physiological measures of swallows.

A year later the author attended a national conference on QoL measures in H&NC. A recognised expert in the field gathered interested clinicians to discuss this aspect of the patient-group. Research relating to the validation of key-questionnaires, the European Organisation for the Rehabilitation and Treatment of Cancer (EORTC) and the University of Washington (UoW), (Aaronson et al., 1993, Hassan and Weymuller, 1993) had been completed within the last four years. It is of note that the addition of the domains mood and anxiety, were not included in the UoW questionnaire until 2002 (Rogers et al., 2002). The conference recommended that QoL questionnaires should be used within clinical settings and suggested that this was starting. The attendance at the conference had an effect not experienced previously by the author. It had always been the author's experience that conferences informed thinking, distilled ideas and developed knowledge. The exact opposite occurred. The author had a real sense of inadequacy around the information relating to QoL questionnaires and an apprehension, as well as a

realisation, that it still felt impossible to include such detail in day-to-day clinical practice. The field of QoL was complex and the author reflected uncomfortably, but without more specific understanding, on how difficult local uptake of a questionnaires use would be. These emotions generated unease, panic and a feeling of uselessness. Temporal measures, as unsatisfactory as they seemed, would not be complemented by QoL patient-specific detail in the clinical environment in which the author worked. The practical issues surrounding their administration and interpretation were factors that were unlikely to be overcome. This aspect was established more formally when members of the UK national surgical group were canvassed (Kanas and Rogers, 2004). Their inclusion became even more of a remote possibility when the recommendations from the Calman-Hine report (The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales, 1995) were realised. It expected temporal targets to be achieved, and ensured that trusts would strive to record the number of patients treated annually in order to achieve or maintain cancer centre status (Williams et al., 2010). At this stage of health service development such pressure was appropriate, but it meant that QoL data would remain of secondary importance.

Over the next five-years the disquiet for the author remained. These feelings stemmed from an acknowledgement that what was measured was not changing the most basic-level of care. It did not explore the human aspect of the experience. The 'not fit for purpose' aspect of these questionnaires is detailed in chapter three and articulates what the author had felt for more than ten years before this study. The author had a sense that the day-to-day clinical experience of patients was not well-represented within the literature. It also seemed as though what was represented were poor reflections of what really mattered to patients. Demanding

clinical issues and organisational reconfiguration blunted the negative emotions generated by the conference. The latter aspect entailed the merger of two health-authorities. At a local level this meant a district hospital and teaching hospital, situated less than two miles apart from another, amalgamated. The consequence of such managerial changes was that the number of consultants in the H&NC unit increased and there was the establishment of more joint speciality working. The number of shared cases increased, as did the complexity of the surgery undertaken. Surgeons stopped operating as single teams, which facilitated more complex surgical procedures, without increasing the overall operating time. One of the consequences of such collaboration for the author's unit was that in 2004 there was a patient who underwent a total glossectomy -an operation advised rarely because of the predicted morbidity. The patient, TG, had a profound effect on the author's thinking. In team discussion post-operatively his surgeon admitted he would be surprised if the patient talked or swallowed again. The team questioned the benefit of the procedure for the patient and predicted that TG would:

- Not be able to communicate orally,
- Have a permanent tracheostomy,
- Not able to eat or drink, so be tube-fed because of the risk of aspiration-pneumonia

There was a belief that TG was alive but at what cost? These worries were, in reality unfounded. The patient, despite sustaining a myocardial-infarct peri-operatively, was discharged in less than three weeks. The speed of discharge was enhanced by better than expected function. The patient could drink fluids, had no tracheostomy and could communicate face-to-face orally, with a slight but evident pre-morbid black-country accent. The patient continued in outpatients to surpass the team's expectations. He talked on the 'phone, would drink socially, did not develop chest infections and returned to his favourite past-time of woodturning. He

reported he was pleased with what he could do, free from pain, and observed that he felt the team had never expected him to be functioning so well, -an insightful, accurate comment. Three factors struck the author and acted as a catalyst to investigate more completely the TG phenomenon:

- Why were the team so poor at predicting how he would function?
- Had TG shown a normal or prodigious reaction to the situation?
- Were there special features that enabled TG to be predisposed to do this well?

Discussion between the author and the surgeon suggested the possibility that the tumour, although advanced at presentation, had grown slowly and insidiously. It appeared that TG had adapted his swallow and used other complex, dynamic structures to overcome the tumour-derived symptoms. He had made adaptations so that, although the tumour had rendered his tongue immobile the flap, that replaced it, had not replaced a tongue that was functioning fully. This situation enabled the author to ask two original research questions:

- If patients were given exercises pre-surgery would they recover more quickly and beyond current expectation?
- Does pre-treatment intervention build a relationship with the patient that helps facilitate better and more targeted recovery?

It was as a desire to answer these specific issues that the author started to enquire about opportunities for post-graduate study. There started to be, through the clinical example of TG, the real questions that should be asked, but could not be answered by QoL measures.

EARLY STAGES OF RESEARCH

Initial discussion with the author's first academic tutor started to identify some of the complexity that had remained peripheral aspects of knowledge to the author. It enabled the author to understand that a randomised controlled trial (RCT), a methodology believed by the author to be the ultimate study method, would be impossible to undertake as a way of researching the aforementioned questions. Chapters one and two have explored and evidenced the situation relating to H&NC. Presentation, causes of disease, outcomes used, the extreme heterogeneity of the circumstances revealed to the author a plethora of hitherto poorly acknowledged variables. The original research question had been formulated around the hierarchy of evidence for interventions based on Sackett's framework (Sackett et al., 2000) presented in table 4.1. It had intended to achieve an RCT examining the value of pre-treatment intervention exercises. If patients carry out pre treatment tailored exercises, can length of stay be shortened?

TABLE 4.1 LEVELS OF EVIDENCE FOR INTERVENTIONS (Sackett et al., 2000)

Level	Type of study
1a	Systematic reviews of randomized controlled trials (RCTs)
1b	Individual RCTs with narrow confidence interval
2a	Systematic reviews of cohort studies. Identification of two groups (cohorts) of patients, one receives the exposure of interest, and one does not, review the cohorts prospectively for the outcome of interest
2b	Individual cohort studies and low-quality RCTs
3a	Systematic reviews of case-control studies identifying patients who have the outcome of interest and control patients without the same outcome, and looking back to see if they had the exposure of interest
3b	Case-controlled studies
4	Case series and poor-quality cohort and case control studies
5	Expert opinion

The author had had unease around how to fit the clinical experience of H&NC cancer patients within the Sackett framework, but these feelings started to subside. This was because there was a realisation that the 'gold standard' of methodologies was not suited for the question being asked -there were too many uncontrolled variables, which would interact over protracted time-intervals. The possible variables are listed below:

Age, gender, occupation, attendance at pre-treatment clinic, social circumstances, smoking, drinking, presence of a specific virus-type (human papillomavirus and Epstein Barr virus), possible co-morbidity, method of being fed (oral vs tube), site and classification of tumour, nodal status, treatment recommended (surgery +/- chemo-radio-therapy), peri-treatment complications, length of stay, patients' traits (optimism, mood, engagement, locus of control), quality of life domains, such as from the EORTC (function, symptom, global QoL score), as well as individual domains (pain, swallow, teeth, mouth-opening, dry-mouth, saliva, senses, cough, speech, feeling ill, social- contact, social-eating, pain, supplements and weight-status).

All of the variables could be measured at baseline and at an agreed post-treatment interval but this could not account for participant compliance, motivation understanding of the situation and patient-team relationship. These aspects would remain difficult to test, vague in their description and yet critical to the outcomes that might be generated. There were also further, vital quality questions:

- Would the exercises be specific enough to target specific muscle groups?
- How would the research be able to verify that a patient was managing to strengthen that particular group of muscles rather than using compensatory movement from other adjacent soft tissue, or using a different strategy, such as an airway protection?

- What effect would the relationship between the patient and the team have? Could it be that attunement by certain patients to members of the team or vice versa would influence compliance?
- Would trust, or belief in the team influence outcome?

The original questions, from the clinical experience of TG for the author, although easy to ask, and alluring in terms of value of intervention, would not be answered by using a quantitative methodology. There was also the personal aspect to the situation. There was no guarantee that patients would either carry out the exercises, or carry them out in a standardised way. The ultimate situation was accepted; too little was known about the patient-group to carry out a quantitative study. More detailed information was needed to understand the patient-group and what really affected them. There was for the author relief, rather than the previous sense of inadequacy. It now seemed possible to advance academic study with reference to this patient group without an RCT paradigm.

Discussion between the author and supervisor started to focus on the poor understanding of QoL domains. It became more apparent that the measures used were perhaps limited in their value. The author had never before considered this as a possibility. It became clearer that the QoL measures debated at conferences and which had generated numerous papers, measured pre-determined domains that might be of limited interest, or meaning to patients. There was no flexibility in their use so that individual needs, beyond the scope of the questionnaires, could not be identified. It seemed as though if the right questions could not be asked there could not possibly be answers that might be relevant clinically. Chapters two and three have illustrated that QoL measures have been used increasingly to supplement objective clinical or biological measures of disease. Despite their

increased prevalence, such measures have been shown by researchers to be limiting. A study by Bowling (1995) investigated the difference between prompt cards and free-responses, in order to investigate patients' QoL. It showed that there were discrepancies between the two stimuli and concluded that standardised measures might not capture QoL. Instead they investigate pre-determined aspects of presumed QoL and predispose the answers by the questions asked. Such a position is at odds with health care plans to create and maintain the role of expert patient. It has echoes also with the sentiments that Porter (2003,p151) expressed and which had become a powerful motivator for the author:

'The hospital was no longer primarily denounced, however, as a gateway to death but as soulless, anonymous, wasteful and inefficient medical factory, performing medicine as medicine demanded it, not as the patient needed it.'

Carr and Higginson, (2001) also had similar conclusions to Bowling. They concluded that newer, individualised approaches, rather than standardised QoL measures, should be investigated so that patients can define their QoL in relation to their goals and expectations. This would enable the goals and expectations to become more appropriate to patients in the clinical setting.

They described the limitations of QoL measures by stating that:

- Quality of life is an individual construct and measures should be sensitive to that facet;
- Many measures are not patient centred because they are not generated directly from patients and as a consequence the patients' choice is constrained to a finite set, which may not be representative for them. (Carr and Higginson, 2001)

They also concluded that such a limitation is fundamental because the measures don't gauge what makes up QoL for all patients and so the accuracy and usefulness of the measure is reduced. They suggested that it is possible to measure QoL in patient centred ways by using individualised measures but that further research is

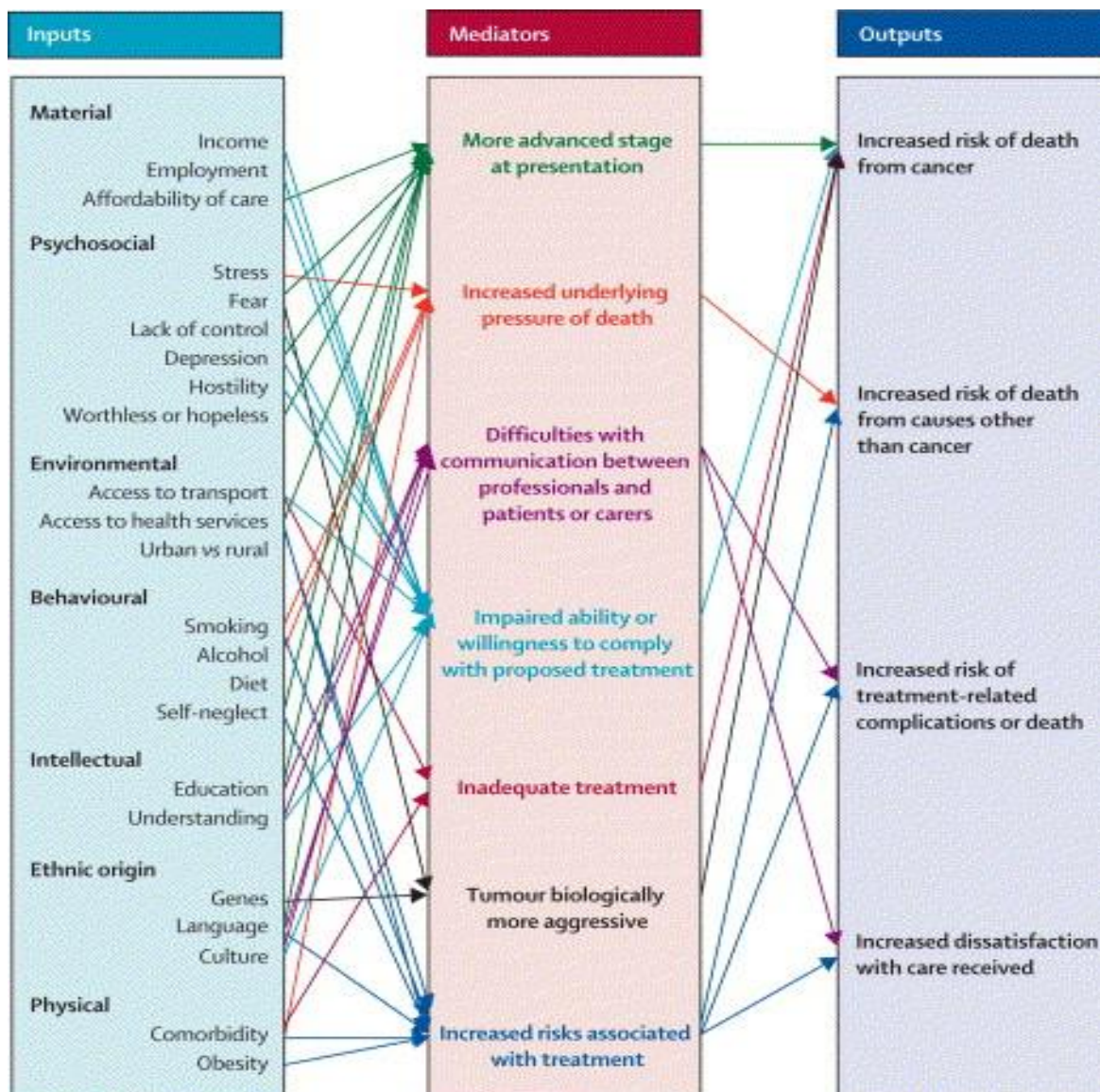
necessary. The natural extension of not implementing Carr and Higginson's recommendations is that patients' health, at an individual and collective-level, is being expressed in terms understood by health professionals or society. The danger is that they have little resemblance to what matters to patients, because it cannot be measured easily or directly. It would seem that Kennedy's (2003) assertion, detailed in chapter two, that health remains the domain of health care professionals rather than patients, is accurate and that more worryingly Porter's (2003, p151) description of hospitals as inefficient medical-factories is perpetuated.

RESEARCH IN THE CLINICAL ENVIRONMENT

To try and counterbalance such challenging commentaries research has to be as inclusive as possible of the real clinical situation. Any investigation that explores the experience of a disease and its treatment should be set in the context of modern health care. It cannot be sanitised; all of the evident features should remain rather than be controlled. Munro,(2005b), an oncologist and academic, has described his frustrations around epidemiological research, which seem to have parallels with the current situation. He suggested in a commentary, 'Why do we know so much but do so little?' that there are tensions between epidemiological and clinical research. He observed that epidemiological and clinical researchers are diametrically opposed. The former uses large numbers of patients, with inclusion criteria and controls for an explicitly identified group of variables that are being tested. The latter uses too few patients, selected with too much clinical detail, from an inherently biased group. In his view the result is that epidemiological conclusions can be viewed as 'robust but vague' and clinical ones as 'precise but flimsy'. This makes it difficult for either party to see the merit in the other's results. Munro (2005) has developed this issue further within a commentary in order to illustrate the

complexities that are very real in clinical practice (Figure 4.1). This is because humans are complex and remain so as patients, both in terms of possible co-morbidities and their reaction to their current illness.

FIGURE 4.1 MODEL OF HOW SOCIO-DEMOGRAPHIC FACTORS (INPUTS) CAN BE MEDIATED TO BECOME POOR OUTCOMES (OUTPUTS) (Munro 2005,P915)



Munro was able to be more specific with his description of function.

Epidemiologists focused on the inputs and outputs whilst clinicians focused on the mediating factors and output. He made the point that there is no linear relationship with input to output and these will vary from patient to patient. It is also reasonable to suggest that some of the input factors may vary over time, as well as be influenced by long-term, yet fluctuating states, such as stress and depression. Such a situation is not going to be investigated satisfactorily using a method that hopes to isolate variables and manipulate them.

He provides a clinical example from within oncology that emphasises the problem further (2005, p193)

“Increased risks associated with treatment” which may be affected by two possible variables:

- Low income, patients have no access to private transport to the treatment centre;
- Poor literacy, patients fail to understand the importance of some of the possible side effects.

The situation is further complicated because patients might fail to appreciate the real implications of symptoms as a consequence of denial, fear, or no motivation to read written information. Such a patient may become at greater risk of an infection due to neutropenia (a possible side-effect of the chemotherapy treatment, low white cell count making the patient susceptible to infection) whilst having their treatment. In its most serious presentation this would mean that unless the health care team can treat the acute infection the patient's recommended treatment cannot be completed. They have in effect failed to tolerate the optimal, advised treatment regime based on factors beyond

those of the disease classification. Such detail, almost without exception, will be overlooked by the epidemiological approach. The result in clinical terms would be, no matter how effective, it is unsuccessful if the patient is unable to comply with the treatment. More meaningfully, the consequence is a missed opportunity to obtain a better understanding of how patients might best be enabled to receive their advised treatment. Munro argues powerfully that it is not sufficient to understand and describe factors; instead there should be a responsive change in the clinical practice that enables the real impact of patients' poor resources to be identified and quantified. These patients should not be excluded from the final study results because they do not complete the treatment. They might represent a significant aspect of the clinical reality. Through such scrutiny, he suggests that clinicians should develop an awareness to both the problems experienced by patients as well as the possible inequalities of healthcare; once identified they should be acted upon. He recommends that there should be a way of mediating the robustness of epidemiological studies with the perceived vagueness of clinical studies. Reflecting upon this in the context of the holistic needs assessment discussed in chapter two, health-policy has begun to be influenced by indifferent or poor outcome. It has started to try and describe the well being of patients rather than remaining with the more absolute outcomes of survival or QoL measures. Munro does not align himself to the hierarchy of evidence framework that Sackett et al (2000) presented. Instead, he suggests that RCTs have had their value and we are on the edge of change. There is the possibility that other methodologies, more suited to be health-care, can be utilised. From a historical

perspective he has suggested that RCTs can no longer be used to address clinical issues. He proposes instead that studies should seek to encapsulate a world of personalised medicine in which variables are included rather than disregarded. Such a situation requires meticulous observation of a patient, and the accumulation of data to establish the optimal management. He asserted that this would move research away from the accruing of more subjects in clinical trials, where enough numbers would mean that eventually a significant-factor could be established. He has recommended that clinical-medicine has to be rooted to the individual human, allowing the power of science to be represented in a humane way in clinical practice. This end-point might be seen as the purpose and reasoning for mixed methodology and allows for clinical judgement and decision-making.

Whilst Munro (2005) discusses his thoughts within the epidemiological and clinical research paradigms, the same framework could be applied to quantitative and qualitative research. Deductive researchers perceive the subjective aspects of qualitative work as being so vague as to have little if any specific-value for large patient-groups. The reality is, however, that patients, many of whom by social circumstance and or diagnosis are vulnerable and will depend upon their clinicians' expertise in delivering the optimal treatment. Clinicians are having to apply aspects of both the technical and humane judgement in order to reach a clinical decision (Downie and Macnaughton, 2000) a point fully discussed in the introduction of the pilot-study paper in chapter three. The treatment that they have may possess only a passing

resemblance to the theoretical models devised as ways to explain complex phenomena. The result is a situation where, for the sake of best methodology, the individuality that might be so valuable to explore is left out in order that statistical rigor can be satisfied. Can such a circumstance really be seen to represent evidenced based medicine or are there so many exceptions and addendums to be included, that the research is still in danger of being a personal -reflection of a clinician? In Sackett's terms (2000) this would mean poor methodological rigor. Clinicians are likely to remain wary about how to generalise the research published into their clinical practice, whilst researchers will be equally frustrated by what they perceive as poor research design and the vague results generated by studies that are poorly constructed.

What Munro (2005) discussed has resonance with the current study.

Deductive research is a dominant methodology within H&NC. Many research papers that investigate H&NC use an experimental design. The studies, whether reviews, pooled data, or directly generated data, conclude, all too frequently, with the recommendation that there should be better-designed studies or that further research is needed in order to substantiate preliminary findings (Ramroth et al., 2011, Rudolph et al., 2011). Such conclusions are made in order to rally researchers and clinicians alike, the implication being that the methodology chosen is correct and just needs more statistical validation.

The sense is that if only the methodology could have more refinement, a succinct, meaningful correlation will be discovered. This may be too naïve a stance, or one that in vain chooses to reduce patient-complexity to variables that are controlled superficially. The conclusion that should be reached is that

the scrutinised topic is never likely to be answered satisfactorily through such investigations because of the numerous variables or protracted treatment times that are inherent, and are, as yet, either invisible or understood only vaguely. This is not to suggest that the sense of the complexity is wholly overlooked, rather that there is an acceptance within reductionist studies that the variables are complex. The paper by Rudolph et al (2011) concluded that they have awareness that the life-style, genetics and nutritional factors remain uncertain when survival factors are being considered. The covert message of such a conclusion is perpetuated, that despite the complexity of the topic, the aim of further research should be to isolate and control the variables, rather than to acknowledge that perhaps the methodology chosen is unlikely to achieve an answer that is meaningful.

The struggle for both clinicians and researchers is to work through how close to the real clinical situation the study has been, and whether the chosen reductionist methodology has any merits. Salander (2011b) suggests, in similar ways to Munro (2005), that within the field of psycho-oncology there is the need to use quasi-experimental design instead of experimental methodology. It would seem possible that within the field of H&NC there is a requirement to use more of an observational, inquisitive and exploratory approach. It should not be that patients' own subjective-view is of little interest because of what Salander termed "methodological narrow-mindedness" (Salander, 2011a). He stated, just as Munro (2005) had concluded, that RCTs should not be seen as the only method of enquiry when studying patients with cancer. He recognised that

patients will have multiple motives and desires (which also may change during treatment). The conclusion he made was that RCTs should be complemented with other research designs, quasi-experimental, interview studies, to ensure that we not only get to know *if* but also *how* something was helpful.

The deductive approach, which includes quantitative methods is well suited to certain experimental situations, but becomes more questionable in multi-factorial, complex and protracted interventions. Answering the 'how' aspect of a research question might need a different approach. Brown et al (2003) stated that the quantitative methodology has been acknowledged as the only truly acceptable way of generating research of sufficient quality to inform clinical practice. However, they described some of the limitations, such as results being presented in a numerical format, which might have very little meaning to the topic under investigation. The ramifications they suggested were that it selects both the questions asked and the way answers are represented. This would mean that if a possible effect cannot be isolated and manipulated, the topic couldn't be explored. From Brown et al's (2003) perspective this means that:

“The search for improved care doesn't begin and end with the randomised controlled trial but instead there can be a recognition of the limitations of this approach and the value of alternatives.” (P86).

It had now become possible for the author to understand and state that the aspect of care being scrutinised by the current thesis, could be addressed by a qualitative method. Patients have to continue their existence beyond their questionnaire filling and there might therefore be real meaning and benefit from capturing observational data. If this could happen there might be a greater understanding of the real impact of H&NC. Perhaps descriptors do not need to

be reduced to an overall survival statistic. Such representations limit data to numerical outcomes - QoL scores pre, peri and post-treatment. Academic clinicians such as Munro (2005) and Salender (2011b) have described the limitations of the RCT methodology in the clinical setting.

Whilst this might be so, it is possible that in a specialty where temporal-data is so dominant it is not likely that qualitative, descriptive approaches will be encouraged. Yet it is not possible, or appropriate, to test a hypothesis because too little is truly understood about the topic. The variables identified from patients, their disease, proposed treatment and individual organisations need to be observed through a longer lens.

CONSIDERING OTHER METHODS THAT ARE NOT QUANTITATIVE

In reviewing other possible methods it was appropriate for the author to consider the use of qualitative methods. There are some attributes of qualitative analysis that might be better at investigating the experience of H&NC. Cousin (2009) described the purpose of the method for research:

- Get at complex meaning from research text or visual data,
- Interpret human behaviour and experiences beyond their surface appearances
- Provide vivid illuminative and substantive evidence of those behaviours and experiences
- Build theory inductively from qualitative data sources.

The result, she suggests, is that the texts explore the information and are able to generate “rich depictions of research settings” (P31). It would have been

possible to consider one of several qualitative approaches when exploring the experience of H&NC, presented in table 4.2.

TABLE 4.2 QUALITATIVE RESEARCH APPROACHES

Type of research	Brief description
Grounded Theory	Unearths the social processes in the subject investigated
Ethnography	Explores a culture, or understanding of a human behaviour
Phenomenology	Unearths the meaning of a situation for an individual
Discourse Analysis	Scrutiny of language in a context of total communication situation so that all aspects of the communication are included.

In reviewing these different qualitative techniques Grounded theory, or a phenomenological approach, would both have been possible methods for the current study. However, there has always been a sense that the author needed to have a level of objectiveness influencing the results, because of having such a close identification with the topic. The author has worked within an acute medical setting for more than twenty years. This aspect of the research situation, although in many ways useful at the interpretation-stage of data, could bring bias if the method relies extensively on interpretation of the results by the author. To counteract this possibility it would seem reasonable that there should be some statistical rigor that supports qualitative data in order to understand objectively what the true meaning for H&NC patients is. It is also of note that the surgical, oncology arena expects results to be presented in terms of statistical significance. Any data derived from the patient-group is likely to be more easily interpreted and accepted if there is a statistical method through

which data can be described. A mixed methodology, which uses both statistics and descriptions, could compliment the gaps that might be levelled at either methodology if it was used on its own. Cresswell and Plano-Clark (2007) have described a mixed-methodology as one that includes both qualitative and quantitative aspects of research. They commented that its use would suggest that the researcher has judged that the topic being investigated is best explored by integrating elements from both methodologies to enhance the results. The results will include both statistical and verbal descriptions.

It is to be hoped that at this stage in the thesis the reader can be drawn to a point from which two premises can be stated with insight into the rationale:

- (i) There is not enough known about the experience of H&NC to use a deductive approach;
- (ii) Discovery, rather than testing reasoning, is a suitable stage of enquiry for the exploration of a patient's experience of H&NC and its treatment.

It is therefore suitable to introduce the methodology chosen for the study by defining and describing it in detail. The methodology chosen was Q methodology.

A DESCRIPTION OF Q-METHODOLOGY

Q-Methodology is an exploratory technique, viewed as a way of bringing a sense of coherence to research questions that have many complex and answers that are contested socially (Watts and Stenner, 2005). It has also been described as a way of analysing text in order to find underlying subjective meanings (Webler et al., 2009a). Q intends to look for holistic patterns that

researchers can classify as viewpoints, perspectives, or narratives (Lazard, 2003). The methodology is able to study, in a systematic fashion, subjective experiences and is regarded as combining the richness of qualitative protocols with the rigors of quantitative ones (Akhtar-Danesh et al., 2008).

SPECIFIC Q-METHODOLOGY TERMS.

Q-methodology has a specific vocabulary used to describe the stages of the method. The total process involves distinct and step-wise stages. Table 4.3 describes the terms and presents them in the order that they are carried out.

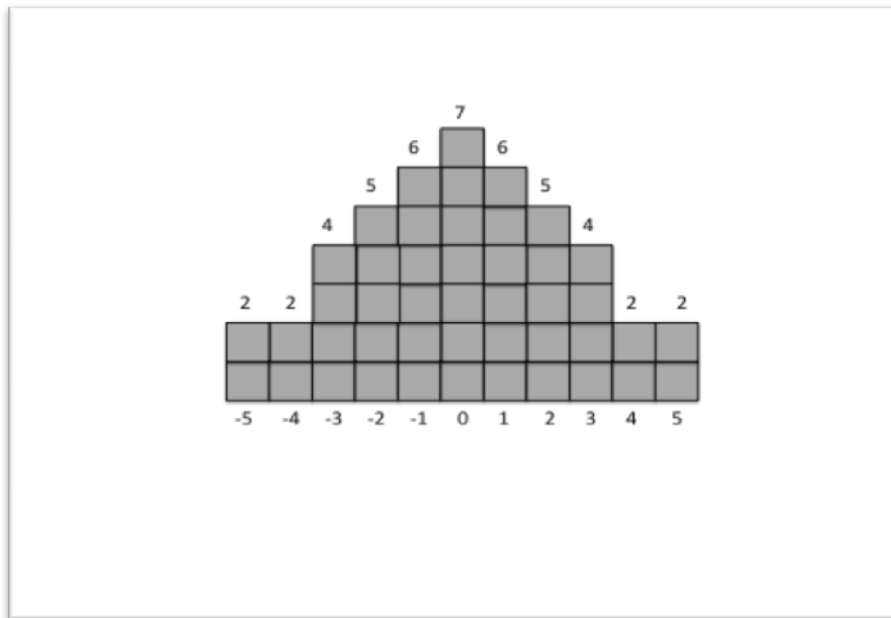
TABLE 4.3 Q-METHODOLOGY TERMS, STAGES AND DEFINITIONS

Q methodology term	Q methodology stage	Definition
Identify and create the concourse	1&2	Contains all the relevant aspects of the topic from numerous sources and is created from a large list of statements
Development of Q sample	3	A reduction of the concourse statements, which will have clear meaning and not be repetitious
Q sort P set	4	Participants rank the statements Group of participants who complete the Q sort
Analysis	5	Computer programme and interview transcription analysis help to form the significant factors

The first two stages are the development and establishment of the concourse - a group of single pieces of thoughts or descriptions, which can be represented by unambiguous phrases. Stage 3 refines the phrases to the final Q sample,

whilst Stage 4 entails these phrases being sorted by a group of participants into a forced distribution curve, represented by a grid.

FIGURE 4.2 Q-METHODOLOGY GRID – STATEMENTS ARE SORTED ONTO AN ALLOCATED SPACE ON THE GRID.



The completed grid is discussed in order so that the placement of the statements in relation to one another can have the subjective and specific perspective for each participant. The fifth and final stage involves each Q-set being analysed; more recently researchers have completed this stage by using a purpose-built software programme, PQ Method (Schmolck, 2002). The distinct viewpoints are created and become known as factors, which are seen as representative of a view. The researcher, with knowledge of the field under investigation and the specific factor distributions, reviews the Q sets for the meanings that they might represent. No particular statement is as important as the complete Q-set statements, although they are constituent-parts are interpreted in the context of all of the others (Webler et al., 2009a).

THE MAIN DIFFERENCES BETWEEN R-METHOD AND Q-METHOD

The Q-method analyses text-based statements in order to determine underlying patterns or meaning (Webler et al., 2009a). As part of the process individuals are clustered, based on how they describe themselves, so that a pre-determined set of statements is investigated for correlations. There is debate as to how Q- methodology might be classified, which means that either proponent of more conventional methodologies can marginalise it. Lazard (2003) appears somewhat irritated by this attitude and suggested that Q- methodology has a shared-focus on both subjectivity, and hypothetico-deductivism.

In chapter two the main outcome descriptors used in H&NC have been described. In quantitative research, respondents are subjects and questions or measures are the variables. Patterns are therefore sought across a range of variables or from a single one for each participant. A hypothesis is cited and tested, for example: 'all patients who have oral tongue cancer have more pain than tumours at other sites'. Traditional factor analysis would explore a group of H&NC patients by describing them through a number of pre-determined tests, measures, or questionnaires. These would aim to classify pain and subject it to factor analysis. Q Methodology inverts the factor analysis so that a specific number of pre-determined statements (tests) are ranked by a number of selected individuals (Watts, 2012). It is the statements rather than the participants that are tested. In the context of Q- methodology the hypothesis set regarding pain would be regarded as too specific. The premise that pain, rather than other symptoms or attitudes, should be singled out, as the specific

factor to be tested would be challenged. Instead it is proposed that the participants need to be given the opportunity to express what *they* consider to be the key-issues rather than what *others* assume. Q methodology therefore would not presuppose that pain is the dominant feature and would collect many of the antecedents or values a patient might have that influence ongoing acute-on-chronic oral pain. Table 4.4 depicts the differences between the two methods. This would seem to be an attempt at describing individualised patient aspects of the disease aspiring to Carr and Higginson's (2001) aspirations and the health documents described in chapter two that seek to discover outcomes beyond patient safety and quality of care.

Table 4.4

**THE MAIN METHODOLOGICAL DIFFERENCES BETWEEN THE
REDUCTIONIST R METHOD APPROACH AND Q METHOD BASED ON
WORK BY WEBLER ET AL (2009a).**

Descriptor	R Method	Q Method
Hypothesis	State a prediction relating to the result that needs testing	Do not predict what meaning might be uncovered as a result of the study
Variable	Survey question	Q sort done by a Q participant who represent different aspects of the topic
Subject Population	Respondent All possible respondents / participants	Q statement Concourse (all possible Q statements)
Goal	Find patterns in how respondents answered different questions	Find patterns in where Q statements appear in different Q sorts knowing that the pattern will not be unique to one person
Factor Analysis	Normal	Inverted, participants not the tests that load onto the factors

Example using each type of methodology:

R methodology question:

Do people with tongue cancer report more pain than other head and neck sites?

Results presented as:

Percentage of population with tongue cancer who perceive their pain to be worse than other cancer sites of the head and neck.

Q methodology question:

What is the experience of pain for patients with H&NC?

Results presented as:

A finite and distinct set of factors will be created which define key-themes for patients that describe how they have experienced pain over the course of their disease and treatment. These are only meaningful in the context of the other statements. An exemplifying Q-sort represents each factor. The results produced are described as factors, which are a range of reports that can be formulated from the individual sorts of participants. A specific trait, gender, age, or type of treatment undergone, will not form the basis of the results revealed but there will be a grouping of participants based on their opinions. This is a fundamental aspect of Q; the researcher is not looking for specific attributes of participants but for their shared opinion.

Subjectivity, in Q-methodology terms, represents a person's communication of their point of view. It is the person's internal frame of reference that becomes

expressed by the ordering of the statements. The result of the Q Sort is the representation of human perception from a personal perspective (Brown, 1993). Such an aspiration is very much sought after in the current context of health care; the views and experiences of patients are seen as central to health care provision. Carr and Higginson (2001) have recommended the individual nature of this experience a point discussed earlier in this chapter, which might be seen to be satisfied by the use of this method. Patients may have a mechanism through which they can describe, in personal ways, the real meaning of a topic. This methodology seeks to keep the sorts as an entity and does not aim to reduce or segment them. It will remain multi-faceted and will never be summarised in numerical terms without the support of text, generated from the individual participants. The text is able to add clarity to the specific statements, and can act as a way of illustrating a point of view. It might be described, therefore, as both a qualitative and quantitative methodology. Hence it is portrayed as mixed-methodology.

The quantitative aspect of the methodology establishes, through inverted factor-analysis, the patterns from a subjective perspective held by the participants. It is the configuration of a finite list of statements presented to participants that are correlated and factor analysed (Brown, 1993). The factor analysis moves from correlation between variables or tests towards correlation between people. The procedure is an inverted factor-analysis; it is the participants rather than test results that load onto the emerging factors. Brown (1993), has detailed the differences that Stephenson saw between the two methods in his historical perspective of the methodology:

“Stephenson referred to R methodology as "a selected population of “n” individuals each of whom has been measured in “m” tests" (note the passive verb has been measured), and Q methodology referred to "a population of “n” different tests (or essays, pictures, traits or other measurable material)”, each of which is measured or scaled by “m” individuals”.

Through the method, Stephenson has created holistic data (Watts, 2012). The individual creates actively this data. However, there is a finite number of distinct viewpoints on any specific topic. The Q sample, (the statements used to explore the topic) contain a wide range of opinions, the resulting Q-sorts will disclose the perspectives (Brown, 1980). A large and representative sample is not needed, because it is *perspectives*, not the *participants* that are being analysed (Brown, 1993, Stainton-Rogers, 1995, Webler et al., 2009b, Webler et al., 2009a).

WHAT THE RESULTS LOOK LIKE AND HOW THEY CAN BE USED

The beginning of the analysis will translate each of the statements that have been sorted by the participants into a numerical value. In this specific study the extreme opinions have a score of +5 or -5. The numbers work back towards the middle so that a zero-point represents ambivalence. Each participant’s sort is inter-correlated with all of the others in the study. A correlation-matrix -a series of “m” variables is presented variable-by-variable in a grid, which can be reviewed by the participant when the sort has been completed (Watts, 2012). For a specific study, participants will have an opportunity to sort statements, which might mean that they sort in very similar ways. These correlation-matrices are then subjected to factor analysis, which are data arrays that are

highly correlated to one another. There are now, from a results perspective, factors that are an indication of how like a particular factor a participant is. If the participant has a factor score of 0.8 they would be judged to have a high and representative array of the factor. This would suggest because a score of 1.0 is an exact replica of the factor, that the subject is expressing eighty percent of the factor discovered. The participant becomes an exemplar of the factor.

Weighted-average scores for each statement within each factor are also obtained. For each statement there is an understanding as to where the statement for this factor would fit. A composite opinion of the topic investigated is represented by each of the factors that have been discovered. This means that each statement has a typical number relating to the forced-distribution matrix. The qualitative part of the study compliments the factor revealed. This part consists of a narrative being written for each, which uses as its source the quotations from the participants who load most closely onto that factor. The commentaries, therefore, are a way of substantiating the Q sorts with phrases that are powerful.

THE PURPOSE AND VALUE OF THE APPROACH TO HEALTH-CARE AND RESEARCH BY USING Q METHODOLOGY

The purpose of Q-methodology is to describe views via a population of viewpoints and not describe a population of people (Risdon et al., 2003). It is likely to be at the inception of a topic being investigated that it is used because it is a way of establishing what hypotheses could be posed at a later stage. The intention of this more preliminary method is to define perspectives, before conducting a survey to measure the frequency of occurrence of those perspectives in a population (Webler et al., 2009a). It makes the assumption that not enough is understood about the topic to isolate particular variables. This method in the current thinking of health care delivery, might satisfy the need to accommodate what matters to patients as noted by the King's Fund and King's College report (2012). It would mean that professionals are able to accommodate, and even change practice, based on patients' perspectives. Q methodology does not try and estimate population statistics, it intends to sample the range and diversity of views expressed and will at no point represent the number of participants who express these claims in a percentage value (Cross, 2005). This in effect means that participants who might have a marginal view or one that is not expressed because of statistical cut-off points is acknowledged as a perspective from the investigation. The value of the methodology is to uncover and represent opinion clusters; it does not intend to make generalised statements beyond the participant group. There is however an intention to discover opinions and clusters within the sample (Webler et al., 2009a). Q methodology has been used within social-sciences and more recently has been

applied to different aspects of health which are multi-factorial and are systematically studying viewpoints:

- patients' understanding of irritable bowel (Stenner et al., 2000)
- Chronic pain (Risdon et al., 2003)
- Patients' viewpoints about health and rehabilitation (Ockander and Timpka, 2005)
- Post-natal symptoms (Herron-Marx et al., 2007)
- Adolescent experience of fatigue during chemotherapy (Lai et al., 2007)
- Attitudes of H&NC patients to alternative methods of feeding and in particular gastrostomy (Merrick, 2012)

The technique offsets many of the methodological problems faced by patients when attempting to reflect upon their own personal experiences because the technique requires the participants to consider individually a range of statements within the context of one another so that a large range of views and experiences are represented by a small group of participants.

The validity of a Q study is established by reviewing the literature on a topic and domain experts reviewing the statements. A pilot-study to verify that the statements are clear and do not have repeated redundant themes should be carried-out.

Reliability of the methodology has been established by examining the test re-test on specific individuals. It has been suggested by Webler et al (2009), that Q methodology is not a good medium through which to represent very dynamic processes because the intention would be that it represents a viewpoint that could be further qualified with each group of participants that present with each specific factor array. The topic under investigation that is depicted by the statements becomes the subject of a factor analysis. Q allows significance to

be associated with the meanings that are discovered (Webler et al., 2009a). There are a finite number of perspectives, but the likelihood of these being produced by chance rather than thought and opinion about the topic is infinitesimally small (Brown, 1993).

ADVANTAGES OF Q METHODOLOGY

Q sorting does require greater involvement by participants than standard questionnaire completion, but it can be broken down into stages so that the whole process does not seem overwhelming. It may be seen as a process that engages the participant in thinking through the topic; it requires them to link each statement in some way to others around them and so is not subject to impulsive poor reasoning skills that questionnaires are vulnerable to.

Participants have to consider their responses more carefully and the intention is that this brings out their true feelings. The statements that represent the Q sort will have been generated, at least in part, from relevant literature but as the participant sorts the cards they bring to the Q-set their specific interpretation.

It is also envisaged that the participant will understand the Q-set because it represents their personal view of the situation. The onus is on the researcher to check-back that the Q set is representative of the participant's particular view.

Webler et al (2009) suggested that an advantage of the Q has over other forms of discourse analysis is that the participants' responses can be compared directly in a consistent manner. All the participants are reading and reacting to the same set of Q statements. This is not the case in other kinds of qualitative

discourse analysis. Other forms of discourse analysis depend on the communication skills of the subjects, which for this patient-population is likely to be compromised. This means that patients who are less likely to be approached because of their reduced oral communication skills are not going to be represented. It is viewed as aspirational to maintain a holistic approach to investigations. The dual quality of both quantitative and qualitative results is also important in the field of H&NC. Clinicians relate to definitive results, which will be expressed with statistical rigor. The presentation of results in such a way ensures that the technique is more acceptable in epistemological terms to the clinicians it might seek to influence.

Q method allows participants' response to be compared in a consistent manner because each participant is exposed to the same Q set; there is some control and thoroughness of the topics covered within the Q set. Another advantage is that unlike surveys and questionnaires in which the investigator imposes the responses, Q determines the categories that are operant (Stainton-Rogers, 1995). The objective of Q methodology is to describe different perspectives, not to achieve a high volume of participants who load onto each of the factors. It is therefore the representation of the different views that is important not the proportion of participants who adhere to the factor. This means that the number of participants in the study can be small (Stainton-Rogers, 1995). It is recommended that the sample size should remain small deliberately, because it should not be that the quantity of participants prevents the detail from the Q sorts and the interviews from being recognised (Webler et al., 2009a).

DISADVANTAGES OF Q-METHODOLOGY

There are several disadvantages to the methodology. These are mainly rooted in the time intensive nature of the process and the vague description of how a Q sample might be created. These two aspects are interrelated, because it is the formation of the Q sample that is likely to take the greater amount of time. It is critical that this part of the method can create a Q set that has been sourced from a range of information about the topic under investigation. Watts and Stenner (2012) suggested that the ultimate Q set will be representative and seamless in its coverage in order to create a balanced Q set. It is not implied that balanced means the Q-set is represented equally by positive and negative statements. It must not be value laden towards one aspect of the topic only. If this were the case it would cease to be representative. A participant, on completion of a Q set, should have a sense that that they have not been restricted in their response so that a whole aspect of the topic has been left unrepresented. If this were the case the participants will not have been able to express their viewpoint. It would be expected, however, that this shortfall would be highlighted within the interview after the Q set at the pilot stage of the research. It would at this point, be possible to review the statements in order to achieve a more representative Q set.

The method used to generate the Q sample has not been well described and is open to individual's preference. Its development is open to interpretation, which might make it difficult for researchers to replicate a study. To counteract the criticism of vague process, Attride-Stirling's method of categorising text for a Q sort (Attride-Stirling, 2001) has been used in this study. The time spent on

creating the concourse should mean that it is representative of the study topic. There should be meticulous and thoughtful sampling in order to achieve a Q sample that will allow the participants to represent a complete account of the topic under discussion. There is a danger that bias is present from the concourse, but it has been suggested that this can be reduced if the Q set includes direct quotes from the participants used to construct the concourse (Robbins and Krueger, 2000). The statements also need to be as transparent as possible so that they are not vague in their meaning for participants (Webler et al., 2009a).

The selection of the Q sample statements is not the only possible area of bias. The other possible arena into which bias can be introduced is the data analysis field because the factor solution and commentary are value judgements, made by the researcher. This difficulty can be to some extent negated because the results are transparent and can be reviewed by the participant and readers of the area of research explored (Webler et al., 2009a).

There is a question over the reliability of responses because this presupposes that attitudes or experiences are likely to remain the same over a year. There is no expectation by researchers who use Q- methodology that the respondent should express the same view on separate occasions. It is thought however, that the study scenario should be one that would be described as having stability, and not one that is likely to alter radically over-time. There has been no longitudinal use of the methodology and it is seen as a way of capturing data at one point in time from an individual (Brown, 1993) rather than at several predetermined intervals.

SUMMARY

This chapter has described the author's first clinical encounters with the H&NC patient population. It has also described how through powerful, clinical examples the accepted ways of describing the possible outcomes were perceived as poor representations of the patients. The lack of clarity and relevance to the clinical situation motivated the author to seek further investigation of the topic through a formal research route. This was brought into more focus after it was realised that QoL questionnaires would not be brought routinely into the author's clinical setting. It had also been the author's expectation that a quantitative study would be used to investigate the experience. However, reflection and learning about possible methodologies were able to guide the author towards a mixed-methodology, and in particular Q-methodology. The methodology has been explained in broad-terms and its potential use within the health care context. There is a particular appeal within the context of health policy because of its stance on remaining holistic rather than becoming too focussed or fragmented. The next chapter will describe more specifically the methods and results for the current study and it will seek to explore the experience of head and neck cancer patients from diagnosis through treatment.

CHAPTER 5

A Q METHODOLOGY STUDY TO EXPLORE THE EXPERIENCE OF PATIENTS DIAGNOSED AND TREATED FOR HEAD AND NECK CANCER

INTRODUCTION

This chapter describes the specific method and results used to investigate the experience of H&NC using Q methodology. Q-has five steps in its process:

- Step 1:** Establish and identify the concourse
- Step 2:** Create a Q sample- a reduced number of statements from the concourse, which remains representative of the concourse
- Step 3:** Rank the statements via a likert-scale on a forced-distribution-grid and engage the participants in a semi-structured interview to discuss the placement of the statements in order to help interpret the placement of the statements
- Step 4:** Analyse the Q Sort data, which will produce a number of discrete factors (viewpoints) through the use of a computer programme
- Step 5:** Interpretation of the factors by reviewing the statements' placements and using the participants' semi-structured interviews understand the rationale for the placement of the statements

Step1 Identify and create the concourse, which has been described in chapter three (pages 83-10) following an approach devised by Attride-Stirling (2001).

The concourse to represent the experience of H&NC was created by the triangulation of representative information from three sources, which were:

- The three most commonly used Quality of Life (QoL) questionnaires in the research literature
- A literature review of the topic Experience and H&NC
- Six semi-structured patient interviews

The hierarchy of themes, devised by Attride-Stirling (2001), entails the development from basic, to organising to global themes. The figures in chapter 3 (3.1-3.6 pages 87-98) are diagrammatic representations of the concourse

established and depict the hierarchy of the six global themes which are listed

as:

1. Day to day physical comfort
2. Emotional well being
3. Place in society
4. Own mortality
5. Quality of care
6. Reality

The concourse created has used a range of different sources in order to be representative of the subject (Brown, 1993). This chapter describes, steps two to five of the Q methodology study that investigated the experience of H&NC from diagnosis up to a year post treatment.

METHOD

STEP 2 CREATION OF THE Q SAMPLE

An analysis of the six participant interviews conducted at the stage of the development of the concourse generated more than 120 statements, which could be judged as representative of the concourse relating to the experience of H&NC. These statements are verbatim from participants and could each be categorised under the six global themes. They were reduced to a final list of 45 by reviewing how representative and salient they were of the themes and the issues within them (Watts, 2012). The statements chosen were reviewed by another member of the research team (DF) for clarity, and thoroughness for the topic. From global theme three 'place in society', the comment, "I have to accept I can't have a good row, it's easier just to stay quiet" became "I cannot

have a good argument now". One statement is able to represent an idea as a stand alone entity. The Q-methodology literature suggests that there should be an attempt to be as inclusive as possible about the topic, but the specific balance of the statements is not particularly important, because each participant will derive this at the time of the Q sort (Brown, 1993). The aim of a Q set is to be as inclusive as possible across themes from original sources to the research question, and be broadly representative of the issues (Watts and Stenner, 2012). In this study therefore the three sources used had been the quality of life questionnaires, the literature review and the semi structured interviews. These had created the six global themes that would now be represented through the Q set. There is a sense that the Q set does not limit the participants in their views and should not have repetitions of ideas. The number of items generated will be large initially these are then refined and reduced as the statements are reviewed for having a single perspective and not having technical or specific jargon. The author, with input from another member of the supervisory team (DF) was able to develop a Q set that was broad, unambiguous with no omissions as well as ensuring that there was no duplication of aspects within themes. The reduction of the statements is shown for the global theme Reality in Appendix 5.1. The number of statements chosen was not arbitrary and refers to work carried out by Webler et al (2009), in which a ratio of statements to minimum number of participants for the study, is calculated.

This paper recommends a ratio of statements to participants of three to one:

- 30 statements need to be used for 10 participants
- 36 statements need to be used for 12 participants
- 42 statements need to be used for 14 participants
- 45 statements need to be used for 15 participants

The statements presented below were judged representative of the six themes and form the Q sample for the study.

FIGURE 5.1

45 REPRESENTATIVE STATEMENTS OF THE EXPERIENCE OF H&NC

- 1. Physical symptoms: day-to-day comfort (8)**
 1. I recovered much slower physically than I expected
 2. I am still in pain
 3. It's hard to remember things you're told
 4. I felt physically very isolated
 5. When I talk it doesn't feel like me anymore
 6. I always think that people are staring at me
 7. Any symptom I get I always think the cancer might be back
 8. Day-to-day existence is physically exhaustin
- 2. Place In Society (7)**
 1. I felt very alone
 2. I didn't want people to know what had happened to me
 3. Everyone around me was so upset
 4. I still don't think anyone can really understand what has happened to me
 5. I cannot have a good argument now
 6. I never think of myself as ill
 7. I do things but on my terms
- 3. Own mortality (7)**
 1. Being cured of the cancer is still the most important thing
 2. It's just as well you don't know what's going to happen or you would never cope
 3. It's very hard to think about your own possible death
 4. You never think it could happen to you
 5. Once I knew they could do something about it that's all I needed to know
 6. You just become really grateful for different things
 7. Life is hard you just have to get on with it

4. Quality of care (8)

1. I didn't understand what was meant by the treatment until I experienced it
2. I felt very vulnerable when I was in hospital
3. Little things like the car park or appointments being cancelled really irritate me
4. I never felt like a number I was always treated as an individual
5. I was most frightened when I came out of hospital
6. I wanted the team always to be honest with me
7. I never read the written information I was given.
8. No two patients are the same

5. Reality (5)

1. You should never have to face this sort of thing on your own
2. If you didn't want to die there was no choice but to have the treatment
3. It's so hard waiting to heal
4. I have to be careful to not upset people
5. I'll talk about things that I wouldn't have done before my diagnosis

6. Emotional well-being (10)

1. I worried a lot how others would cope
2. When I was told I had the cancer I knew I had to face it.
3. I wish I'd never been treated
4. My appearance was much better than I expected
5. I am much more irritable than I used to be
6. I cannot do things on the spur of the moment.
7. It really affected my confidence
8. It's amazing how much you can adjust to all the physical changes
9. Life will never be the same again
10. I never appreciated how long it would take to get better

The statements were printed onto small flash cards that were laminated and assigned a number randomly so that each theme did not have sequential numbering. This Q set is reproduced in Appendix 5.2. The set was tested initially on two participants to assess the transparency of the statements and the ease of the actual process. Both participants felt that the statements were easy

to understand and felt that they could be described as representing possible aspects of the experience.

STEP 3 THE Q SORT

SELECTION OF PARTICIPANTS FOR THE Q SORT

Q-methodology, as described in chapter 4, is an inversion of R methodological research techniques. The reality of this is that the 45 items in the Q set are the study sample and the participants are the variables. The aim is to avoid a homogenous group of participants. Brown (1980) suggested that the participants who carry out the Q sort should be “theoretical.....not accidental”. He suggests that there is real purpose in achieving a range of participants from different experiences. In this specific study it would be an assumption rather than a fact, that there is a correlation between the disease size or treatment modality, which could predict the likely participant response. Participants were therefore sought with a range of tumour sites and treatments, using a purposive sampling strategy. A patient database from the cancer centre that the author works at, provided a list of patients who had been diagnosed and treated over a year period and might therefore be eligible to take part in the study. The number of participants judged necessary was taken from a recommended formula of at least one participant for every three statements (Webler et al., 2009a) (described on page 162 of this chapter). This would suggest that there should be at least fifteen participants when 45 statements are used.

INCLUSION CRITERIA

The criteria for participation in the study were:

- Aged over 18
- Able to understand and speak English
- Completed treatment with curative intent at a UK cancer centre for H&NC:
 - surgery only
 - surgery plus radiotherapy
 - surgery plus chemo-radiotherapy
 - chemo-radiotherapy

EXCLUSION CRITERIA

- Known to have a co-existing malignancy
- Co-existing cognitive disorder
- Treatment that was being used with known palliative intent

At the time of the Q sort the participants were without any clinical sign of recurrent disease. Twenty patients were approached when they were attending outpatient reviews, by the author. Two declined to take part; eighteen participants completed the study. The bio-clinical information for the participants is presented as each factor is described.

Q SORT PROCEDURE

The participants completed the Q sort in two stages:

- (i) An initial, broad sort that separated the statement cards into one of three categories

(ii) A more detailed one when the statement cards were placed onto the forced distribution grid. The format of the distribution grid has been discussed in the Chapter 4 and presented as figure 4.2 (page 145).

In order to carry out the first sort, participants were instructed by the researcher to read through all of the statement cards initially so that they could establish the range of statements that were for consideration. They were then asked to sort each of the statement cards into one of three distinct piles. This statement is:

- Most like I think
- Least like I think
- I am ambivalent about this in relation to my experience of head and neck cancer

The participants kept the groups of statement cards separate, but in essence they had started to form a physical continuum. The participant was next instructed to look at the forced distribution grid sheet on an A1 sized card with the -5 to +5 range. Two cards could be placed at +5 and represented their strongest agreement with statements. The same process continued until the participants had worked their way back to the position of +1. They then were asked to turn their attention to the other extreme group –‘least like I think’, and to decide, in a similar way, what were the two statement cards that represented how they least thought. These statements were placed at -5. The process was repeated until the participants had the 'least like I think' dimension filled-up with the statement cards. As they made progress towards the centre of the chart' the participants were told that there was more scope to have more statement cards in the central positions. Each card had to have its own space, so that no blanks or doubling-up of allotted spaces could occur. The participants were

also given the explanation that the height of the distribution placement did not matter, what mattered was the numbered position from +5 through to -5. It was explained that in order to make a statement card 'most like I think' the card should be moved towards +5 and in the opposite direction for 'the least like I think'. This meant that there were frequent discussions concerning those statements about which participants had ambivalent thoughts, before a decision was made as to where the statements might be placed. The grid became a personal construction of a forced distribution curve. Due to the almost infinitesimal permeations of the arrangements for the statement cards when two participants have a consistent patterned response; the participants are responding to the topic in a meaningful and similar, rather than random way (Webler et al., 2009a). Once all the cards had been allocated to a place, each participant had time to review the position they had given to each statement. The array was recorded on a scoring grid that represents the layout of the distribution sheet. A completed example of a scored Q sort for one of the participants is presented in Appendix 5.3.

After the sort, participants were asked whether they felt that the statements reflected their experience of the disease and treatment and whether in their opinion there were any omissions. The participants were also asked if the zero mark really represented indifference, or whether this needed to be moved within the scale (Webler et al., 2009a). The participants were now able to discuss with the author their rationale for placing certain statements at the extremes, or in the centre of the distribution grid, so that more detail surrounding the placement of the statements could be gathered. This discussion was recorded

and later transcribed by the researcher. One such semi-structured interview transcript is presented in Appendix 5.4. Adding line and page number tabulates the transcript which enables the interviews to be found within the results. The text generated is helpful in the interpretation of the factors when they have been discovered statistically. It was decided by the author to carry out a face-to-face Q sort. Some of the patients would have been difficult to understand if there had not been the face-to-face cue, because of how their speech had been compromised by the disease and or treatment. It also felt that for a Q sort that might provoke emotion, the researcher should be able to advise the participant of possible further support that could be accessed after the participation in the study.

STEP 4 AND 5 ANALYSES OF THE RESULTS AND INTERPRETATION

The completed Q sorts were analysed using a software programme that is available via the internet, the PQ method 2.1 programme (Schmolck, 2002). It analyses the sorts so that participants who are presenting similar experiences are clustered together and form a factor. The participants have rank ordered the statements which have been analysed statistically. The product of this analysis creates the clusters or variables that are known as factors. The analysis produces an ordering of the statements that become specific to one factor over another. Statements in similar positions for all the factors are called the consensus statements because they are in the same place within each factor. The factors are interpreted by reviewing them both in terms of the

consensus and contention statements. The semi-structured interviews from the participants are able to elaborate and help the researcher interpret further the ranking of the statements by each participant. Q Methodology has the option to use varimax rotation (an automatic way of generating variables which are called factors). The use of varimax rotation is recommended for larger data sets so that the factors uncovered account for the maximum amount of study variance. The intention is that it is possible to consider and recognise the importance of each factor relating to the topic under investigation (Watts and Stenner, 2012 P.125). Eigen values, used in R methodology when factor analysis is carried out, are used to decide the variance extracted from each factor. It has been recommended that only factors with an eigenvalue greater than 1 are analysed (Brown, 1996), but the coherence of the factor as well as the eigenvalue should be taken into account (Coogan and Herrington, 2011). Q methodology is holistic in its nature and therefore it has been suggested that the value has little meaning in the context of Q methodology because they are based on an arbitrary number of individuals (Brown 1980). The other specific issue to recognise is that factor analysis will break-up the topic investigated into separate components and Q methodology relies on the participant being their own reference point. Figure 5.2 represents the different and step-wise stages of the study; the results are presented in the subsequent section.

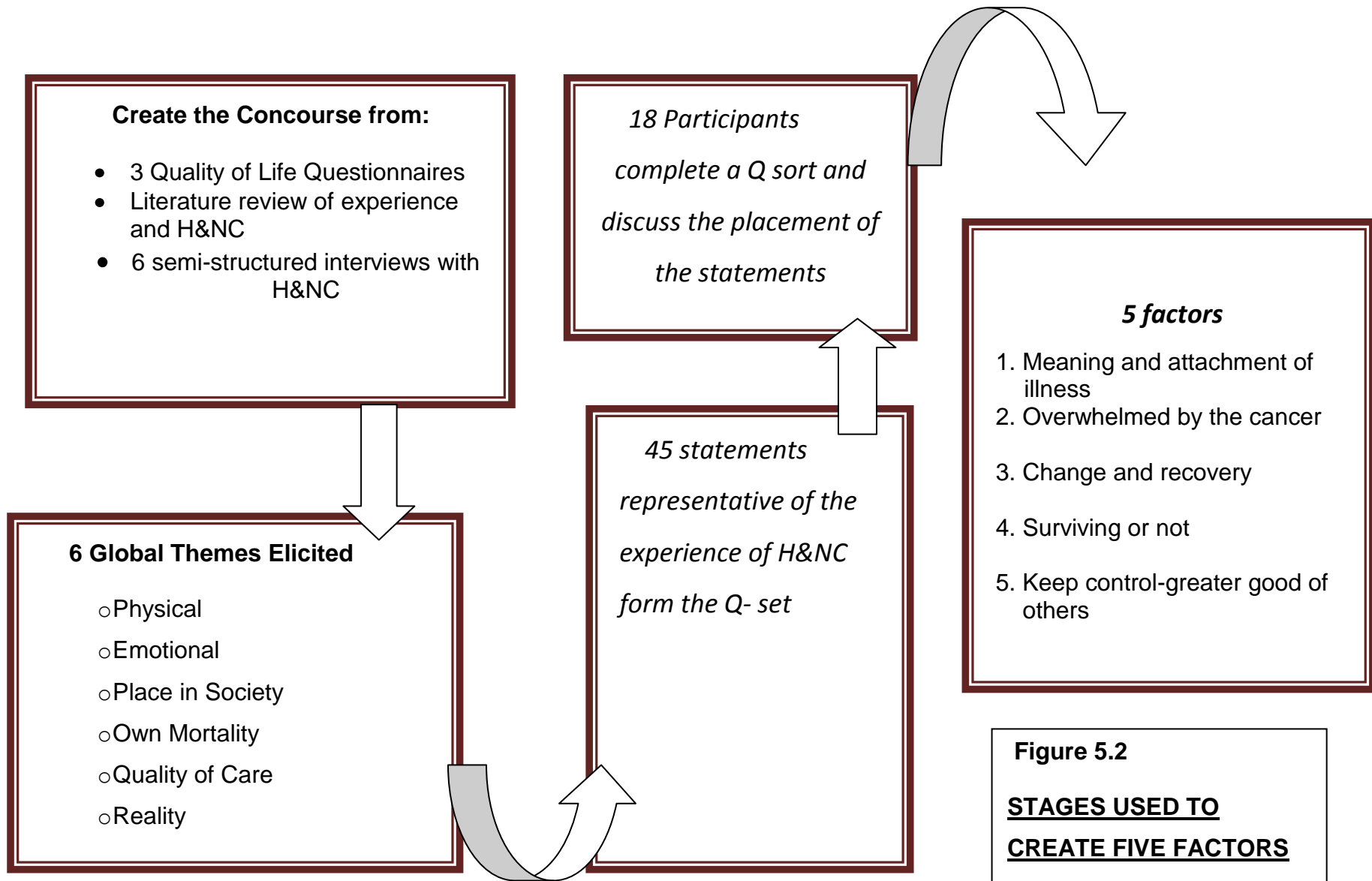


Figure 5.2

**STAGES USED TO
CREATE FIVE FACTORS**

RESULTS

Eighteen participants, twelve men and six women completed the Q sorts. The age-range was 37-77 years all of their details with reference to the treatments they had are presented as table 5.1. pages 173-174

This investigation of the experience of H&NC suggests that there are complex and interactive patient characteristics that will impact upon patients. The semi-structured interviews, which contributed to the formation of the concourse, identified in participants a re-appraisal of values, numerous coping strategies, and adaptation to the disease. The paper in chapter three 'HRQoL questionnaires are they fit for purpose?' (Reid et al; 2012) has demonstrated that there are aspects of the experience, which are represented poorly within HRQoL questionnaires. These are represented by the global themes, Quality of care and Reality.

In its most basic form after the Q sorts had been completed there were 18 Q sort grids populated with statement cards, with a corresponding digital audio-recorded discussion by each participant associated with them. The statement distributions were analysed using the P-Q method programme 2.1 (Schmolck, 2002) and the comments generated from discussion of the placement of the statements were transcribed.

The results are presented in three ways:

- Factor matrix denoting defining sorts for each factor (Table 5.2 Page 175)
- Distinguishing statements with a significance value for each factor, (Figure 5.3 page 177-178)
- Placement of statements for each factor, presented as a range from statements with most consensus through to most contention (Table 5.3 page 180-181)

The factor matrix Table 5.2 Page 175 of each Q sort demonstrates the individual's concordance with each factor. The level of agreement between the individual sorts gives insight into whether the participants share similar viewpoints. A positive loading with a high score represents a typical example of the factor, conversely a negative loading shows that the participant rejects that particular factor. Each Q Sort has a score for each factor between one and zero and is a measure of the correlation that each sort has to each particular factor. This means that Q-sort 1 is most correlated with factor one and possess a factor loading of 0.70, which is 70% of the positive factor one loading.

The normalised factor scores produce the statements that most and least typify each of the factors; they are presented as Z scores and form part of the data presented in figure 5.3. The statements need to be interpreted in the light of the other statements because it is the overall configuration that creates a more subtle meaning than a particular statement in isolation (Shemmings, 2006). It is for this reason that more recently Watts and Stenner (Watts, 2012) have suggested that whilst the research has tended to focus on results for statements at the extremes of the grid, some of the central ones occupying the minus one, zero and plus one can also be enlightening because they might corroborate the reasoning behind the placement of some of the more extreme statements.

TABLE 5.1 BIO-DETAILS FOR ALL THE PARTICIPANTS

Sort number	Factor	Gender	Age at Q sort	Employment	Site	T	N	Treatment modality	Time of Q sort from last treatment (years:months)	Total length of treatment (days)
1 CS	1	M	55.10	IT manager	Floor of mouth	T3	N2	Surgery& Chemo,RT	1.10	104
2 SS	1	M	46.04	Unemployed metal worker	Retro-molar Soft palate	T4	N2b	Surgery& RT	0.11	70
6 MH	1	M	61.07	Salesman	Tonsil	T1	N3	Chemo,RT	1.03	103
12MG	1	F	37.04	Accountant	Buccal and mandible	T4	N2b	Surgery RT	0.6	70
13 KG	1	F	51.09	Catering business owner	Tongue base	T3	N1	Chemo RT & neck dissection	.10	136
14 RP	1	M	62.06	Retired policeman	Tonsil	T2	N2a	Surgery & RT	1.0	48
17 PW	1	M	64.06	Retired IT manager	Larynx	T3	N1	Chemo RT Surgery	1.00	98
9 AB	2	F	65.01	Retired health care worker	Tongue base	T4	N2c	Chemo RT Plus neck dissection	.04	167
16 GHU	2	M	55.05	Dustman	Tonsil	T1	N1	Surgery RT	.10	90
4 GM	3	F	65.09	Retired care worker	Tonsil	T2	N2b	Chemo RT	1.04	88
5 EN	3	F	55.01	Office worker	Tonsil	T2	N1	Surgery Chemo,RT	1.07	90
18 JH	3	M	60.01	Salesman	Oral Pharynx	T3	N0	Surgery RT	1.00	97

TABLE 5.1 BIO-DETAILS FOR ALL THE PARTICIPANTS

Sort number	Factor	Gender	Age at Q sort	Employment	Site	T	N	Treatment modality	Time of Q sort from last treatment (years:months)	Total length of treatment (days)
3 GG	4	M	77.06	Retired builder	Oral tongue	T1	N0	Surgery	1.0	0
7 SN	4	M	61.07	Builder	Larynx	T3	N0	Surgery	1.0	0
11 CA	4	F	58.07	Shop worker	Larynx	T2	N0	Surgery	1.01	0
10 AS	5	M	40.02	Computer programmer	Mandible	T4	N0	Surgery RT	.06	76
15 KK	5	M	61.05	IT worker	Floor of mouth	T2	N1	Surgery RT	.09	90
9 BT	none	M	69.07	Retired driver	Maxilla	T4	N0	Surgery	1.0	0

Seventeen of the eighteen participants (94%) loaded onto one of the five factors. No one person loaded onto two factors, an indication that the factors have a degree of independence from one another (Webler et al., 2009a). The percentage variation accounted for by the five factors was 87 percent.

TABLE 5.2 FACTOR MATRIX

Q Sort	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
1	0.7092*	0.3838	0.0809	0.3204	0.0659
2	0.6743*	-0.1689	0.4317	0.0005	0.2438
3	0.1381	0.0304	0.2301	0.7660*	0.1605
4	0.2145	-0.0843	0.6781*	0.1057	0.1255
5	0.0544	0.3262	0.6743*	0.1653	0.0375
6	0.8582*	-0.0405	0.1736	0.2001	-0.0803
7	0.1487	-0.2704	0.1121	0.6455*	-0.0075
9	0.0910	0.6103*	0.4766	0.1814	0.1956
8	0.5984	0.0484	0.2089	0.6271	0.1521
10	0.3482	0.1187	-0.0499	0.1236	0.7800*
11	0.2600	0.1310	-0.0215	0.6691*	0.4597
12	0.6518*	0.0597	0.0656	0.3881	0.2847
13	0.6443*	-0.0088	0.0949	0.2418	0.4051
14	0.6396*	0.0948	0.4238	0.1839	0.3133
15	0.0622	-0.0985	0.4527	0.3060	0.6992*
16	0.0403	0.8471*	-0.0881	-0.2151	-0.0313
17	0.6058*	0.1180	0.4504	-0.1925	0.3164
18	0.2288	-0.0639	0.6404*	0.1027	-0.0493

*** = defining sort**

Each factor represents a group of individual points of view that are correlated highly with each other. Any percentage of the study variance above 35-40 percentage is considered a credible solution to the factors (Watts, 2012).

Five Factors were identified:

1. Meaning and attachment to illness
2. Overwhelmed by the cancer
3. Change and recovery
4. Surviving or not
5. Keep control-greater good of others

Figure 5.3 represents a summary of statistical data:

- Distinguishing statements for each factor,
- Eigenvalues
- Z scores.

The latter is a measure of how closely a statement is situated to the middle of a distribution. Such that a Z score of -2.00 is 2 standard deviations from the mid-point of the distribution, and so would be to the left of the Q sort distribution grid.

Figure 5.3 DISTINGUISHING STATEMENTS FOR EACH FACTOR

Factor (eigenvalue)	Number of respondents loading to factor	Factor Name	% variance accounted for	(Statement number) Statement	rank	z-score
1 (7.0796)	7	Meaning and attachment of illness	39	26 It's very hard to think about your own possible death	-3	-1.09**
2 (1.7221)	2	Overwhelmed by the cancer	10	41 Day-to-day existence is physically exhausting	5	1.73**
				11 Little things like the car park or appointments being cancelled irritate me	5	1.51**
				37 I cannot do things on the spur of the moment	3	1.38**
				38 I am much more irritable than I used to be	3	1.27**
				45 I am still in pain	1	0.35*
				12 I wanted the team always to be honest with me	-2	-0.93**
				39 My appearance was much better than I expected	-5	-1.84**
				13 If you didn't want to die there was no choice but to have treatment	-5	-2.07*

* Indicates $P < .05$ ** Indicates $P < .01$

Figure 5.3 DISTINGUISHING STATEMENTS FOR EACH FACTOR

Factor (eigenvalue)	Number of respondents loading to factor	Factor Name	% variance accounted for	Statement number Statement	rank	z-score
3 (1.3900)	3	Change and recovery	8	1 I recovered much slower physically than I expected	4	2.00**
				24 Once I knew they could do something about it that's all I needed to know	4	1.97*
				13 If you didn't want to die there was no choice but to have treatment	1	0.03**
				38 I am much more irritable than I used to be	-3	-1.40*
				29 I never think of myself as ill	-4	-1.46**
				15 I'll talk about things that I wouldn't have done before my diagnosis	-4	-1.48**
4 (1.2857)	3	Surviving or not	24	42 When I talk it doesn't feel like me anymore	2	1.05**
				33 I never appreciated how long it would take to get better	-2	-0.90**
				1 I recovered much slower physically than I expected	-2	-1.04**
				14 It's so hard waiting to heal	-3	-1.11**
				45 I am still in pain	-5	-2.31*
5 (0.9950)	2	Keep control - greater good of others	6	22 I felt very vulnerable when I was in hospital	4	1.43**
				40 I worried a lot how others would cope	3	1.33**

* Indicates $P < .05$ ** Indicates $P < .01$

Eigen values of less than 1.00 are taken as the cut-off point for the retention of factors. Closer inspection of factor five revealed that there was a significant and different factor story with coherence that was being told by this group and therefore it was decided to leave this factor in. Five statements were statistically significant consensus statements and were towards the centre of the distribution. Table 5.3 displays the statement scores that are consensus statements between the factors.

TABLE 5.3 STATEMENTS FOR ALL FIVE FACTORS ARRANGED FROM CONSENSUS TO CONTENTION.

No	Statement	Factor					Range
		1	2	3	4	5	
F&R34	Life will never be the same again	1	0	1	0	0	1
R 16	I have to be careful to not upset people	-1	-2	-2	-1	-2	1
R 17	You should never have to face this sort of thing on your own	2	2	3	4	3	2
R 23	I didn't understand what was meant by the treatment until I had it	0	0	0	2	0	2
F&R 19	No two patients are the same	1	1	-1	-1	0	2
R 4	When I was told I had the cancer I knew I had to face it	3	2	2	4	4	2
R 6	I didn't want people to know what had happened to me	-1	-3	-1	-1	-3	2
R 36	I wish I'd never been treated	-5	-3	-5	-5	-5	2
F&R 10	You just become really grateful for different things	2	-1	0	0	0	3
R 31	I cannot have a good argument now	-2	-3	-3	-3	-5	3
R 30	Everyone around me was so upset	0	-1	-1	1	2	3
R 40	I worried a lot how others would cope	0	0	0	0	3**	3
R 44	It's hard to remember things you're told	-2	2	-2	1	-1	3
R 5	It really affected my confidence	-2	0	-1	2	1	3
F&R 27	I do things but on my terms	1	-1	-2	-2	0	3
R 32	I felt very alone	-4	-2	0	-2	-1	3
F&R 25	It's just as well you don't know what's going to happen you	-3	-1	-1	0	-3	3
R 21	I never felt like a number I was always treated as an individual	4	5	2	3	1	4
R 26	It's very hard to think about your own possible death	-3**	1	2	1	1	4
R 20	I was most frightened when I came out of hospital	-5	-4	-1	-1	-1	4
F 28	Being cured of the cancer is still the most important thing	5	3	5	5	1	4
R 7	No one can really understand what has happened to me	0	1	1	-3	-3	4
F&R 9	Life is hard you just have to get on with it	1	-2	3	0	1	5
F18	I never read the written information I was given	0	-2	1	0	-4	5

T

No	Statement	Factor					Range
R 43	I always think that people are staring at me	-2	0	-5	-3	-1	5
R 8	You never think it could happen to you	1	0	-2	3	2	5
F35	It's amazing how much you can adjust to all the physical changes	3	-1	2	-1	2	4
F42	When I talk it doesn't feel like me anymore	0	-3	0	2	-2	5
F2	I felt physically very isolated	-3	2	2	0	-2	5
F&R 3	Any symptom I get I always think the cancer might be back	-2	3	-1	3	0	5
R 15	I'll talk about things that I wouldn't have done before my diagnosis	-1	1	-4**	-2	-2	5
F14	It's so hard waiting to heal	1	2	3	-3	2	6
F45	I am still in pain	-1	1*	-3	-5	-2	6
R 38	I am much more irritable than I used to be	-1	-3**	-3	0	-1	6
F1	I recovered much slower physically than I expected	2	1	4**	-2	1	6
F11	Little things like the car park or appointments being cancelled really irritated me	-3	4**	-3	-1	-1	7
F39	My appearance was much better than I expected	2	-5**	0	2	1	7
R 29	I never think of myself as ill	3	0	-4**	1	2	7
F 37	I cannot do things on the spur of the moment	0	3**	-2	-4	-4	7
R 24	Once I knew they could do something about it that's all I needed to know	2	-2	4*	2	-3	7
R 33	I never appreciated how long it would take to get better	3	4	5	-2	2	7
R 12	I wanted the team always to be honest with me	4	-2**	3	5	5	7
R 22	I felt very vulnerable when I was in hospital	-4	-4	1	1	4**	8
R 41	Day-to-day existence is physically exhausting	-1	5**	0	-4	-2	9
F&R13	If you didn't want to die there was no choice but to have treatment	5	-5**	1**	3	5	10

These consensus statements suggest that participants do not feel as though the experience of disease and treatment had been catastrophic. They were not secretive about the diagnosis that they had had, they believed that it was not the sort of thing to be faced alone, and they did not feel that they had to be careful not to upset people they knew. Each factor will now be interpreted based on the sorts that loaded to the factor. Q methodology convention identifies statements by their number and their position in the Q sort. The statement number, followed by the position on the grid, is placed within a set of brackets. This style of presenting the statement results will be used within this study.

FACTOR 1: MEANING AND ATTACHMENT TO ILLNESS

Seven subjects were associated significantly with this factor, five men, and two women. This factor was identified as the one which seems pragmatic but will have interpreted the diagnosis and treatment in their own way. They think that that being cured of cancer is the most important thing (28: +5) and strongly do not think that there was any choice but to have the treatment offered (13: +5).

'When I was diagnosed it just went bang in my head, but you have to get on with it'

Sort number 1: 1.1-1.2. (The figures for each text quoted is presented as the page number followed by the line number from the start to the end.)

Their attitude was reiterated by them agreeing that once they knew treatment could be offered that was all they needed to know (24:+2) and further re-enforced by an equally strong rejection of the idea of wishing they had never been treated (36:-5).

There was one statement that was a defining statement for this factor presented in Table 5.4. It related to the group's apparent rejection that it was hard to consider their mortality as a result of the diagnosis and treatment. The four other factors agreed slightly with the statement, whilst factor one subjects quite strongly did not.

TABLE 5.4 DISTINGUISHING STATEMENT FOR FACTOR 1

Statement	Factor				
	1	2	3	4	5
16 Its very hard to think of your own possible death	-3**	1	2	1	1

**=P<.01

They appreciated that they had to face the fact they had cancer (8+3) but were ambivalent towards the concept that others truly understood what had happened to them (23:0). One of the participants who completed their Q sort reflected, during their review of the statements, that from their perspective they had heard about acquaintances having cancer and how they would not really understand the true implications of it. They had been polite, but the impact of other people's diagnosis that they had experienced previously had been somewhat superficial.

'I think everybody in general cannot take on board other people's symptoms and its only really if they are close to you. You hear it so many times; so and so has cancer or whatever, and you say "oh dear I'm sorry" but you never really have any real understanding of those words.....'

Sort number 13: 1.19-2,5

They wanted strongly that the team caring for them would be honest with them (12:+4),

'I wouldn't have wanted someone to give me false hopeyou need to put it (the disease) in perspective in your own mindgives you an understanding of where you are on the spectrum'

Sort number 13: 5.21-5.25

They had no feeling of being treated by the team in an anonymous way (21: +4). Their positive experience of the process was further illustrated by their belief that they did not feel vulnerable whilst in hospital (22: -3) and strongly refuted feeling frightened when they left hospital (20: -5). These participants did not feel alone (32: -4) or think they were physically isolated (2: -4). The Meaning and Attachment to Illness group did not particularly have a strong view that patients were the same (14:+1); had an indifferent response to a change in self (42:0), or worrying how others would cope (40:0), or that the people around them were not upset (30:0). They did however, have a different emphasis on what mattered to them (10:+2). They thought but did not find themselves talking about topics they would previously have avoided as a consequence of a life threatening diagnosis (15; -1). They did not agree to a vulnerability of being likely to attribute a symptom they had as a possible recurrence (3: -1). This vague thought was substantiated by the view that they did not think specifically about their own mortality as a consequence of the H&NC diagnosis (26: -3).

'Possible death? Well I've been in the Royal engineers and a special constablein the army we were fired on once ...I thought I'd been shot I was screaming on the floor and the medic came and said "you're fine don't worry get up it's OK" and I said "I can feel a warm liquid on my leg" and he said " yeah that's your water bottle that saved you". The bullet had scudded the water bottle not me so my number still wasn't up no bullet with my name on it....'

Sort number 4: 1.26-2,25.

The experience was however by no means easy for anyone. They had a poor appreciation for how long it would take to heal (7:+3) and they took much longer to heal than they expected (1:+2) They knew they did things on their own terms (14:+2) and thought that no one should ever have to face the experience of H&NC and its treatment on their own (17:+2).

FACTOR 2: OVERWHELMED BY THE CANCER

Two subjects were significantly associated with this factor. These participants felt isolated physically (2:+2) and they thought it hard waiting to heal (14:+2). Despite their particular thoughts related to poor physical recovery they are ambivalent about describing themselves as ill (29:0). They thought strongly that they were treated as an individual by the medical team caring for them (21:+5) but did not want the team to be completely honest with them (12:-2). They found it hard to remember what was said to them (44:+2), which is why they were more likely to rely on the written information provided (18: -2). This aspect is reinforced by the view that they don't think that once a treatment plan has been devised, that's all they needed to know (24:-1). For them there are many more details that have to be understood.

They did not think that anyone should have to deal with the experience on their own (17:+2), but personal isolation is exacerbated, because they think no one can understand what has happened to them (7:+1). They did not feel vulnerable in hospital (22:- 4), or frightened out of hospital (20:-4), but were strongly irritated by health processes (11:+4) and would acknowledge that they are

generally more irritable (38:+3). They never appreciated how long it took to get better (33:+4) and cannot do things on the spur of the moment (37:+3). They strongly did not think that they had adjusted well physically, (35:-1) but like all the other factors had no difficulties with people knowing what had happened to them (6:-4).

They disagree strongly that there was no choice but to have treatment (13:-5)

'I can't understand not being treated, on a bad day I can. I feel guilty though- I don't think about it a lot- but to have no treatment. Being cured of cancer and when I was told the cancer was there I had to face it- means there is no choice so I have to get on with it. The two paths are different alive or dead'

Sort number 9: 3.7- 3.13

The participants who loaded to this factor seemed very limited by the physical aspects of their disease and treatment. They felt their existence was physically exhausting (41:+5), which would in part explain why they could not do things spontaneously and were in pain, this was more than any of the other groups (45:+1). The real hopelessness is expressed in the interview with participant 16.

'Unless you've been through it that battle of emotions they just can't appreciate the ups and downs. I just feel very vulnerable- I've given up work.....no one can understand what's happened to meI don't think anyone, unless you experience it what it actually does to you mentally or physically'

Sort number 16: 2.33-2.38

This was also the group who had not had their expectations met with reference to their physical appearance (39:-5). It is of note that neither of the participants had needed extensive surgery to their oral cavity. Whilst one had had a neck dissection, they both had been treated primarily by chemo-radiotherapy. This treatment is routinely described as organ preserving, and might be thought to

be less mutilating than surgery. This was despite them still identifying with what they sounded like when they talked (42:-2).

There were eight statements that were defining from a statistical significance perspective, which are represented in Table 5.6. All of these significant statements build a picture of being overwhelmed by the disease. They were the group who wanted the team to recognise their weakness and to temper their honesty at times. They trusted the teams to decide how much more information they could cope with.

TABLE 5.5

DISTINGUISHING STATEMENTS FOR FACTOR 2 *= $P < 0.05$ **= $P < .01$

Statement	Factor				
	1	2	3	4	5
Day to day existence is physically exhausting	-1	5**	0	-4	-2
Little things like the car park and appointments being changed annoy me	-3	4**	-3	-1	-1
I cannot do things on the spur of the moment	0	3**	-2	-4	-4
I am much more irritable	-1	3**	-3	0	-1
I am still in pain	-1	1*	-3	-5	-2
I wanted the team always to be honest with me	4	-2**	3	5	5
My appearance was much better than I thought	2	-5**	0	2	-1
If you didn't want to die there was no choice but to have treatment	5	-5**	1	3	5

FACTOR 3: CHANGE AND RECOVERY

Three subjects were associated significantly with this factor- two females one male. Factor three participants strongly think that being cured of cancer is still the most important thing (33:+5) and refute strongly that they wish they had never been treated (36:-5). When they knew something could be done that was all that mattered (24:+4), and they knew that to have treatment was the only option (13:+1). This was in great contrast to factor two, overwhelmed by the cancer, who had scored the same statements as -2 and -5 respectively.

They did not find the treatment easy, but seemed to take the view that realistically they just had to get on with it no matter how bad it was. They seemed to have the end point in their sights

'That horrible mask.... I got through it with will power I had to have the treatment to have the treatment I knew I had to wear the mask and that's that.'

Sort number 4: 4.33-5.3

They disagree strongly that people stare at them (43:-5) and they are ambivalent about the effect the treatment and disease has had on their appearance (39:0). This group strongly think of themselves as ill (29:-4). They also think they recovered much more slowly than they expected (1:+4) but have got to a point where they are not really in pain (45:-3).

'The last time I was in hospital was 18th October and I thought there was a possibility of going back to work before Easter. Even then ... I thought once I'm off that tube (Nasogastric tube) I'll be up and away and off I'll go; and the first meeting I had about going back to work was the April the following year.'

Sort number 6: 1.34-1.40

They did not think that the treatment had meant that they talked about things they would not have done previously (15:-4). They found it hard waiting to heal

(14:+3) but were surprised at how well they were able to physically adjust (35:+2). They experienced vulnerability in hospital (22:+1) but were not frightened when they were discharged (20:-1). They felt physically isolated (2:+2) and agreed that they never read the written information they were given (18:+1).

'I never read the info. I guess I didn't want to knowmy wife read up on it I just did not want to know, it was as if the detail didn't bother me I wanted to know a little bit but when they give you a book that thick on neck dissection that was of no interest'

Sort number 18: 1.1-1.7

This placement of the statement compliments and helps to explain statement 24 'once I knew they could do something that's all I needed to know' (24:+4).

It seems their resources were focused on the reality and the present, and that they were unable to cope with any more information apart from what they dealt with currently. They were also ambivalent about understanding the treatment until they had experienced it (23;0), but expressed this with more detail to suggest they were not prepared for the changes they experienced.

'No, nothing like the reality the long term effects are not particularly explained the fact I am numb from the top of my ear, puffy round the neck that was never really explained.....'

Sort number 18: 1.10-1.14

They thought they were treated as an individual (21:+2) and did not find it hard to remember what they were told (44:-2). This was perhaps important in the light that they were not likely to read the information they were given.

'We hung on every word my partner, my sister, my brother, we are from the old school the consultants are God.'

Sort number 5 2.8-2.9

Table 5.8 presents the distinguishing factors for factor 3.

TABLE 5.6

DISTINGUISHING STATEMENTS FOR FACTOR 3 *=P<0.05 **=P<.01

Statement	1	2	3	4	5
I recovered much slower than I expected	2	1	4**	-2	1
Once I knew they could do something that's all I needed to know	2	-2	4*	2	-3
If you didn't want to die there was no choice but to have treatment	5	-5	1**	3	5
I am much more irritable than I used to be	-1	3	-3*	0	-1
I never think of myself as ill	3	0	-4**	1	2
I'll talk about things that I wouldn't have done before my diagnosis	-1	1	-4**	-2	2

The statements suggest that this group identified strongly with being ill, but just wanted something to be done. They were, however, more irritable and didn't feel they talked about different topics since their diagnosis. They did think it was possible for them to be diagnosed with cancer (8:+2)

'I always thought it could happen to me. Both my parents died of cancer so I'd be stupid not to think that after the CT scan.'
Sort number 5: 2.33-2.35

Despite having had close family members who had had cancer and been treated they did not think that any symptom they had was a recurrence of the disease (3:+1) but they admitted that it is hard to contemplate their own death (26:+2) and this also meant they thought that life would not be the same again (34 +1).

They also thought that people cannot understand what has happened to them (7:+1). They were ambivalent about feeling exhausted physically (41:0) or

being isolated physically (32:0). They were also ambivalent about others coping (40:0), or being grateful for different things (10:0).

This factor, change and recovery, seemed to present an image of not researching the disease and treatment, being reliant on the MDT for the information, and accepting that it was perfectly possible for them to have cancer. They were aware they had been through a quite terrible process but seemed to have recovered to a point where they were not preoccupied by insidious and pervasive symptoms.

FACTOR 4: SURVIVING OR NOT

Three subjects were significantly associated with this factor- two male one female. All of the participants in this group underwent a single modality of treatment. Therefore, after they were discharged from hospital from their definitive surgical treatment, they believed they were able to be on a trajectory of recovery.

It is of note that the sort number 9, who did not load onto any of the factors, was closest to the factor four experience with a factor loading of .0627. These participants thought that honesty from the team was paramount (12:+5) and that being cured of cancer was the most important thing (28:+5). They had no regrets at all about having treatment (36: -5) and they were not in pain (45: -5). They thought strongly that you should not have to face the experience

alone (17:+4) and knew that when they had been told the diagnosis that they had to face it (4:+4).

'All I wanted to do was get it out of my body"...I had a choice I could have had radiotherapy and all I could think was no I just want it out of my body.'
Sort number 11: 3.16-3.20

'I know I had to have the treatment, I didn't want to die so no choice....but awkward to think about'
Sort number 7: 2.23-2.24

Being cured of cancer, they thought, was still the most important thing (28:+5), and they wanted the team to be honest with them (12:+5). They could still be impulsive (37:-4) and they did not think that day-to-day life was exhausting physically (41:-4). They thought they recovered quickly (1:-2) but did not think that they had appreciated how long it would take to recover (33:-2). They did not feel alone and (32:-2) and did not think they needed to do things on their own terms (27:-2). This group thought that it would never happen to them (8:+3) and thought that any symptom they experienced was likely to be a recurrence (3:+3).

'Once you've had it there's a fear at the back of your mind..and you hear of people and talk to people that have had cancer and it comes back and I think will that be me?'
Sort number 11: 1.11-1.15

Physically it did not feel like them when they talked, (42:+2) but their appearance was much better than they expected (39:+2). This was an interesting idea because this factor had a participant who loaded to it who had had a laryngectomy. It might have been assumed that they had had a great deal of body image changes to cope with, and yet this participant scored his treatment as leading him to have a better physical appearance than the factor

two group, overwhelmed by the cancer, who had had chemo-radiotherapy. They did not understand what was meant by the treatment until they had it (23:+2) and don't have strong thoughts about reading the written information they were given, (18:0). This aspect is also in stark contrast to factor two and factor five who did read the literature given to them.

For some of the patients it was standard practice (from national guidelines) that they should have an opportunity to meet patients who have had a similar operation to the one that they are going to have. However, even with this most tangible piece of information, one of the participants was unable to understand the reality of the operation, and in effect got little from the meeting.

'I didn't understand what happened to me even when I spoke to a guy who had had it; (a laryngectomy) it went over my head, when I left the appointment I didn't know where I was. I met him and it made no sense.'

Sort number 7: 1.11-1-13

This group didn't find it hard to be waiting to heal (14:-3) and did not feel that they recovered physically much more slowly than expected (1:-2). They did not mind others knowing what had happened to them (6:-1) and they were not annoyed by the process of the health-care they received (11:-1). They were ambivalent about life that life would never be the same again, (34:0) and of experiencing physical isolation (2:0) but there is still a sense of change and adjustment and reflecting on the impact of the disease and treatment.

'You do just have to get on with it. I felt isolated to start with and then it got easier, but people I have known all my life you look at them and they have no idea and you think.....(looks into middle space) well it's their choice.'

Sort number 7: 7 2.3-2.5

The distinguishing factors for this group show elements of change and recovery and reflect the single modality treatment of surgery to recovery.

TABLE 5.7 DISTINGUISHING STATEMENTS FOR FACTOR 4 **= $P < 0.05$

Statement	1	2	3	4	5
When I talk it doesn't feel like me	0	-3	0	2**	-2
I never appreciated how long it would take to get better	3	4	5	-2**	1
I recovered much slower than I expected	2	1	4	-2**	1
Its so hard waiting to heal	1	2	3	-3**	2
I am still in pain	-1	1	-3	-5**	-2

**= $P < .01$

FACTOR 5: KEEP CONTROL - GREATER GOOD OF OTHERS

Two subjects, both male, were associated significantly with this factor. This was the factor that had by a very small margin, an eigen value of less than one. But review of the presentation of the statements suggested that they were a discrete group presenting a different story of the experience.

TABLE 5.8 DISTINGUISHING STATEMENTS FOR FACTOR 5 **= $P < .01$

Statement	Factor				
	1	2	3	4	5
I felt very vulnerable in hospital	-4	-4	1	1	4**
I worried a lot how others would cope	0	0	0	1	3**

This group strongly thought there was no choice but to have treatment (13: +5) and wanted the team to be honest with them (12:+5). They read all the literature

'It was the easiest choice (to have treatment) I made because there was no choice. Once I knew something could be done I wanted to know all the ins and outs of every little detail, all the jargon, I wanted to know, on the assumption I would get over it I wanted to know how I would be.'

Participant 15 1.12-1.19

They disagreed strongly with the thought of never being treated (36:-5) and were very active communicators such that they felt they could still have a good argument (31:-5) even with a temporary tracheostomy in-situ, three days post surgery.

'I had a row using capital letters on my paper with the ward sister'

Sort no 10: 4.39

This group expressed a sense of vulnerability in hospital (22:+4).

'Coming out of hospital was frightening but I was equally frightened in hospital, because you had no control over what happened to you so you were totally reliant on other people you put your life literally in someone else's hands.'

Sort no 15: 1.31-1.35

They don't think that they are restricted from doing things on the spur of the moment (37:-4), read the written information they were given, (18:-4) and don't think that ignorance would mean you could cope better with the experience (25:-3). They were not frightened when they were discharged (20:-1) and worried how others would cope, (40:+3) a significant value, with an acknowledgement that those around them were upset (30:+2). They are also amazed how much they have adapted to the physical changes (18:+2) but qualified this by saying:

'I've adapted and tried to adjust ...It was slower than I would have liked I would have expected it to be physically exhausting but it's not now and you get to

know your limitations you become much more aware and very wise but it's so hard.'

Sort number 15: 2.12 -2.

They felt it was hard waiting to heal (14:+2) and agreed that you should not have to face the treatment on your own (17:+3). This factor talks about things that prior to their diagnosis they would not have done (15:+2).

'I have had 40 years of being a good corporate citizen somewhat repressed...but now I do not need to deal with the mundane and idiosyncratic parts of the corporate world'

Sort number 10: 2.8-2.12

They did not think it could happen to them (8:+2) and do not think of themselves as ill (29+2) despite having extensive treatment.

'I never thought of myself as ill going in or coming out I limped around couldn't open my mouth properly- all the accoutrements of illness- but without feeling particularly ill; so it's not like I have a long-term disease even though I can still visualize a fixed chunk of time as opposed to a chronic condition...some people do define themselves by their illness this does not define me at all my values define me and none of those include being ill'

Sort number 10: 2.31-3.9

These participants do not see being cured of cancer as the most important aspect of their experience (28:+1). They did not have such a strong sense of being treated as an individual (21:+1) by the clinical team. They are not concerned that people stare at them (43:-1), did not think they were more irritable and were not irritated by changes of appointments (11:-1). They did not think they were more irritable in general (38-1).

However, there is the sense of a higher role within this system of needing to check for others that processes are working properly, keeping control.

'When an appointment gets cancelled and gets pushed back by 2 months I phone up and they say "oh no we can give you an appointment the next day ...I

do get annoyed for other people who can't do that (phone)and might think fine I don't need to see him for 2 months- that's fine meanwhile the condition might not be as controlled as mine and might cause a clinical risk. I get wound up for other people, on behalf of the greater population -my desire to fix things'
Sort number 10: 3.13-3.41

This group seemed to struggle with handing over their health to others. They found it difficult to trust the teams and this was to such an extent that they felt much more vulnerable in hospital (22:+4). They were also, perhaps because of the lack of perceived control likely to question their care. They seemed to find the need to test out the system and then comment on it from a system and future patients' perspective.

This chapter has presented the results from the Q study. Chapter six discusses these results further and explores the clinical implications and its context in terms of current healthy policy.

CHAPTER 6

DISCUSSION AND CLINICAL IMPLICATIONS OF THE STUDY

This study has presented evidence to describe how patients experience both the disease and treatment of H&NC. It has identified that these experiences are varied and described them in detail. Patients who have had a diagnosis of H&NC have generated this detail. The results counterbalance the remarks by Kennedy (2003) that health-care is provided by consulting HCPs, not patients, and by underlining the human aspects of the experience that Porter, (2003) suggested were being lost if hospitals performed medicine as medicine demands it, not as patients need.

DISCUSSION OF THE FACTORS

The discussion of the five factors illustrates the relational aspects of the experience for patients, described in the document 'What Matters to Patients' (King's Fund 2012). The report suggested these aspects of care are under-represented in research. Seven participants loaded to the first factor labelled 'Meaning and Attachment to Illness', they were in no doubt that their diagnosis was momentous and wanted to be treated for the disease. They seemed to have weighed-up the impact of disease and treatment even though this was hard:

"You might not want to believe it but that's different from not having it explained to you".

Sort number 1: 1.15-1.16

They did not feel that anyone else understood what had happened to them, but they could relate the reactions of others to how they had felt prior to their diagnosis if they had heard of acquaintances had a diagnosis of cancer. They recognised the importance of their team being honest with them. One participant qualified this by acknowledging that sometimes it was right that the team were not always honest. He recalled having a surgical drain removed from his neck after his operation.

“They said it wasn’t going to hurt when they took the drain out, it did, but what are they supposed to say? This is going to hurt a great deal so just tense up and watch how painful it can be.....”(ironic laugh).

Sort number 1: 1.22-1.24

Their expectations of the team were enhanced by them experiencing care that they felt was at an individual level. This group seemed to have been able to manage to cope with both the information and the symptoms that they experienced so that they were able to be ambivalent around a change in themselves from the experience. This meant they were not aware of talking about different things with their family after their treatment, and did not consider that this was the first time they had felt the need to contemplate their own mortality.

“I fairly much believe tomorrow’s going to happen and you are going to have to get through tomorrow and the day and week after and thinking and curling in a corner and not facing it you know moaning about it won’t change a thing, and I s’pose if my mother used to say if moaning would change it I’d moan night and day but it won’t so get on with it and that was the sort of ethos I was brought up with ,.....there is not a plan B”

Sort number 6: 2.21-2.29

These participants had adjusted to their experience so well that they were not likely to fear that a symptom they experienced after their treatment was

recurrence. The surveillance out patient appointments were summed up by one participant as:

“Seeing Mr P (participant’s surgeon)if you like what ever will be will be if it’s going to come back seeing Mr P or not seeing Mr P won’t stop it, but me seeing Mr P might mean he can do something about it”

Sort number 6: 4.19-4.22

There seemed to be a realistic decision made by the participant that there were limitations of what could be done by the MDT but that there was a need to stay engaged with the system in order that clinical decisions could be made. Such an opinion could not be said to be a manifestation of denial around either the existence of the disease or treatment experienced. They were aware that they took much longer to heal than they had expected, and used a lot of their energies to concentrate on recovery.

The second factor, labelled ‘Overwhelmed by the Cancer’, is in stark contrast to all the other factors. The two participants who loaded to it had symptoms that dominated their existence, which they felt no one understood. They seemed frail both emotionally and physically and were unique in this study group in their belief that for them there had been a real choice about accepting or refusing treatment. It seemed the active aspect in their care extended to the ultimate choice of choosing to be treated

“I can’t understand not being treated,on a bad day I can, I don’t feel guilty about that though – I don’t think about it a lot but to have no treatment being cured of cancer when I was told the cancer was there I had to face it means there is no choice so I have to get on with it. The two paths are different alive or dead.”

Sort number 9: 3.7-3.13

They trusted the clinical team and made the assumption that the team would be aware when they could cope with information. This trust extended into their hope that at times they might expect the team to choose not to tell them too much information too quickly, because they would be unable to deal with the consequences of it. They felt that their care was individual and had a sense that the communication between team members was such that they felt supported well enough by the team. Despite their evident frailties, they were not at all passive in their care and sought dialogue actively about their care. They demonstrated this active aspect by agreeing that they read and assimilated information prior to further consultations so that they could discuss their care with a general understanding of the topic.

This group appeared overwhelmed by the day-to-day aspects of the symptoms that they could describe:

"I need to be hopefulI still feel there is room for recovery so that's why I am trying to be hopeful I don't want to get carried away it's trying to keep a balance like my speech, now I have written very little down (during this interview), which is a surprise I feel exhausted around my neck all the tightness the compression".

Sort number 9: 2.20-2.28

These unremitting symptoms make it easier to understand why they might become irritated and worn out by processes. They were exhausted physically, aware of a change of body image, in pain, unable to do things on the spur of the moment, felt very isolated and more irritated in general.

Neither of these participants had needed extensive surgery and had not undergone surgical reconstruction; they had been treated with chemo-radiotherapy but struggled with their change of body image. This is an

important aspect to highlight. Chemo-therapy has been described as an organ preserving technique and yet the participants, who had received this and not had reconstructive surgery reported a change in body image that was greater than the other participants. The fibrosis (scarring from the treatment that alters the composition of the soft tissues in the head and neck region) had led the patients to feel that their body image had been altered.

The third factor, labelled 'Change and Recovery', represents another distinct way of experiencing H&NC and its treatment. This group of participants wanted to get on with the treatment with little information. Knowing that something could be done and being cured of cancer were strong themes. Unlike factor two they were not as engaged with what they thought were the nuances of treatment planning. They seemed to have a day-at-a-time approach and tried to stay as resolute as possible during indescribable treatments. They were not aware of people staring at them and were ambivalent that their appearance had changed. This group seemed to deal only with situations as they arose, but when they arose they were sensitive to lots of different cues, verbal and non-verbal. Sort number 5 described her experience of ultra sound guided biopsy:

"You are vulnerable to the non-verbals because you are looking for signs of what's going on and if people are behaving differently with you and appearing to be hiding things in a way I'm just thinking if someone were to say "we can see something on the screen that's what is on the screen" because you knew there was going to be something on the screen because that was what they were trying to biopsy the issue was if we are looking for something that is in your neck is this malignant? Is it cancerous? or is it a cyst? So they could have at least got to the point of being able to describe to you "OK we can see what we are trying to get at" whatever -you knew that bit"

Sort number 5: 6.24-7.8

Fear of recurrence was not a constant worry and in the context of other experiences was only thought about slightly. This group presented an image of not researching the disease and treatment, being reliant on the MDT for the information, and accepting that it was perfectly possible for them to have cancer. They were open about not reading the information:

"I never read the info I guess I didn't want to knowmy wife read up on it I just did not want to know, it was if the detail didn't bother me I wanted to know a little bit but when they give you a book that thick (uses thumb and index finger to illustrate an inch) on neck dissection that was of no interest."

Sort number 18: 1.1-1.6

They were aware they had been through a terrible experience but seemed to have recovered to a point that they could see they would be as good as they could be but this did not mean back to pre-morbid levels. The following excerpt illustrates that this participant recognised that.

"I was walking up Kidderminster and people were coming out of Greggs eating sausage rolls and pasties and it was difficult I wouldn't even have done that and it's because it's been taken off me its imposed on me and makes me feel very different."

Sort number 18 2.26-2.31

This participant also knew he would not improve and realised that there had been a double dip from the surgery to radiotherapy. There was sense that change and recovery did not mean back to normal. It did mean back to functioning.

"I thought I had been through the worst (after the surgery) and it turned out that there was worse (radiotherapy) and that you don't get better."

Sort number 18: 2.12-2.14

Factor four, labelled 'Surviving or Not' was able to be categorical about some of their symptoms. They were not in pain, had no regrets in having treatment, and felt that being cured of cancer was paramount. They were not trying to avoid the news of their diagnosis and knew strongly that they had to deal with it. This group seemed to have some normality in their lives. They could be spontaneous and were not exhausted on a daily basis from their symptoms, but had insight into the fact that their life was different. It seemed that despite their treatment they had returned to pre-morbid routines. They admitted surprise that they had been diagnosed with cancer, something they had never contemplated, and had at the back of their minds the constant worry of any symptom they experienced being recurrence.

Sort number 3, with the smallest of the oral tumours diagnosed, who had a primary closure rather than needing a flap, was fearful of recurrence and expressed it in the following comments:

"This (looking at the statement 3) 'Any symptom I have I think is the cancer coming back' is obviously still an issue any symptom I get I think the cancer might be back.....I always feel there is a possibility that it might come back and therefore I feel in any pains down my neck or anything like that it does concern me, but my surgeon said I'm doing so well and instead of seeing me once a month he's seeing me every 8 or 10 weeks, although originally he said I'll see you once a month for the first 12 months and then stretch it out."

Sort number 3: 8.8-8.20

There is a sense that he was disconcerted in the change of management in the review periods. This group healed within their expected time-frame, and did not seem irritated by the health-care processes that might need altering.

The fifth and final factor, labelled 'Keep Control -Greater Good of Others', felt the need to challenge the health-care system. A lot of their experience seemed to be driven by the need to question and improve the care for future patients. They did feel able to argue even when they might have to resort to writing instead of talking. They were anxious in hospital and recognised they felt at their most vulnerable when they were in-patients, having their surgery.

Researcher "What made you feel vulnerable in hospital?"

Sort number 10 "Most of it was around lack of nursing care lack of support especially at night I felt vulnerable mostly at night because there was an agitated patient who was not being cared for and that was very inappropriate. I had a very bad experience on my second night in hospital I didn't sleep for three or four nights which was not good it was a traumatic both of us thought that something was going to happen it wasn't because I was in pain but I was refused medication because of inappropriate nursing care."

Sort number 10: 5.4-5.18

They wanted to be back at home where they could have more control of their lives again. They would worry if appointments were cancelled, not for themselves, because they knew they could interrogate and challenge the system, but for others, who might not appreciate the significance of not having a review appointment in a timely, frequent way. Both participants seemed to analyse and comment on their treatment and did not find relinquishing their health to others easy. Despite most significant amounts of surgery and oncological treatment they were not defined by their disease, and refuted the idea of being ill.

Sort number 15 was able to crystallise his ideas with his final comments of his semi-structured interview.

"I've been in hospital but I still don't think I'm ill. Yes survivor and victim and choice you said it (pointing at statement 13) if you didn't want to die you have treatment and patients say I don't have choice, I'm not ill, you push me into a

group about physical symptoms,and they are in recovery rehab which is a big shift for a hospital system I came in and you made me better but I am not poorly.”

Sort number 15: 2.27-2.36

Like his counterpart who also loaded to factor five, this participant, despite all the context of being a patient, still did not see himself as ill but as recovering.

DISCUSSION OF EXTREME AND CONSENSUS SCORES

Q Methodology uses a process in which all of the statements are seen within the context of the others within the Q sample. It would seem therefore, important to discuss specifically some of the extreme range or consensus scores that were evidenced through the eighteen Q sorts. Despite, in quantitative terms, a small sample of participants some statements had a wide range of response scores. Those with a range of nine or more out of a possible eleven, are detailed in table 6.1

TABLE 6.1

STATEMENTS THAT REPRESENTED THE WIDEST RANGE OF SCORES BETWEEN Q SORTS

Statement	Range (Scores)
13 'If you didn't want to die there was no choice but to have treatment'	11(-5-+5)
41 'Day to day life is physically exhausting'	10 (-4-+5)
22 'I felt very vulnerable when I was in hospital'	9 (-4-+4)

None of these statements could be measured reliably without direct reference to participants. This aspect of the experience seems essential to know if a team is going to be able to care for patients in a way that is individual and centred around them. These statements demonstrate extremes participants might have felt relating to vulnerability, fatigue and how they felt when in hospital. These aspects, whilst unpredictable in terms of their possible responses, are imperative if teams are going to respond to patients in ways that are likely to be constructive to them at an individual level. Not recognising these elements of the experience for patients might create barriers to communication because patients are not being helped to understand the treatment and their recovery through methods that they would prefer.

The statements with the least range of responses, two, represent some consensus between the participants taking part in the study and are detailed in table 6.2.

TABLE 6.2 CONSENSUS STATEMENTS BETWEEN THE Q SORTS

Statement	Range (scores)
34 'Life will never be the same again'	1(0-1)
16 'I have to be careful not to upset people'	1(1-2)
17 "You shouldn't have to face this sort of thing on your own"	2(2-4)
36 'I wish I'd had never been treated'	2(5-3)
4 'When I was told I had cancer I knew I had to face it'	2(4-2)
6 'I didn't want people to know what had happened to me'	2(1-3)
19 'No two patients are the same'	2(1-1)

The responses to statements 34 and 16 would seem to suggest that for all the participants despite going through a diagnosis and treatment for H&NC, there was no real sense of life not returning to normal or a need for them to change their interpersonal behaviours. It suggests that the disease has not overshadowed their lives and they are not guarded in the way they might interact with others. Such a belief is a facet that can be emphasised more by members of the MDT when they meet patients prior to their treatment. Patients who have not undergone definitive treatment will ask if they will be back to normal. It would be informative to draw on the evidence of this research that suggests that as a group, participants did not feel that their lives would 'never be the same again'. This does not answer satisfactorily when will I be back to normal? but does demonstrate that they will adjust and cope with the experience of the disease and treatment.

All participants agreed that no one should have to face this experience on their own. It is of note however, some of the participants, who lived on their own, felt they had support and were not alone because they identified the clinical team members as their support. This would suggest teams need to have knowledge around how much of an external support-network patients have in order to know whether there is a possibility that patients need to be more reliant on health professionals for their support. It might also be that patients who appear to have support are looking for more external, professional support because of not wanting to burden their families. The NICE guidelines (2004) acknowledge that patients who have a diagnosis of H&NC need psychosocial support at the time

of diagnosis, as well as during and after their treatment. This recommendation becomes more forceful when it is known that H&NC patients are reluctant to seek specialist psychological services because of the many and specific symptoms that they might experience. Moore et al(2004) suggested that for this patient group this was because of a fear of being overwhelmed by the identification of more losses that could not be rectified. Recent research has also indicated that in general terms cancer patients, as a group, are likely to experience anxiety and distress beyond the first year of their treatment (Carlson et al., 2011). Such evidence implies that it is likely to be the MDT who work with patients in relation to physical symptoms, who should act as the support because they can help patients to recognise the emotional aspects as well as the physical that a patient is likely to experience. Salender's work, has suggested that patients will seek support to reduce their psychological burden and that this might be done through a reappraisal of their life (Salender, 2011). The statements would appear to be a medium through which the diagnosis and treatment can be explored by the patient.

All participants strongly rejected the notion of wishing they had not been treated (statement 36), but perhaps this was in part due to their point in recovery and no recurrence of disease. It would seem for these participants, having cancer was not a taboo topic of conversation and they did not object to people knowing of their diagnosis. The final statement that only had a range of two, statement 19, 'no two patients are the same' might be something that health teams should consider. Given the tremendous range of presentation, aetiology and treatment choices that are possible, it would seem patients really hope that teams can

predict how they will respond to treatment. They seem to believe an experienced group of health professionals can predict what might happen and will base their care on previous, similar patients. Much of this thesis has developed the idea that it is not easy to predict the impact on patients of either the disease or treatment at an individual level. This, it would seem, is a hard notion for the participants to contemplate.

ADVANTAGES OF Q METHODOLOGY

The strength of this format and content is that a small sample of patients who have been treated for H&NC have generated all of the statements. The process is objective, transparent and has validity. No assumptions have been made in their creation, because the direct sources are the responses generated during semi-structured interviews at the stage of developing the concourse.

Q methodology is not a method that requires a representative sample of a patient- population to be used. Q sorts are not influenced by bio-clinical qualities, although they are presented, in order to give detail to the subjects taking part in a study. The criteria for being in the study, is instead, set more broadly and aims to include a group of participants taken from all possible combinations of treatments in order to examine the experience of patients who had undergone treatment for H&NC with curative intent.

This type of qualitative method also has a quantitative aspect, an advantage in a clinical environment that relates to absolute answers and definite correlations. The methodology has complimentary aspects therefore. A consequence of

providing data that has both aspects is that it is intended that the results can influence clinicians and researchers who might more naturally be allied to a specific type of methodology. The statistical results are exemplified by participants' comments, which mean that the qualitative analysis adds more detail to the quantitative information. The data is less open to misinterpretation by researchers because the participants are able to support the placement of the statements with explanations rather than researchers presuming a rationale for the statistical data.

This methodology does seem to have advantages over qualitative ones that might use interviews as the way of collecting data. The statements act as a consistent structure that all participants have to make a decision, and the process has output in the form of the ranked statements. A participant might not have considered explicitly the issues represented by the statements until given the opportunity to do so from the finite list. The process enables them to decide what is meaningful, valuable and significant, rather than the researcher (Ward, 2010). The statements have to be viewed within the context of the whole group of statements. One statement in a position should be substantiated and evidenced by other statement placements - an active process for each participant and not one through which they can be passive. The arrangement allows the patient to explain relevant experiences that influence their answer, rather than the researcher or health-care worker making assumptions on their behalf.

The statements that have been used to form the Q set are a framework through which H&NC patients translate some of their experience of the disease and

treatment from their perspective. The structure allows others who have not experienced the disease to understand what matters to them, in a format that they can relate to. Sort number 9 commented on the statements as she reviewed them:

“Written down they are very therapeutic and that is such a big help there is relief to just read it and realise you are not on your own.” (As the participant reads statement 7 again in reviewing the placement of the statements, which she placed at position +1).

Sort number 9: 2.9-2.11

“No one can understand what has happened to me- I have just one friend and I suppose she’s worried I am not going to get my speech back and be left like this she has insight.....I think she is voicing it, others don’t and until they hear it from me they’re holding back and that’s ok. There’s no expectation I am not hiding anything we just don’t know.”

Sort number 9: 2.9-2.19

LIMITATIONS OF Q METHODOLOGY

The results of any Q methodology study cannot be generalised to larger populations of patients in other locations. The results have to be viewed within the context of the study environment, from which the participants were recruited, in this case a UK cancer centre. The method of producing the concourse is both intensive and protracted, and this might explain why for many studies it is not feasible, to use as a methodology. The time-intensive development of the concourse becomes more problematic because its creation is not reported routinely and is therefore not transparent. In order to counteract this particular issue and to enable the study to be replicated more easily, the author chose a methodological technique that has been described as a way of analysing data that is in a text format (Attride-Stirling., 2001).

The author collected the Q sort data and carried out the semi-structured interviews. Her presence and identification as a member of the MDT and as the sole researcher for the study may have influenced and limited what the participants chose to reveal about their experiences and more specifically their quality of care. However, all of the participants had completed their treatment and were on outpatient reviews. They were not dependent on their teams for ongoing direct treatment, and the responses were such that frank discussion and reflection took place around the two global themes of quality of care and reality.

The decision was taken by the research team that participants were likely to be more communicative if they had an opportunity for discussion, rather than being requested to write down their views. It is possible that because the interviews were face to face the participants edited or chose not to disclose certain aspects of their care.

All of the participants spoke and read English. It is not possible to suggest that these experiences can be reframed or presented as the results that are likely for other cultures. All of the participants for this study were English speaking and able to read and write. The results cannot be generalised because, just like other Q methodology studies, these results cannot claim to go beyond this participant group. The methodology captures and interprets points of view about the phenomenon investigated rather than back to the population studied (Ward, 2010).

IMPLICATIONS OF THIS STUDY IN RELATION TO HEALTH POLICY AND CLINICAL PRACTICE

The clinical application and the way in which this research relates to health-care policy will now be considered. It should be remembered that the Q methodology study was built upon from two previous studies by the author. It has been demonstrated by the author (Reid et al, 2009) that health care professionals are unlikely to draw conclusions relating to quality of life measures for patients based on tumour size because they recognise that this information is not relevant or is not well aligned to such a subjective and dynamic concept as quality of life. This means that patients should not have assumptions made on their behalf by the MDT who instead should seek to discuss the issues relating to experience with the patient. The value of this Q methodology study is that the forty-five statements have originated from H&NC patients and were arranged by them in order to create a personal constellation, which has produced the five views of the experience of H&NC and its treatment. Such detailed results relating to the experience is not evident in the current literature relating to H&NC.

Downie and Mcnaughton's work (2000), discussed in **chapter three page 107**, had identified that there should be a fusion of technical and humane skills in order that clinical decisions can be made. The technical skills of both the oncology and surgical specialities that treat H&NC patients have become more sophisticated, demonstrated by the increasing intricacy and complexity of surgical techniques, drug and radiotherapy regimes. However, it is vital that

whilst these technical skills advance the humane aspects of care and decision-making develops too. This study starts to provide the detail on how this might happen because it has identified distinct views that patients have about their context and experiences. The method has provided both an assessment of the patients' experience and a medium through which patients might influence their care. This means that the humane part of health care can become more refined and in so doing inform patients, clinicians and researchers of the experiences. HCPs can then be said to be responding to modern health care policy, in which it is stated that care should be patient centred, holistic and involve them throughout. If this is not achieved then the experience is likely to be routine, or applied in a random and impersonal ways, i.e. as medicine wants it, rather than as patients need.

Table 6.3 lists the different levels that the framework of the experience for patients with H&NC can be related to, and defines how this might be put into professional practice at clinical, service and political levels.

TABLE 6.3 LEVELS OF HEALTH-CARE AND DESCRIPTIONS WITH REFERENCE TO THE FRAMEWORK

Level identified	Description of issues at each level
Translation of the 45 statements and the five factors at a clinical level:	<p>The statements or factors can be represented by:</p> <ol style="list-style-type: none"> 1.The Development of questionnaire using the statements to explore the experience of treatment and disease 2.A psychometric measure through which patients are able to compare their experience and reaction with that of the five factors by discussion relating to how similar or different they think they are to the factors 3.The completion of a Q sort so that patients engage actively with the statements identified by participants in the study 4.The statements act as framework through which a semi structured interview can elicit the experience for patients and influence their future care
Profession Level: Speech and Language Therapy (SLT)	<p>SLTs in clinical practice treat patients from the pre treatment stage through to their recovery. SLTs will assess a patient in order to establish a change in speech and swallowing function. Discussion with patients using an impairment-based model enables patients to develop, through exercises and techniques, skills to improve their swallowing and communication. The interaction is likely to be task and process driven. In its extreme form this clinical relationship ignores how a patient is managing to respond emotionally to fundamental and personal functions. Patients are likely to be vulnerable and can be supported in a patient-centred holistic way if there can be some identification of their concerns. If this can be achieved they and the SLT will become aware of optimal ways that they experience their care. This is relevant in relation to how patient assimilate information, and the ways patients interact successfully with the MDT. If such concepts can be understood there is likely to be less distress which will enable patients to be more active in their rehabilitation.</p> <p>Such a method and framework should be taught to SLTs at both an undergraduate and post graduate stages of training.</p>

Table 6.3 (continued)

Level identified	Description of issues at each level
<p>Service Level Advancing technical skills that are forgetting or overlooking the relational aspects of care</p>	<p>Patients have treatments that are increasingly advanced, but if services cannot respond to patients at an individual and specific level they will be more vulnerable and dependent on services. Such demands are not sustainable because of the demand to treat other patients who are more recently diagnosed. The use of the results of this study, in one of the formats described at the clinical level, allows for their relational aspects to be represented and enables the service to respond to them in ways that are most suited to them, and account for many different aspects of their experience</p>
<p>Political level</p>	<p>More patients are surviving cancer (Maddens (2009). The budget available in real terms is diminishing whilst the expenditure continues to increase. The NHS is projected, via financial reforms, to save 20 billion pounds by 2014. Resources will diminish and have to demonstrate that they can make a difference to how patients might cope at both a physical and emotional level. The nursing profession has re-emphasised the relational aspect of care through 'Compassion in Practice' (Commissioning Board Chief Nursing Officer and DH Chief Nursing Adviser, 2012) what have become known as the 6 Cs of the NHS constitution i.e. care, compassion, competence, communication, courage and commitment. All these aspects remain vital and not ones that can be left out or reduced when caring for patients by any discipline</p>

The different levels identified in table 6.3 can be demonstrated through a description of a patient that the author treated in December 2012. Neil, (a pseudonym), worked as a university science lecturer. He had not been seen by the author pre-treatment but had undergone surgery to remove his left maxilla (roof of mouth) which was replaced temporarily with an obturator (soft acrylic plate, covering the left side of his roof of mouth). The procedure was to be completed in eight weeks time by having a free flap reconstruction (fibula) that would include both bone and soft tissue. The surgical team asked the author to review the patient's swallowing and communication twenty-four hours after his operation because they had identified that he was neither swallowing nor communicating easily. The author was able to assess the patient with reference to these two specific functions and discuss with him and his wife the impact that the diagnosis and treatment had had on them. The patient was due to go home the next day and he wanted to know whether the stage he was at physically and emotionally was normal. He expressed feelings of being very shocked at the diagnosis and being unable to make sense of what was happening in his oral cavity. The author, at a point of immersion in writing up the results and discussion of the factors from the Q study, was able to suggest that he was behaving as someone who might be seeking to find the meaning and attachment to illness. The author gave examples of what this might mean to the patient, which prompted the patient to question if he was in denial. Again the author could reference what might be the evidence to demonstrate that the patient was not in denial, but instead trying to make sense of the treatment in relation to his symptoms. This was achieved by using some of the statements

in the form of a semi-structured interview. At the end of the discussion the patient declared that he felt so relieved because he was starting to recognise and interpret some of his feelings. It appeared that the patient felt that his reaction was being validated and translated in ways that he could understand. He said it was first time that anyone had spent time to ask him how he felt. This may or may not have been the case, but it appeared that the timing and way in which the information was presented was tailored to this patient's needs. The author was able to share with the patient that she had been working with the H&NC patient group for more than fifteen years and that she was completing this research. The author was able to demonstrate attunement with the patient through the framework of the current study.

This example illustrates the absolute importance of the current work at a clinical, educational and policy level. No assumptions should be made, based on preconceived ideas, patients should be able to discuss their experience using the statements and factors as a framework to inform and guide the MDT about their experiences. The statements and factors provide a structure for this discussion. It is for this reason that it would not be the author's intention to restrict patients' discussion to a questionnaire on the experience of disease and treatment. If a questionnaire was the medium, the process is open to the same criticism that has been used within this thesis, regarding the QoL questionnaires.

Reflection with specific reference to this patient meant that the author could identify that if the patient had gone home without a review of the current situation, after his first procedure, he would have been likely to have struggled to make sense of how he had been affected at both a physical and emotional level. These two aspects of the reaction should be seen as being equally important and that the one will influence the other. It is not unusual to fail to consider the emotional aspects for patients and how they might have reacted to the experience (Bultz and Carlson;2003) and any attempt to predict their mood, without direct reference to patients is inaccurate (Mitchell et al; 2008).

Table 6.3 (P217-218) at the SLT clinical level acknowledges that within the author's profession it is not routine practice to appraise how the emotional aspects of the diagnosis and treatment have impacted on the patient. In relation to Neil and his wife the intervention by the author also meant that they could start to see how they might interpret information that they were given. It had been vital for them to have an opportunity to explore how they felt. If this can be achieved they are more likely to process the current events because they have been treated as complete entities.

'Patients who are treated considerately, who are not left to endure anxiety and worry, who are treated attentively, who are given full and prompt information, who understand what they are being told and who are given the opportunity to ask questions, are more likely to have better clinical outcomes. A good patient experience goes with good clinical care – and patients need both.' (Patient-led NHS p8 2005).

Whilst efficiency is implicit in order to respond to the volume of patients there is a need to improve the quality of the care. The author was able to achieve the philosophy of this policy during her clinical interaction with Neil. The author's

intervention meant that the patient was discharged from hospital the next day able to drink, eat soft foods and communicate orally. At his initial assessment he had been pipetting water into his mouth at a very slow rate. Since the patient's initial assessment he and his wife have been seen in pre treatment clinic to discuss the second operation. He and his wife were able to recall that they did not want to read information or look on the internet. They wanted to discuss with the team the next stage. They asked if Neil would ever return to normal. This prompted the author to recall the evidence from this study that patients seemed more concerned about other aspects of the experience than the impact it might have had on their lives. In the context of the experience there are many other aspect of the experience that become more important, which creates the sense that the notion of 'life will never be the same again' having limited meaning.

From an education and training perspective the framework could be explained and taught to SLT at both an undergraduate and post-graduate level. It should be that in order to be effective clinically SLTs can use a framework that reviews how patients might experience disease and treatment and integrate these aspects with the technical expertise they need to help the patient achieve. Unless this aspect is accounted for, it is very possible that patients are less able to assimilate the technical aspects of their communication and swallowing management. The implications of this are that SLT interventions are less effective because patients are not being managed in ways that respond to factors that might influence their experiences. In the knowledge that the

author's intervention is not standard, and has merits that should be identified in order that they can be generalised into the routine practice of other SLTs, a further study is being designed to describe and measure the impact of this style of intervention.

The health resources available to patients are finite and, as they are exposed regularly to HCPs, they should have the opportunity to challenge the purpose and effectiveness of the interventions they experience. The intention is not to score or grade the experience, but to enable patients to understand how they are affected as well as provide a structure that can enable them to influence their care by appreciating how they react to the experience. Through this method patients can be more engaged and responsive with their teams. If patients are given the vocabulary, in terms they can understand, they are more likely to express what they want and how they feel, which will be described through the six global themes and represented by the forty-five statements. The arrangement of the statements and responses to them through a semi-structured interview does not mean that what a patient thinks is limited to predictable conclusions; instead the responses should act as a way of orientating the team to what matters to patients about their experience. Through this technique HCPs have a starting-point from which they might enquire further with the patient how they have experienced their disease and treatment. It is likely that this work provides a structure that compliments the advanced communication training courses which have been set up as a way of facilitating best practice for patients with cancer to discuss with HCPs specific issues they might have at the time of diagnosis and during their treatment.

Policies have recognised the importance of addressing the emotional, as well as physical aspects of care; table 6.4 lists some of these documents and describes the intended role of the patient.

TABLE 6.4 HEALTH POLICIES RELATING TO THE EXPECTATION OF PATIENTS' ROLES.

Policy	Expectation of patients' roles.
The Expert Patient, (2001)	Patients' independence facilitated by knowledge and information relating to their disease and possible treatments
Creating a Patient-Led Service (2005)	Patients have a more thorough understanding information with dialogue
High Quality for All (2008)	Safety and effectiveness of treatments should also include the experience of care
The Shared Decision Making Policy (2011)	Development of the concept of decision making beyond treatment choices, to self-management and personalised care-planning
Outcomes Strategy Framework (2012)	Patients' experience of care, with reference to relational aspects should be identified. Patients should be active in deciding how they might want to engage with aspects of their care

The five factors from this study evidence the personal experience of H&NC in a research arena that is dominated by quantitative approaches to research questions. These quantitative aspects focus on survival intervals and other temporal descriptors, but there remains the need for research and clinical practice to assure them that the quality of their survival will be represented and can influence future experiences of patients.

In the introduction to this thesis three fundamental questions were asked in the knowledge that these areas of enquiry were not answered satisfactorily:

- What is the experience for patients of the diagnosis and treatment of head and neck cancer?
- Why do patients with apparently similar disease classification and treatment appear to have such different reactions to the treatment?

This study gives detailed answers to these questions. Five ways of experiencing the disease and treatment have been identified. These factors are discrete from one another in their presentation and cannot be predicted by the disease classification or treatment used. Instead, the way participants internalise the experience is the credible explanation as to how patients who have similar treatments might react differently. This also helps explain why patients diagnosed with small tumours can appear to be so limited in their function, whilst others with large disease and protracted treatments can do so well. It is not possible yet to predict how a patient might work through the experience, but there is benefit in understanding how patients have dealt with previous life-changing experiences and used these to achieve some state of well being previously. They might employ similar strategies or be able to understand why the experience is so difficult. From these results the only aspect of the bio-clinical information that might be related to a particular factor was from the responses to factor four, 'Surviving or Not'. All of these participants had surgery only and might be said to have expected to be on a trajectory of recovery from the date of their surgery. They did not receive dual-modality treatment, and it could be that the other participants loaded onto the other factors as a reaction to intense, protracted treatments. Unfortunately, as

described in chapter one, most patients present with late stages of the disease so that their treatment, if possible, needs to involve both surgical and oncological management.

Whilst transcribing the recordings of the semi-structured interviews, the author could start to identify some of the missing gaps that she had suspected if QoL questionnaires were used. The questionnaires were constraining the outcomes with pre-determined domains and gave little scope for patients to explain, across themes, the ways they responded to the experience. The interviews, which were products of the Q sort, gave the participants a way of articulating some of their experiences. Sort number 15 loaded onto factor five, 'Keep Control -Greater Good of Others', exemplifies his factor descriptor in part of his semi-structured interview.

Participant "Once I knew something could be done I wanted to know all the ins and outs of it, every little detail all the jargon. I wanted to know on the assumption I would get over the treatment I wanted to know how I would be"

Researcher: "So cure wasn't the only issue?"

Participant: "No it was the quality of life after and what I was told was remarkably accurate that ties in with the statement you wanted the team to be honestI wanted to know [how it would be] not just about the length of life- it's the qualityits not at all costs..... take it to the extreme if I was a cabbage what's the point?"

Sort number 15:1.15-1.22

The same participant demonstrated his tenacity when he got home (living alone and caring for himself).

"Having got from hospital to home under my own steam I proved I could do things - not as well as I did do physical areas, I was OK but mentally I wasn't sure because you look like you have done ten rounds with Mike Tyson and you can't talk and that's very daunting..... I had to write everything down for months because of the voice- like through the glass screen (at the post office)

they couldn't understand me because I had no voice its hard enough at the checkout but with a screenbut the response I got was remarkably good people didn't know what had happened but they were really sympathetic you saw the nicer side of people."

Sort number 15: 2.1-2.11

The detail in such commentaries is neither shown nor assimilated in routine clinical practice by the MDT, despite the possibility that it could be used to influence patients' ongoing or future care.

Health-care systems will remain under tremendous process and budget pressures, and this might tempt clinicians and managers of health to measure superficial aspects of the experience of disease and care. Such a position means that the outcome of care is represented almost exclusively at a functional level, characterised by data generated from the satisfaction of care and efficiency of the service delivery.

Defining what matters in the representation of their experience needs structure. The statements are a way of giving patients the vocabulary to express their individual experiences. A limitation is that it is a finite list of patient experiences. There is therefore a skill in their use by HCPs to facilitate the patient in order to identify the key features of experience. It cannot be suggested that this is the only way of achieving an understanding of a patient's experience, but the way of producing the structure has been derived from patients and means that patients have consistent structure through which to express these.

Cancer patients do not arrive at an initial consultation with knowledge of the terms used by HCPs or a dictionary to translate them. Hitchens, an intellectual

who died of oesophageal cancer in 2011, wrote a reflection of his NHS care. His remarks enabled some further reflection of the application of the current study into clinical practice beyond the H&NC specialty for the author. His commentary relating his transition from being a member of the public to a cancer patient was so striking to the author, that it is quoted on the title page of this study. It captured the quintessential features that this study explores:

‘..moving from the country of the well across the stark frontier that marks off the land of malady....The new land is quite welcoming in its way. Everybody smiles encouragingly.....the country has a language of its ownyou feel swamped with passivity and impotence’ (Hitchens, 2012)

One might expect that an intellectual reflecting on his disease and treatment would have a good grasp of the health-phrases and assimilate the experience because of the adept language system he possesses. Worryingly this was not the case, worryingly and like many other patients he was unable to grasp or assimilate the experience and felt unable to be active. It is the job of clinicians to give patients, at their individual pace, the right phrase book that can decode their care. This can be achieved by patients if they are able to isolate some of the key components of their experience for themselves.

Many of the statements used in the Q-study are not disease-specific and go beyond the boundaries of disease categories, and are part of the human condition. The language, generated from H&NC patients, can inform the experiences of patients who have had different diseases or traumas. It could be

that these statements, with little translation, are meaningful to other patient groups. Many questionnaires classify the physical aspects; this study has not intended to address this facet of care. Instead, the author's work has created a unique tool that presents, at a personal level, the reality of the experience of disease and treatment. Its achievement is that it does this by allowing patients to reflect and synthesize the information from their individual perspective, and compare aspects of their care that have been viewed as relevant by other H&NC patients.

It is the intention of the author to work within her current trust to establish whether other similar, but different patient groups, have shared factors to the ones discovered by the current study. The statements are a medium through which patients and medical teams can be clearer about patients' needs and shared decision-making manifested. The statements are prompts through which patients can be asked directly about their experience so that they do not become marginalised or under-represented by minimal easy-to-measure data sets. Health-care workers have to have the energy to respond to patients as people who have their own particular concerns; these should be addressed rather than overlooked. They cannot excuse themselves of the issue by stating that the complexity of the situation and the volume of patients have overwhelmed them. Teams have to have both technical and humane expertise (Downie and Mcnaughton., 2000) and to disregard patient views is not acceptable. It is the belief of the author that this thesis adds detail to the experience and treatment of H&NC, which has not previously been investigated

using this methodological technique. Here also is a framework through which ideas can be introduced and feelings expressed relating to the experience of disease and treatment. Porter's (2003) and Kennedy's (2010) observations relating to health care need to be reacted to by thorough and reasoned research so that the experience of patients with reference to their disease and treatment can be known and influence their care. This study has provided some of the detail that has been missing with particular reference to patients with H&NC. It is a foundation from which more patients can be supported through the unfamiliar territory of health care, which Hitchens described as the land of malady.

APPENDIX 1.1

**FIGURE 1 LATERAL SCHEMATIC DIAGRAM OF HEAD AND NECK DETAILING
MAIN AREAS OF THE HEAD AND NECK. (SIGN, 2006 PAGE 74)**

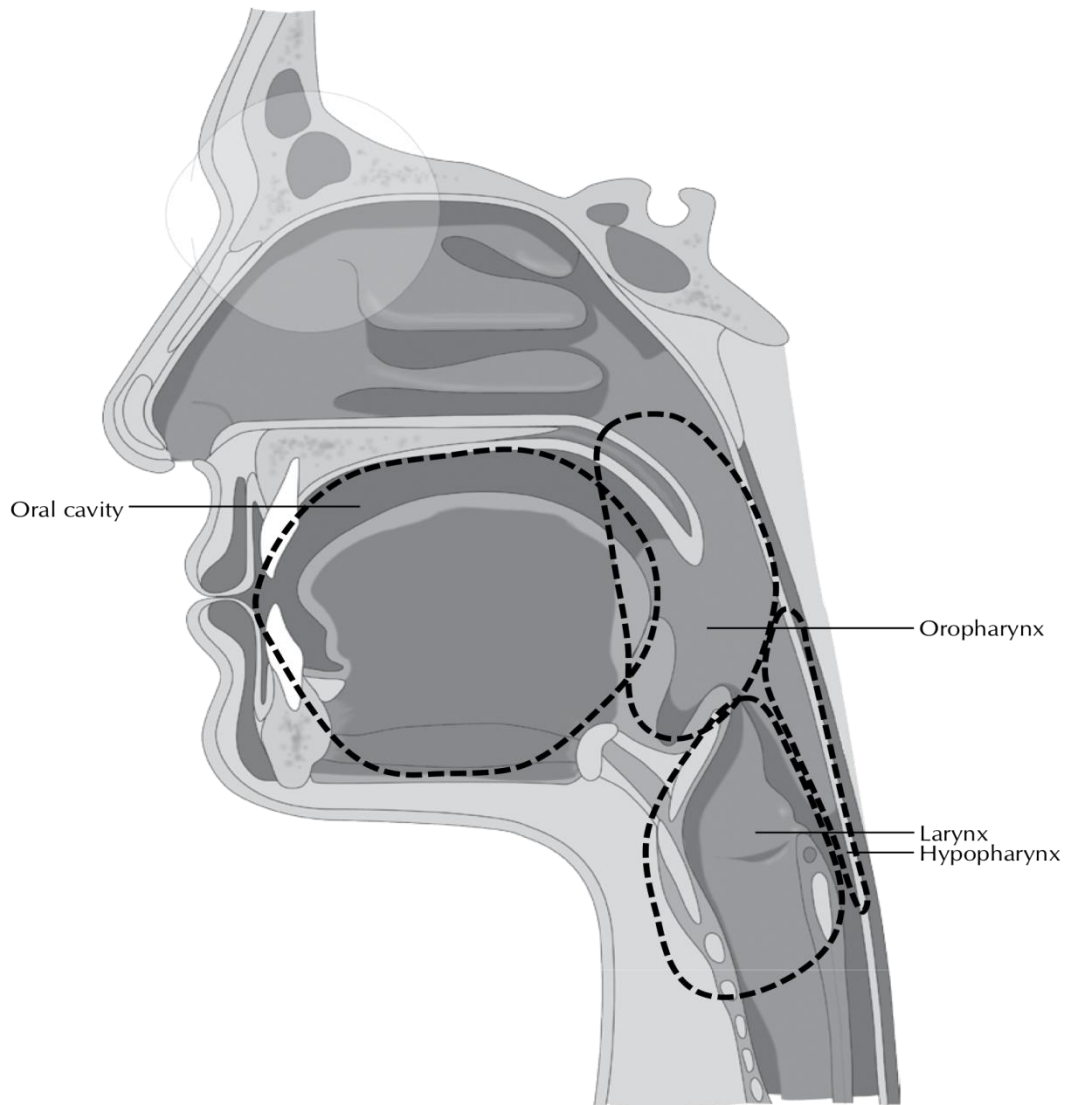


FIGURE2 MAIN STRUCTURES OF THE ORAL CAVITY DORSAL ASPECT OF TONGUE (SIGN, 2006 PAGE75)

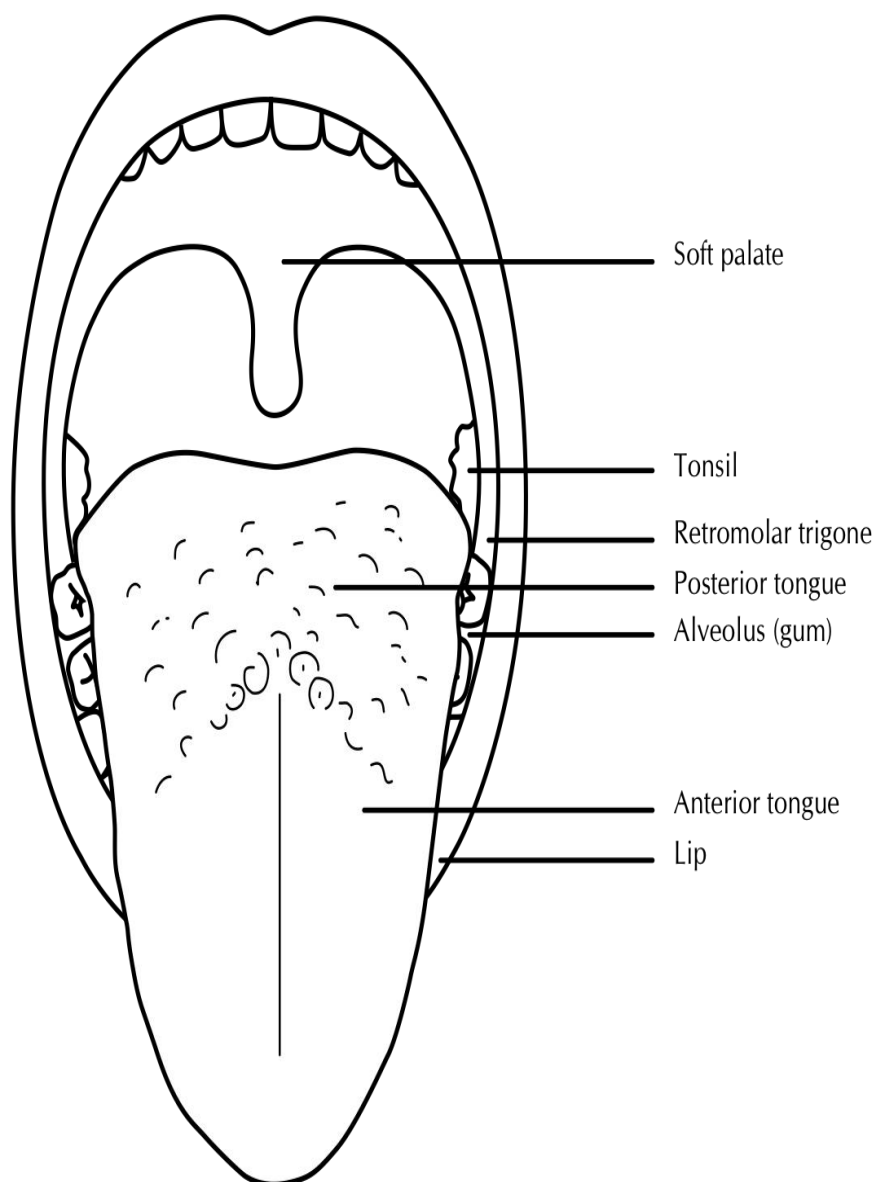
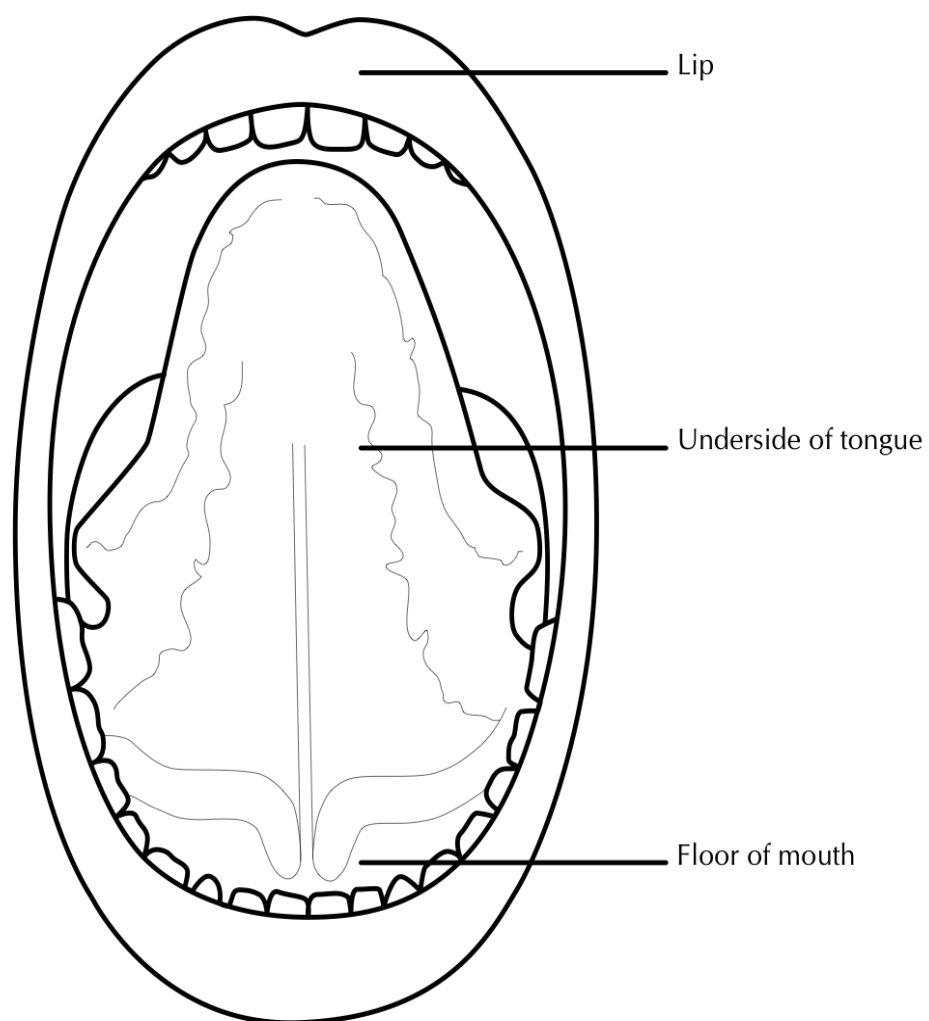


FIGURE 3 VENTRAL ASPECT OF TONGUE. (SIGN, 2006 PAGE 75)



**APPENDIX 1.2 TUMOUR CATEGORIES FOR ORAL, ORAL PHARYNGEAL AND
HYPOHARYNGEAL CANCERS INCLUDING NODAL DESCRIPTORS FROM UICC
TNM CLASSIFICATION OF MALIGNANT TUMOURS (SIGN, 2006 PAGE 70)**

Stage	
TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Tis	Carcinoma in situ
	Oral cavity
T1	≤ 2 cm
T2	> 2 cm to 4 cm
T3	> 4 cm
T4a	Through cortical bone, deep/extrinsic muscle of tongue, maxillary sinus, skin
T4b	Masticator space, pterygoid plates, skull base, internal carotid artery
	Oropharynx
T1	≤ 2 cm
T2	> 2 cm to 4 cm
T3	> 4 cm
T4a	Larynx, deep/extrinsic muscle of tongue, medial pterygoid, hard palate, mandible
T4b	Lateral pterygoid muscle, pterygoid plates, lateral nasopharynx, skull base, carotid artery
	Hypopharynx
T1	≤ 2 cm and limited to one subsite
T2	> 2 cm to 4 cm or more than one subsite
T3	> 4 cm or with hemilarynx fixation
T4a	Thyroid/cricoid cartilage, hyoid bone, thyroid gland, oesophagus, central compartment soft tissue
T4b	Prevertebral fascia, carotid artery, mediastinal structures

TUMOUR CATEGORIES FOR LARYNGEAL CANCERS (SIGN 2006 PAGE 71)

Larynx	
Supraglottis	
T1	One subsite, normal mobility
T2	Mucosa of more than one adjacent subsite of supraglottis or glottis or adjacent region outside the supraglottis; without fixation
T3	Cord fixation or invades postcricoid area, pre-epiglottic tissues, paraglottic space, thyroid cartilage erosion
T4a	Through thyroid cartilage; trachea, soft tissues of neck: deep/extrinsic muscle of tongue, strap muscles, thyroid, oesophagus
T4b	Prevertebral space, mediastinal structures, carotid artery
Glottis	
T1	Limited to vocal cord(s), normal mobility
T1a	one cord
T1b	both cords
T2	Supraglottis, subglottis, impaired cord mobility
T3	Cord fixation, paraglottic space, thyroid cartilage erosion
T4a	Through thyroid cartilage; trachea, soft tissues of neck: deep/extrinsic muscle of tongue, strap muscles, thyroid, oesophagus
T4b	Prevertebral space, mediastinal structures, carotid artery
Subglottis	
T1	Limited to subglottis
T2	Extends to vocal cord(s) with normal/impaired mobility
T3	Cord fixation
T4a	Through cricoid or thyroid cartilage; trachea, soft tissues of neck: deep/extrinsic muscle of tongue, strap muscles, thyroid, oesophagus
T4b	Prevertebral space, mediastinal structures, carotid artery

NODAL AND METASTATIC CATEGORIES FOR H&NC TUMOURS (SIGN, 2006

PAGE

73)

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph nodes metastasis
N1	Ipsilateral single ≤ 3 cm
N2	a. Ipsilateral single > 3 to 6 cm b. Ipsilateral multiple ≤ 6 cm c. Bilateral, contralateral ≤ 6 cm
N3	> 6 cm

M categories for oral cavity, oropharyngeal, hypopharyngeal and laryngeal and cancers from UICC:TNM Classification of Malignant Tumours⁴

MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis

Stage grouping for oral cavity, oropharyngeal, hypopharyngeal and laryngeal and cancers from UICC:TNM Classification of Malignant Tumours⁴

Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T1, T2	N1	M0
	T3	N0, N1	M0
Stage IVA	T1, T2, T3	N2	M0
	T4a	N0, N1, N2	M0
Stage IVB	T4b	Any N	M0
	Any T	N3	M0
Stage IVC	Any T	Any N	M1

Appendix 2.1 DISTRESS THERMOMETER

Patient's name: _____

Treatment Review

First please circle the number (0-10) that best describes how much distress in general you have been experiencing over the past week, including today.

Second, if any of the following has been a problem for you over the past week, including today, please tick the box next to it. Leave it blank if it does not apply to you. Then rank your top 4 difficulties (1 would be the biggest problem, 4 would be your fourth biggest concern)

<p style="text-align: center;">THERMOMETER</p> <div style="text-align: center;"> </div>	<p>RANKING</p> <p>Practical Problems:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Child care <input type="checkbox"/> Housing <input type="checkbox"/> Finances <input type="checkbox"/> Transportation <input type="checkbox"/> Work/school <p>Family Problems:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Dealing with children <input type="checkbox"/> Dealing with partner <p>Emotional Problems:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Depression <input type="checkbox"/> Fears <input type="checkbox"/> Nervousness <input type="checkbox"/> Sadness <input type="checkbox"/> Worry <input type="checkbox"/> Anger <input type="checkbox"/> Unable to make plans <p>Spiritual/religious concerns:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Loss of faith <input type="checkbox"/> Relating to God <input type="checkbox"/> Loss of meaning or purpose of life <p>Other Problems:</p>	<p>RANKING</p> <p>Physical Problems:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Appearance <input type="checkbox"/> Bathing/dressing <input type="checkbox"/> Breathing <input type="checkbox"/> Changes in sensation <input type="checkbox"/> Constipation <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Gating <input type="checkbox"/> Fatigue / Tiredness <input type="checkbox"/> Feeling swollen <input type="checkbox"/> Fvents <input type="checkbox"/> Getting around <input type="checkbox"/> Indigestion <input type="checkbox"/> Mouth sores <input type="checkbox"/> Nausea <input type="checkbox"/> Nose dry/clogged <input type="checkbox"/> Pain <input type="checkbox"/> Sexual <input type="checkbox"/> Skin dry/itchy <input type="checkbox"/> Sleep <input type="checkbox"/> Tingling in hands/feet <input type="checkbox"/> Metallic taste in mouth
--	--	--

Patient details

Signed by staff member:	Today's Date:	
	DURATION OF INTERVIEW: (in minutes)	
Diagnosis:		



Highest ranked concerns	RATING	Description and history of problems	Plan of action
1.			
2.			
3.			
4.			





EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:

--	--	--	--	--

Your birthdate (Day, Month, Year):

--	--	--	--	--	--	--	--	--	--	--	--

Today's date (Day, Month, Year):

31

--	--	--	--	--	--	--	--	--	--	--	--

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4

Please go on to the next page



EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:	Not at all	A little	Quite a bit	Very much
31. Have you had pain in your mouth?	1	2	3	4
32. Have you had pain in your jaw?	1	2	3	4
33. Have you had soreness in your mouth?	1	2	3	4
34. Have you had a painful throat?	1	2	3	4
35. Have you had problems swallowing liquids?	1	2	3	4
36. Have you had problems swallowing pureed food?	1	2	3	4
37. Have you had problems swallowing solid food?	1	2	3	4
38. Have you choked when swallowing?	1	2	3	4
39. Have you had problems with your teeth?	1	2	3	4
40. Have you had problems opening your mouth wide?	1	2	3	4
41. Have you had a dry mouth?	1	2	3	4
42. Have you had sticky saliva?	1	2	3	4
43. Have you had problems with your sense of smell?	1	2	3	4
44. Have you had problems with your sense of taste?	1	2	3	4
45. Have you coughed?	1	2	3	4
46. Have you been hoarse?	1	2	3	4
47. Have you felt ill?	1	2	3	4
48. Has your appearance bothered you?	1	2	3	4

Please go on to the next page

During the past week:

	Not at all	A little	Quite a bit	Very much
49. Have you had trouble eating?	1	2	3	4
50. Have you had trouble eating in front of your family?	1	2	3	4
51. Have you had trouble eating in front of other people?	1	2	3	4
52. Have you had trouble enjoying your meals?	1	2	3	4
53. Have you had trouble talking to other people?	1	2	3	4
54. Have you had trouble talking on the telephone?	1	2	3	4
55. Have you had trouble having social contact with your family?	1	2	3	4
56. Have you had trouble having social contact with friends?	1	2	3	4
57. Have you had trouble going out in public?	1	2	3	4
58. Have you had trouble having physical contact with family or friends?	1	2	3	4
59. Have you felt less interest in sex?	1	2	3	4
60. Have you felt less sexual enjoyment?	1	2	3	4

During the past week:

		No	Yes
61. Have you used pain-killers?		1	2
62. Have you taken any nutritional supplements (excluding vitamins)?		1	2
63. Have you used a feeding tube?		1	2
64. Have you lost weight?		1	2
65. Have you gained weight?		1	2

Appendix 3.2

Q methodology Gathering the concourse.

LITERATURE SOURCES THAT GENERATED THE SEMI-STRUCTURED INTERVIEW QUESTIONS

Below are the questions that were generated by an examination of the literature that had been reviewed when searching for “experience” and coping and head and neck cancer

Did you suspect you had cancer when you first went to your doctor?

If so, what made you suspect this?

Scott S, McGurk M, Grunfeld E

Patient delay for potentially malignant oral symptoms.. Eur J Oral Sci. 2008

Apr;116(2):141-7.

Scott SE, Grunfeld EA, Main J, McGurk M.

Patient delay in oral cancer: a qualitative study of patients' experiences.

Psychooncology. 2006 Jun;15(6):474-85.

SE, Grunfeld EA, McGurk M.

Patient's delay in oral cancer: A systematic review. Scott Community Dent Oral Epidemiol. 2006 Oct;34(5):337-43.

At the time of diagnosis, what mattered most to you?

List MA, Rutherford JL, Stracks J, Pauloski BR, Logemann JA, Lundy D,

Sullivan P, Goodwin W, Kies M, Vokes EE.

Prioritizing treatment outcomes: head and neck cancer patients versus non-patients. Head Neck. 2004 Feb;26(2):163-70.

What expectations had you got of the treatment?

Humphris GM, Field EA.

The immediate effect on knowledge, attitudes and intentions in primary care attenders of a patient information leaflet: a randomized control trial replication and extension. [Br Dent J](#). 2003 Jun 28;194(12):683-8;

How do you feel about the care you've been given?

All the people that you have had to meet directly so you're your care could take place?

Recommendation of what assessments and people that the patient should meet pre treatment. Improving outcome Guidelines 2004

How did having a diagnosis of H&NC impact on your life before you were treated?

Hammerlid E, Bjordal K, Ahlner-Elmqvist M, Boysen M, Evensen JF, Bijorklund A, et al.

A prospective study of quality of life in head and neck cancer patients. Part 1: At diagnosis.

The Laryngoscope 2001; 111: 669-680

Colangelo LA, Logemann JA, Rademaker AW.

Tumour size and pre treatment speech and swallowing in patients with resectable tumours.

Otolaryngol Head Neck Surg 2000; 122:653-61

Chen AM, Jennelle RL, Grady V, Tovar A, Bowen K, Simonin P, Tracy J,

McCrudden D, Stella JR, Vijayakumar S

Prospective Study of Psychosocial Distress Among Patients Undergoing

Radiotherapy for Head and Neck Cancer..

Int J Radiat Oncol Biol Phys. 2008 May 28.

Scharloo M, Baatenburg de Jong RJ, Langeveld TP, van Velzen-Verkaik E,

Doorn-op den Akker MM, Kaptein AA.

Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer.

[Head Neck](#). 2005 Oct;27(10):857-63.

How do you feel about the information you've been given? You can always use prompts.

Llewellyn C., McGurck M., Wineman J.

Striking the balance a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer
Psychology Health and Medicine 2005 10;(2) 180-19.

IOG 2004 says that patients should be given written information at the time of diagnosis to take away with them.

Can you explain the effect the amount of information had on you?

What has been the best thing about the information?

The worst thing?

May be positive in outcome De Boer 1995, Yu et al 2001 Kreitler et al 1995

Psychosocial effect of the information given can have a greater impact than the actual size and severity of the disease. Mediation by the patient on the disease and the situation they find themselves in

Scharloo M, Baatenburg de Jong RJ, Langeveld TP, van Velzen-Verkaik E, Doorn-op den Akker MM, Kaptein AA.

Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer.

[Head Neck](#). 2005 Oct;27(10):857-63.

Who did you feel the key people were...

Five main factors were associated with varying degrees with HR-QoL, personality, social support, satisfaction with consultation and information, behavioural factors, such as consuming alcohol and smoking, and depressive symptoms.

Llewellyn CD, McGurk M, Weinman J. Are psycho-social and behavioural factors related to health related-quality of life in patients with head and neck cancer? A systematic review.

[Oral Oncol](#). 2005 May;41(5):440-54.

What helped you to cope with the pre treatment phase?

Sharp HM, List M, MacCracken E, Stenson K, Stocking C, Siegler M. Patients' priorities among treatment effects in head and neck cancer: evaluation of a new assessment tool. *Head Neck*. 1999 Sep;21(6):538-46.

What are your main concerns now?

The positive association between psychological morbidity and fears of recurrence was significant at the majority of data collection points, with the exception that depression was more independent of these concerns.

Humphris GM, Rogers S, McNally D, Lee-Jones C, Brown J, Vaughan D.

Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients. [Int J Oral Maxillofac Surg.](#) 2003 Oct;32(5):486-91.

Fears of recurrence were not related to any socio-demographic factor (age, gender, ethnicity, marital status, and educational attainment) or disease, treatment, or symptom-related factors. Path analyses demonstrated that fears of cancer recurrence after treatment were directly predicted by pre-treatment fears and optimism. CONCLUSION: Although components of the CSM (cognitive and emotional representations, coping strategies) were associated with fears of recurrence, optimism was found to be the strongest predictor of fear, independent of anxiety and level of fear reported prior to treatment.

Llewellyn CD, Weinman J, McGurk M, Humphris G.J Can we predict which head and neck cancer survivors develop fears of recurrence? *Psychosom Res.* 2008 Dec;65(6):525-32.

Has the H&NC affected the way you see yourself?

Aspiration, weight loss, and quality of life in head and neck cancer survivors.

Campbell BH, Spinelli K, Marbella AM, Myers KB, Kuhn JC, Layde PM.

[Arch Otolaryngol Head Neck Surg.](#) 2004 Sep;130(9):1100-3.

While their main postoperative concern was the oral reconstruction site, after about 1 year, the donor site became more important to patients. However, the results were good. A 100 percent take of the FTSG at the donor site should produce good results. Surgeons should pay adequate attention not only to the outcome at the reconstruction site, but also to the closure of the donor site

Ito O, Igawa HH, Suzuki S, Muneuchi G, Kawazoe T, Saso Y, Onodera M, Park S, Hata Y. Evaluation of the donor site in patients who underwent reconstruction with a free radial forearm flap

[J Reconstr Microsurg.](#) 2005 Feb;21(2):113-7.

Huang CH, Chen HC, Huang YL, Mardini S, Feng GM

Comparison of the radial forearm flap and the thinned anterolateral thigh cutaneous flap for reconstruction of tongue defects: an evaluation of donor-site morbidity.

[Plast Reconstr Surg.](#) 2004 Dec;114(7):1704-10.

Long-term survivors of head and neck cancer continue to have both objective and subjective deficits in speech parameters five years after treatment.

Objective deficits are associated with subjective concerns about speech, eating, and recreation.

Meyer TK, Kuhn JC, Campbell BH, Marbella AM, Myers KB, Layde PM

Speech intelligibility and quality of life in head and neck cancer survivors.

[Laryngoscope.](#) 2004 Nov;114(11):1977-81

When disfigurement/dysfunction is associated with treatment, quality of life may be profoundly and adversely affected. Findings from the studies presented indicate a significant correlation between postoperative self-care and reduction in level of anxiety.

Dropkin MJ.

Body image and quality of life after head and neck cancer surgery.

[Cancer Pract.](#) 1999 Nov-Dec;7(6):309-13.

Although previous studies have shown that many of the effects of cancer treatment disappear between 1 and 3 years, this study shows that the dental status has a persistent impact on subjective quality of life.

Duke RL, Campbell BH, Indresano AT, Eaton DJ, Marbella AM, Myers KB, Layde PM

Dental status and quality of life in long-term head and neck cancer survivors.

[Laryngoscope.](#) 2005 Apr;115(4):678-83

What was the lowest point for you over the past year?

Fatigue during head-and-neck radiotherapy: prospective study on 117 consecutive patients. Jerezek-Fossa BA, Santoro L, Alterio D, Franchi B, Fiore MR, Fossati P, Kowalczyk A, Canino P, Ansarin M, Orecchia R. *Int J Radiat Oncol Biol Phys.* 2007 Jun 1;68(2):403-15.

Has anything been particularly difficult to cope with? The incidence of anxiety and/or depression was 25% and the socio-demographic and medical characteristics showed poor correlation with the psychological outcome in this study. Deteriorated functional status and ineffective coping strategies are strongly associated with poor psychological outcome in patients with oral cancer.

Hassanein KA, Musgrove BT, Bradbury E. Psychological outcome of patients following treatment of oral cancer and its relation with functional status and coping mechanisms. *J Craniomaxillofac Surg.* 2005 Dec;33(6):404-9.

The commonest coping mechanisms used were helplessness and fatalism. Resolution was noted in less than 40% of the frequent concerns. As compared to laryngeal cancer patients, those with oral cancer significantly more often had concerns about current illness, subjective evaluation of health, eating and chewing, social interactions, pain and disfigurement ($P < 0.05$). Most subjects had numerous unresolved concerns. Mainly ineffective coping mechanisms such as helplessness and fatalism were employed leading to incomplete resolution. Interventions to minimise these concerns and to handle associated anxiety and depression would improve their quality of life. Chaturvedi SK, Shenoy A, Prasad KM, Senthilnathan SM, Premlatha BS. Concerns, coping and quality of life in head and neck cancer patients. *Support Care Cancer.* 1996 May;4(3):186-90.

Are there particular symptoms that you continue to experience?

Long-term survivors of head and neck cancer experience QOL effects well after completion of treatment. Effects are most pronounced in survivors who required combined surgery/radiation therapy

Campbell BH, Marbella A, Layde PM. Quality of life and recurrence concern in survivors of head and neck cancer. [Laryngoscope.](#) 2000 Jun;110(6):895-906

Almost half of long-term nonlaryngectomy head and neck cancer survivors demonstrated at least some degree of aspiration. The presence of aspiration is associated with substantial weight loss, advanced initial tumor stage, diminished oropharyngeal swallowing efficiency, and lower scores on a variety of QOL scales. Campbell BH, Spinelli K, Marbella AM, Myers KB, Kuhn JC, Layde PM

Aspiration, weight loss, and quality of life in head and neck cancer survivors..

[Arch Otolaryngol Head Neck Surg.](#) 2004 Sep;130(9):1100-3.

Pain.

Hassan and Weymuller 1993; Ward et al 1993; Long et al 1996; Deleyiannis et al 1999; Grtz et al 1999; Chaplin and Morton 1999; Gellrich et al 2002 Talami 2002).

Zeleftsky MJ, Gaynor J, Kraus D, Strong EW, Shaw JP, Harrison LB. Long-term subjective functional outcome of surgery plus postoperative radiotherapy for advanced stage oral cavity and oropharyngeal carcinoma. *Am J Surg.* 1996;171:258-262.

Hammerlid E, Silander E, Hornestam L, Sullivan M. Health related quality of life three years after diagnosis of head and neck cancer—a longitudinal study. *Head Neck.* 2001;23:113-125.

Pandey M, Devi N, Thomas BC, Kumar SV, Krishnan R, Ramdas K.

Distress overlaps with anxiety and depression in patients with head and neck cancer.

Psycho oncology. 2007 Jun;16(6):582-6

Attitudinal ratings appear to contribute an important aspect of the patients' perspective, with substantially different variances between function and attitude. Karnell LH, Funk GF, Tomblin JB, Hoffman HT.

Quality of life measurements of speech in the head and neck cancer patient population. *Head Neck.* 1999 May;21(3):229-38.

How comfortable have you felt when discussing your situation with the team and why?

This research attempts to redress the balance through exploring the patient experience postoperatively, in particular the issues related to communication for this patient group.

The results also highlight the emotional trauma experienced by patients and the mechanisms healthcare staff employ to support these patients.

Dobbins M, Gunson J, Bale S, Neary M, Ingrams D, Brown M.

Improving patient care and quality of life after laryngectomy/glossectomy. Br J Nurs.

2005 Jun 23-Jul 13;14(12):634-40.

What has been the most difficult time or thing to deal with?

Have you had any psychological symptoms since your treatment?

(Kugaya 1999 High prevalence of depression post treatment in H&NC patients

De Leeuw et al 2000

continued impact of depression post treatment increased risk of suicide in this group Davies et al 1986)

Are you still smoking or drinking -why? Will they tell you? Will it make them feel bad?

past and current smoking behaviour is associated with psychological distress in patients with oral and oropharyngeal malignancy in their first 15 months of

recovery following initial treatment. This behaviour successfully identified a psychologically at-risk group.

Humphris GM, Rogers SN.

The association of cigarette smoking and anxiety, depression and fears of recurrence in patients following treatment of oral and oropharyngeal malignancy

[Eur J Cancer Care \(Engl\)](#). 2004 Sep;13(4):328-35

Controlling for clinical and demographic variables, linear-regression analyses showed that depressive symptoms had a strong negative association with all 12 quality-of-life scales; smoking had a negative association on all but one of the quality-of-life scales; and problem drinking was not associated with any of the quality-of-life scales. Interventions targeting depression, smoking, and problem drinking need to be integrated into oncology clinics.

Duffy SA, Ronis DL, Valenstein M, Fowler KE, Lambert MT, Bishop C, Terrell JE. Depressive symptoms, smoking, drinking, and quality of life among head and neck cancer patients. [Psychosomatics](#). 2007 Mar-Apr;48(2):142-8.

Try - Is there anything particular that the team can do to help you cope?

Patients do not discuss with their team their feelings Chaplain and Morton 1999

Moore 1990)

Significant levels of frustration were associated with the nurses' goal of addressing the pain management needs of the speech impaired and the patients' pursuit of reporting the uniqueness of their pain experience.

Rodriguez CS, VanCott ML Speech impairment in the postoperative head and neck cancer patient: nurses' and patients' perceptions..Qual Health Res. 2005 Sep;15(7):897-911.

What enables you to cope with all that has happened?

Few head and neck cancer survivors are participating in any moderate or vigorous exercise, and over half are completely sedentary. Meaningful and potentially beneficial associations between total exercise minutes, QoL, and fatigue were demonstrated.

Rogers LQ, Courneya KS, Robbins KT, et al. Physical activity and quality of life in head and neck cancer survivors. Support Care Cancer 2006;14:1012–1019

Results showed that the strongest independent correlates of physical activity were This study suggests that head and neck cancer patients with post-treatment psychosocial dysfunction can benefit from a problem-focused psychosocial intervention. Such evidence can inform practice, policy and future research, aimed at improving post-treatment quality of life for patients with head and neck cancer.

Semple CJ, Dunwoody L, Kernohan WG, McCaughan E..Development and evaluation of a problem-focused psychosocial intervention for patients with head and neck cancer. Support Care Cancer. 2008

The identification of positive outcomes from adversity has been commonly termed benefit finding. This cross-sectional questionnaire study aimed to identify the extent to which benefit finding occurs among head and neck cancer (HNC) patients and what factors are associated. HNC patients treated 6 months to 10 years previously (n = 76), completed the following measures: the LOT-R, HADS, the Brief COPE, and a measure of benefit finding. Moderate to high

levels of benefit finding were reported. Optimism and positive reappraisal were positively associated with benefit finding, with optimism acting independently of positive reappraisal coping. These findings have implications for the development of interventions to maximize positive psychological outcomes after treatment. Harrington S, McGurk M, Llewellyn CD Positive consequences of head and neck cancer: key correlates of finding benefit..J Psychosoc Oncol. 2008;26(3):43-62

How do you feel about being reviewed in outpatients, do you think that the team managing you have any idea how the treatment and disease has impacted on you? Do you feel the team understands your problems and concerns?

Both psychosocial and physiologic factors influence QOL in patients with head and neck cancer, but many QOL measures are most strongly influenced by psychosocial considerations. Physicians and surgeons caring for long-term head and neck cancer survivors should be cognizant of the importance of psychosocial risk factors in the QOL of their patients.

Holloway RL, Hellewell JL, Marbella AM, Layde PM, Myers KB, Campbell BH.

Psychosocial effects in long-term head and neck cancer survivors.

Head Neck. 2005 Apr;27(4):281-8

Mean length of time spent with each out-patient was 11 min.

Birchall M, Brown PM, Browne J. The organisation of head and neck oncology services in the UK: The Royal College of Surgeons of England and British Association of Head and Neck Oncologists' preliminary multidisciplinary head and neck oncology audit. Ann R Coll Surg Engl. 2003 May;85(3):154-7.

Is there anything you wish you could tell the team that would make a

difference to your care or others? The routine pre- and postoperative assessment of health-related quality of life may contribute to evaluate treatment effectiveness, which would otherwise rely exclusively on assessing end-point results such as survival and tumor relapse. This information is relevant to attenuate the prejudicial impact of surgery on the physical and psychosocial functioning of patients.

Biazevic MG, Antunes JL, Togni J, de Andrade FP, de Carvalho MB, Wünsch-Filho V.J Immediate impact of primary surgery on health-related quality of life of hospitalized patients with oral and oropharyngeal cancer. *Oral Maxillofac Surg.* 2008 Jul;66(7):1343-50.

What have been your feelings about undergoing the treatment?

(Patients suffer irrational fears of damage and death because of erroneous preconceptions of radiation which doctors fail to correct.

Peck A, Boland J.

Emotional reactions to radiation treatment [Cancer](#). 1977 Jul;40(1):180-4.)

The importance of understanding the patients' situation during treatment and their desire for a return to normal living and normal mouth functions at treatment end. If possible, plans for oral rehabilitation should be considered in initial treatment planning. As the treatment of oral cancer is multiprofessional, this knowledge may be useful in guiding the organization of oral cancer care and multiprofessional collaboration.

Röing M, Hirsch JM, Holmström I. The uncanny mouth - a phenomenological approach to oral cancer. *Patient Educ Couns.* 2007 Aug;67(3):301-6.

Since the treatment how do you think the disease and the treatment has impacted upon you psychologically?

Feelings of reduced self esteem confidence fear of addictions to pain killers feelings of hopelessness and loss. Moore RJ Chamberlain RM Khuri RR 2004 European Journal of cancer care **13** 53-64. Communicating suffering in primary stage head and neck cancer

What were the expectations you had of the disease and treatment and how did the reality compare?

Llewellyn C., McGurck M., Wineman J. Striking the balance a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer Psychology Health and Medicine 2005 10;(2) 180-193

Can you explain how the information written or verbal impacted on your ability to cope with the situation?

Llewellyn C., McGurck M., Wineman J. Striking the balance a qualitative pilot study examining the role of information on the development of expectations in patients treated for head and neck cancer Psychology Health and Medicine 2005 10;(2) 180-193

How has your disease and treatment impacted on those around you at home and socially? Distress is often present in spouses and patients treated for head and neck cancer. Routine screening for psychologic distress is recommended.

Verdonck-de Leeuw IM, Eerenstein SE, Van der Linden MH, Kuik DJ, de Bree R, Leemans CR.

Distress in spouses and patients after treatment for head and neck cancer.

Laryngoscope. 2007 Feb;117(2):238-41.

Quality of life evaluation tools need to be improved. At present, most tools only partially evaluate patient quality of life, concentrating on the global impact of disease and its treatment on patients' physical and psychological condition. The "sociability" of individual patients is rarely evaluated, and the development of qualitative studies in this domain will enable improved understanding of the social factors involved in each patient's adaptability to disease, its treatment and after-effects. Babin E, Joly F, Vadillo M, Dehesdin D Oncology and quality of life. Study in head and neck cancer [Ann Otolaryngol Chir Cervicofac](#). 2005 Jun;122(3):134-41.

The relationship between coping effectiveness and degree of postoperative disfigurement and dysfunction has been described. Current nationwide mandates for more cost-effective health care warrant continued efforts to describe this patient population in relation to coping patterns. Those patients who do not cope adequately should be considered for more intensive intervention while still in the therapeutic environment of the hospital. More creative and innovative solutions are needed to facilitate effectiveness of intervention and predictability of outcomes within an appropriate time frame and in a fiscally responsible manner. In the interim, inability to cope with disfigurement and dysfunction at discharge can predispose the patient to infection or non compliance with follow-up care, pathological obsession with or denial of the defect, depression, and social isolation.

Dropkin MJ. Coping with disfigurement and dysfunction after head and neck cancer surgery: a conceptual framework. *Semin Oncol Nurs*. 1989 Aug;5(3):213-9.

The findings reveal that the experience of lived relations changes from being spouse to supportive carer, the lived body is neglected and lived space and time becomes restricted. The essence of their lived experience can be described as living in a state of

suspension. This knowledge may be useful in the education and organization of supportive communication for multiprofessional caregivers.

Röing M, Hirsch JM, Holmström I. Living in a state of suspension--a phenomenological approach to the spouse's experience of oral cancer.

Scand J Caring Sci. 2008 Mar;22(1):40-7.

Quality of life correlates stronger with the quality of relationship in spouses than in patients. Generally, marital satisfaction appears to be an important moderating factor regarding QoL and psychological distress

Jenewein J, Zwahlen RA, Zwahlen D, Drabe N, Moergeli H, Büchi S. Quality of life and dyadic adjustment in oral cancer patients and their female partners. Eur J Cancer Care (Engl). 2008 Mar;17(2):127-35.

Standardized measures of social support, depressive symptoms, well-being, and life happiness were used. RESULTS: The sample as a whole displayed high levels of life happiness, low levels of depression, and positive feelings of well-being. Women demonstrated higher levels of depression and lower life happiness; subjects with greater disfigurement were more depressed. Social support seemed to buffer the impact of greater levels of disfigurement on well-being for women but not for men.

CONCLUSION: These results suggest that women with head and neck cancer who experience low social support and face disfiguring treatment are at greatest risk for psychosocial dysfunction.

Katz MR, Irish JC, Devins GM, Rodin GM, Gullane PJ. Psychosocial adjustment in head and neck cancer: the impact of disfigurement, gender and social support. Head Neck. 2003 Feb;25(2):103-12.

There appears to be some association between selected psycho-social factors and long-term survival from head and neck cancer. However this relationship is currently neither strong nor proven, requiring examination by multi centred trials with standardisation of research definitions and methodologies, and examination of post-treatment psycho-social factors.

Mehanna HM, De Boer MF, Morton RP.

The association of psycho-social factors and survival in head and neck cancer. Clin Otolaryngol. 2008 Apr;33(2):83-9.

Questions I would like to have answers to but no literature on them relating to head and neck cancer.

- Do you feel that you have had uncertainty and ambiguity, mixed messages or contradictory information during your care?

- What can you believe who can you trust?
- Are there certain topics you find difficult or impossible to talk about?
- How would you advise someone starting on the same experience that you have had?
- Do you think opting for treatment was the right thing for you to do as you look back on your care?
- Have you felt that the care you have received has given consistent messages, or have you felt when you have seen people they have given you different information which has been confusing.
- In what way have you been changed by the cancer?

APPENDIX 3.3

1. Generating themes from QoL questionnaires

Basic themes	Organising Themes	Global Themes
Symptoms/function Disease and treatment Psychological balance Psychological symptoms Engagement with others Fear of Recurrence	Physical impact of symptoms Psychological impact Impact on QoL Social relationships Purpose Fear	Day to day physical comfort Emotional Well being Place in Society Own mortality

2. Generating themes from literature associated with the literature review

Basic themes	Organising Themes	Global Themes
Symptoms/function Disease and treatment Health risk Psychological balance Psychological symptoms Coping Body image Character/Resilience Positive reframing Expectations/assumptions Engagement with others Alienation Role Fear of Recurrence Survival vs day to day existence Fatalism Humane aspects of care Individual adjustment to information Info timely Compliance Jargon Communication loss and needs Accessibility and demeanour of team Comprehensive /time intensive	Physical impact of symptoms Unpredictability/uncertainty, risk appraisal Psychological impact Impact on QoL Social relationships Purpose Inter personal relationships Fear Internal personal struggle Team interaction with patient	Day to day physical comfort Emotional Well being Place in Society Own mortality Quality of care

3. Themes derived from semi-structured interviews

Basic themes	Organising Themes	Global Themes
Symptoms/function Disease and treatment Physical loneliness Health risk Addictive behaviours	Physical impact of symptoms Unpredictability/uncertainty, risk appraisal	Day to day physical comfort
Psychological balance Psychological symptoms Coping Body image Character/Resilience Positive reframing/secondary gains	Psychological impact Impact on QoL	Emotional Well being
Expectations/assumptions Engagement with others Alienation Legitimate review of life and roles	Social relationships Purpose Inter personal relationships	Place in Society
Fear of Recurrence Survival vs day to day existence Fatalism Review other deaths known regrets	Fear Internal personal struggle Review of life and future	Own mortality
Humane aspects of care Practical objective issues Tangible care Individual adjustment to information Info timely Compliance Jargon Communication loss and needs Accessibility and demeanour of team Comprehensive /time intensive Mismatch of outcome expectations and timescales	Team interaction with patient	Quality of care
Outcome of treatment vs no treatment not the same Survive at all costs	Stark choices	
poor rest/down time Physical and emotional loneliness Cyclical impact Accepting impact on life Observer role with poor control Alienation Engagement with others and control support network	Inner strength Unremitting symptoms Reactive state	Reality

APPENDIX 3.4

QUESTIONNAIRE COMPLETED BY THE MDT FOR T4 CASE STUDY

Kate's Questionnaire.

Attached is a fictitious case history of a patient that may present to the unit. Please read the case history and then rate the 20 statements with particular reference to the patient you have just read about. Please do not ponder too long over each statement – it is your immediate response we are looking for.

There is of course no right or wrong answer and you are not being tested. Please do not discuss this study or your answers with anyone else because we need each individual's perspectives. Thank you for your help and happy reading!

About you:- Please fill in

Job title: _____

Grade if you are graded _____

Number of years working with patients with head and neck cancer : (tick the box)

Less than 5yrs

5-10yrs

10-15 years

15-20 yrs

more than 20 yrs

Do you work with (tick the box) inpatients, outpatients both

Do you work mainly (tick the box) days nights both

Fictitious patient case history

A 50 year old person who works behind a bar is married with 2 children

They smoke 20 cigarettes a day and drink socially.

There are no co morbidities

Diagnosis: T4 N1* moderately differentiated squamous cell carcinoma situated on the right lateral border of the oral tongue not crossing the midline

(Note that in T2 example the scenario was identical, but the term T2 incorporated rather than T4)

Management plan: partial glossectomy right selective neck dissection tracheostomy,
reconstruction with radial fore arm free flap

Surgery is planned for two weeks time; the patient has not been in hospital for many years, and admits to being apprehensive to the planned admission.

Put a vertical line through the horizontal line to illustrate where on the scale you would expect this patient to be for each question.

E.g.

- **How easily would you expect this patient to have found where the ward is?**

Really difficult

no problems straight to it

This indicates that the ward was not too hard, but they got a bit lost!

Please try and make a judgement based on how the patient will have been in the last week

- **How tense do you think the patient has been?**

Not at all tense

Very tense

- **In the past week how tired do you think this patient has been?**

Utterly exhausted

Extremely energetic

- **In the past week how well do you think the patient will have slept?**

Very badly

Excellently

- **In the past week what do you think the patient's appetite has been like?**

Very poor

Excellent

- **How difficult do you think it has been for the patient to remember things?**

Very poor

Excellent

- **How depressed do you think the patient will have been since diagnosis?**

Not at all

Very depressed.

- **How limited do you think the patient has been at work by their disease?**

Not at all

Very much

- **How much pain do you think the patient has been in?**

None at all

Unbearable pain.

- **How likely do you think it is that this patient will have choked when swallowing?**

Not at all likely

very likely

- **Would you expect the patient to have been worried?**

Not at all

A great deal

- **Would you expect the patient to have trouble talking on the telephone?**

Not at all

A great deal

- **Would you expect the patient to have less sexual enjoyment?**

Not at all

A great deal

- **Would you expect the patient to have problems swallowing solid food?**

Not at all

A great deal

- **Would you expect the patient to have trouble with sticky saliva?**

Not at all

A great deal

- **Would you expect the patient to have trouble eating in front of other people?**

Not at all

A great deal

- **Would you expect the patient to be using oral supplements?**

Not at all

A great deal

- **Do you think the patient would have had a sore mouth**

Not at all

very sore

- **Do you think they would have a dry mouth?**

Not at all

A great deal

- **How do you think the patient would rate their overall health in the last week?**

Very poor

Excellent

- **How do you think the patient would rate their overall quality of life in the last week?**

Very poor

Excellent

Any comments that you want to add?

APPENDIX 5.1

Original quotes for the theme reality

The reality was much better than what I imagined.

I thought I would be much better sooner than I was.

It's part of life now. but i'll talk about things I wouldn't have

There is no choice because the result of saying no to treatment would be certain death

You never feel the same again

You should never have to do this alone

It doesn't help to analyse things too deeply- You feel very different from other people and don't need to burden them with that

You might look similar but you feel very different you know that but no one else does

Its very hard to keep going have the energy for things

You have to believe the treatment is going to work you cannot start to think it won't

If the team think you are OK you think it is alright to have the symptoms so you don't tell them in case they then notice others and become worried

It all goes on for such a long time a long time to recover

I still feel like a victim and you have to watch not to upset the relationships you have

I still think it's not fair and why me?

Final statements used to represent the global themes reality

You should never have to face this sort of thing on your own

If you didn't want to die there was no choice but to have the treatment

It's so hard waiting to heal

I have to be careful to not upset people

I'll talk about things that I wouldn't have done before my diagnosis

APPENDIX 5.2

CONCOURSE STATEMENTS NUMBERED.

- 1 I recovered much slower physically than I expected
- 2 I felt physically very isolated
- 3 Any symptom I get I always think the cancer might be back
- 4 When I was told I had the cancer I knew I had to face it
- 5 It really affected my confidence
- 6 I didn't want people to know what had happened to me
- 7 No one can really understand what has happened to me
- 8 You never think it could happen to you
- 9 Life is hard you just have to get on with it
- 10 You just become really grateful for different things
- 11 Little things like the car park or appointments being cancelled really irritate
me
- 12 I wanted the team always to be honest with me
- 13 If you didn't want to die there was no choice but to have treatment
- 14 It's so hard waiting to heal
- 15 I'll talk about things that I wouldn't have done before my diagnosis
- 16 I have to be careful to not upset people
- 17 You should never have to face this sort of thing on your own
- 18 I never read the written information I was given
- 19 No two patients are the same
- 20 I was most frightened when I came out of hospital

- 21 I never felt like a number I was always treated as an individual
- 22 I felt very vulnerable when I was in hospital
- 23 I didn't understand what was meant by the treatment until I experienced it
- 24 Once I knew they could do something about it that's all I needed to know
- 25 It's just as well you don't know what's going to happen you'd never cope
- 26 It's very hard to think about your own possible death
- 27 I do things but on my terms
- 28 Being cured of the cancer is still the most important thing
- 29 I never think of myself as ill
- 30 Everyone around me was so upset
- 31 I cannot have a good argument now
- 32 I felt very alone
- 33 I never appreciated how long it would take to get better
- 34 Life will never be the same again
- 35 It's amazing how much you can adjust to all the physical changes
- 36 I wish I'd never been treated
- 37 I cannot do things on the spur of the moment
- 38 I am much more irritable than I used to be
- 39 My appearance was much better than I expected
- 40 I worried a lot how others would cope
- 41 Day-to-day existence is physically exhausting
- 42 When I talk it doesn't feel like me anymore
- 43 I always think that people are staring at me

44 It's hard to remember things you're told

45 I am still in pain

Appendix 5.3 COMPLETED EXAMPLE OF Q SORT

					7					
				6		6				
		4	4				4	4		
2	2								2	2
-5	-4	-3	-2	-1	0	+1	+2	+3	+4	+5

Least like I think

No Opinion

Most like I think

APPENDIX 5.4 SEMISTRUCTURE INTERVIEW FOR SORT NUMBER 9

R	1.1 1.2 1.3	<i>So why does it make you cringe your husband asking how long will it be before you swallow what's the problem,</i>	
P	1.4 1.5	<i>because sometimes there is no definite answer and he wants definite answers</i>	
R	1.6 1.7 1.8 1.9 1.10 1.11 1.12 1.13 1.16 1.17 1.18 1.19	<i>go but we need to know that because he is frustrated he needs definite answers he needs a time scale and I imagine that this is related to his job deadlines so working with sales deadlines are really how he works and as you know working in the health service well bodies don't respond to that at all and it's the meeting of 2 value systems one that's based on time another based on symptoms and you know as I do it's not about the time its about describing by where you currently are and what the next step might be which would mean we have movement in a forward direction</i>	
P	1.20 1.21 1.22 1.23 1.24	<i>I think he would benefit from that explanation. It's very hard on him he tends to laugh in situations that are really not funny and he more or less said yesterday I'm glad it's you and not me ha ha ha it's difficult.</i>	<p>Kate Reid 28/4/11 19:58 Comment: Aware of there being no sense of time but more symptom driven</p>
R	1.25 1.26	<i>and I would guess that you would agree with that as in you are an easier patient than him</i>	
P	1.27	<i>oooooooooooo</i>	<p>Kate Reid 28/4/11 19:59 Comment: Patient role and handling those issues</p>
R	1.28 1.29 1.30 1.31	<i>and that's honest of him to acknowledge that he would be very angry and you are acknowledging that whilst you are anything but ecstatic you are at least dealing with it</i>	
P	1.32	<i>Absolutely</i>	
R	1.33 1.34 1.35	<i>Whilst dealing with it you are not going to feel the same in terms of fatigue pain and worry weakness and symptoms living with quite fixed tongue it must be quite hard.....</i>	
P	1.36 1.37	<i>it is in some ways and trying not to think about it in the detail</i>	
P	1.38 1.39	<i>one way of handling it is not to concentrate on it and to park it so that you can see that some</i>	<p>Kate Reid 28/4/11 20:02 Comment: Use of denial as a way of coping not dealing</p>

	2.1	<i>symptoms are progressing</i>	
P	2.2	The doctor came this morning and said that the tests	
	2.3	are all normal but that does not explain the	
	2.4	symptoms as to why my speech has deteriorated.	
	2.5	I didn't realise how much I needed to come into	
	2.6	hospital when you asked me some weeks ago I	
	2.7	should have said yesbut I just	
	2.8	wanted to plod on and cope	
P	2.9	Written down they are very therapeutic and that is	Kate Reid 28/4/11 20:05 Comment: <i>written</i>
(having	2.10	such a big help there is relief to just read it and	
read	2.11	realise you are not on your own	
statements	2.12	<i>no</i> one can understand what has happened to me) I	Kate Reid 28/4/11 20:06 Comment: <i>written</i> less isolated and relieved at the thought of others expressing some of the same feeling
through)	2.13	have just one friend and I suppose she's worried I	
	2.14	am not going to get my speech back and be left this	
	2.15	she has insight.....I think she is voicing it that	
	2.16	the others don't and until they hear it from me	
	2.17	they're holding back and that's ok. There's no	Kate Reid 28/4/11 20:06 Comment: Permission from the patient to talk about the symptoms that might be obvious but very abnormal fear of what they might mean and the permanency
	2.18	expectation I am not hiding anything we just don't	
	2.19	know.	
	2.20	I need to be <i>hopeful</i> I still feel there is	
	2.21	room for recovery so that's why I am trying to be	
	2.22	hopeful and I am trying to be realistic but I have	
	2.23	become better recently. I keep grounded in that I	
	2.24	don't want to get carried away it's trying to keep a	
	2.25	balance like my speech now I have written very	
	2.26	little down which is a surprise it is still able to be	
	2.27	explained to me I feel exhausted around my neck all	
	2.28	the tightness the compression it feels as though it's	
	2.29	getting better	
R	2.30	Let's look at the strongly agree -why shouldn't you	Kate Reid 28/4/11 20:06 Comment: Really balanced with hope
	2.31	have to face it on your own?	
P	2.32	Well this is devastating news isn't it and I didn't I	
	2.33	have family and friends and faith – so you have your	
	2.34	supportive inner self that gives me back hope love –	
	2.35	so they are letting you recharge you by seeing you	Kate Reid 28/4/11 20:07 Comment: Coping mechanisms based on the need to focus with others on positive aspects of life despite the symptoms and the diagnosis
	2.36	as you letting you recharge and seeing you as a	
	2.37	human being.	
P	2.38	I never felt like a number I always felt the	
	2.39	communication has been amazing the complexity of	
	2.40	my case and the sense of good communication	
	2.41	between the team.	
R	2.42	You put that you do read all the information which	
	2.43	is general how does that fit with the being treated as	
	2.44	an <i>individual</i> I'll write this down	
	2.45R reads it out	
P	2.46	I relate very well to the written word and yes the	
	2.47	information might be general but worth reading – so	
	3.1	you are saying if you read it it gives you the ability	
	3.2	to discuss the individual bits because you	

3.1	you are saying if you read it it gives you the ability
3.2	to discuss the individual bits because you
3.3	understand the volume information to ask how does
3.4	this effect me as an individual you remember the
3.5	very specific thingsspot on!
3.6	this feels a release
3.7	I can't understand not being treated, on a bad day I
3.8	can, I don't feel guilty about though - I don't think
3.9	about it a lot but to have no treatment being cured of
3.1	cancer and when I was told the cancer was there I
3.11	had to face it means there is no choice so I have to
3.12	get on with it. The two paths are different alive or
3.13	dead.

Kate Reid 28/4/11 20:10

Comment: For this patient not being treated is a possibility but not one really that can be considered

Kate Reid 28/4/11 20:10

Comment: No choice resilience to the reality

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